[BIOMATRIX]

NEWS

DEDICATED TO MAKING A DIFFERENCE

FALL 2019
VOLUME 14 | ISSUE 4

> “Every moment is a fresh beginning.”
> — T.S. Eliot

VOLUME 14| ISSUE 4
FALL 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 **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

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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:

So begins another fall season! Shorter days and cooler nights are already here (open those windows!). Thoughts have shifted from summer camp and time at the swimming pool to packing school lunches and planning holiday celebrations.

As we approach year's end, I cannot help but think of the time that's gone by. When my family was young, due to employment opportunities, we moved around quite a bit. We lived in Illinois, Texas, Georgia, Colorado and back again to Illinois. With 4 kids in tow, 2 with severe hemophilia and a husband who was gone for months, things were sometimes challenging!

There was always the worry of finding a home near a treatment center or at least near a good hospital. Would we have issues with the new insurance? Would we have the liberty to choose our preferred doctors and medical facilities? By 5th grade my oldest child was in her 5th school - would the kids have adjustment issues leaving friends and starting over? Away from relatives, who could I turn to for help especially in case of an emergency?

Although my family is not in the military and I didn't have the added worry of having a husband overseas in dangerous territory, I did get a *very small* taste of what our service families go through. In addition to the many sacrifices they make in support of our country and freedom, military families with a bleeding disorder may face even more unsettling challenges as they are moved at a moment's notice to various military bases.

In this issue, we speak to members of the bleeding disorder community serving our country and explore how they navigate and overcome challenges associated with military life.

Enjoy the fall weather and the upcoming holidays!

Maria Santucci Vetter
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WOODSTOCK, HEMOPHILIA AND FREEDOM

BY JONATHAN ALAN HILL

Scores of sick and injured patrons of the Aquarian Festival jam a first-aid station at the Bethel site.

The Times Herald Record, Middletown, NY
Saturday, August 16, 1969

In celebration of the 50th anniversary of Woodstock, I watched the PBS documentary, *"Woodstock: Three Days That Defined a Generation."*

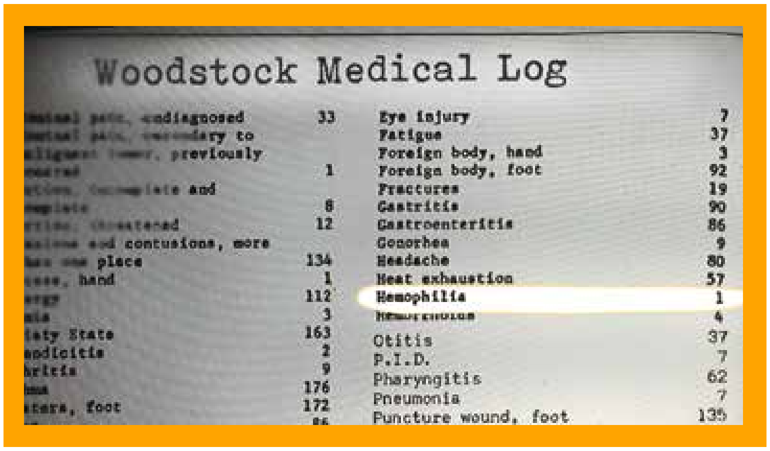
In August 1969, over a half million people descended on a farm in rural upstate New York for an art and music festival. The promoters were not prepared for a crowd that size.

They did not have enough food, supplies or medical personnel so they were forced to fly staff, volunteers and even the performers in by helicopter since the roads were closed by all the attendees' abandoned vehicles. Amazingly there were only two deaths: a sleeping teenager crushed by a tractor and a heroin overdose.

In the section about the medical crisis, the documentary briefly showed the Woodstock Medical Log from the first aid center. Listed among the many foot injuries, abrasions, and puncture wounds was the entry of a person treated for hemophilia. That caught my eye.

These were the early days of hemophilia treatment. Factor concentrate did not exist yet and cryoprecipitate had just been developed in 1965. Hemophilia treatment centers were not yet established, and self-infusion was still years away. Yet here was record of a person with hemophilia at Woodstock. I could not find any more information about the patient's treatment but clearly, they did not die at Woodstock.

> **“Yet here was record of a person with hemophilia at Woodstock.”**



Woodstock Medical Log

undiagnosed	33	Eye injury	7
secondary to		Fatigue	37
previously		Foreign body, hand	3
	1	Foreign body, foot	92
and		Fractures	19
	8	Gastritis	90
	12	Gastroenteritis	86
contusions, more		Gonorhea	9
place	134	Headache	80
hand	1	Heat exhaustion	57
	112	Hemophilia	1
	3	[illegible]	4
State	163	Otitis	37
	2	P.I.D.	7
	9	Pharyngitis	62
	176	Pneumonia	7
foot	172	Puncture wound, foot	135

I often talk about my generation as trailblazers of hemophilia. We were the first to have HTCs, self-infusion and did things that no one had seen hemophilia patients do before, but here was proof that someone with hemophilia went to the world's greatest music festival in 1969 (the year of my birth).

He would have had to walk miles to get to the farm from where traffic was stopped. He would have had to camp two or three nights with limited supplies. Many of the attendees were barefoot accounting for the many foot injuries. It is hard to imagine a person with hemophilia walking around barefoot without a bleed. This is just amazing to me. Here was proof of a real trailblazer in the counterculture of the late 1960s.

In my mind's eye, I can see my two older blood brothers Mike and Val hitchhiking to the festival from Buffalo. I see them standing for hours each day listening to the likes of Richie Havens, Santana, Grateful Dead, The Who, Jefferson Airplane, Janis Joplin, Crosby, Stills and Nash (their first performance!), and of course Jimi Hendrix. Sleeping in tents near the dairy farm and grooving out to the music and art.

The idea of a person with hemophilia going to Woodstock, for me, is the definition of *freedom*. All my respect to the hemophilia patient who undertook this adventure.

Two women administer care to festival goers in a medical tent at Woodstock.

FACEBOOK IS WATCHING YOU

BY SHELBY SMOAK

More than 68% of Americans use Facebook which now boasts over 2.38 billion users monthly. Of its users, almost 74% log on daily and almost half of those check in multiple times a day.[1] Facebook then, has become part of many Americans' daily lives.

We check in. We post. We like. We share.

Such familiarity may lead one to believe Facebook is safe, innocuous, our "friend." We may forget that Facebook is a business whose trade is in the data and information we provide them. We may forget that the information we share isn't private but is sold to advertisers.

We shouldn't.

For starters, Facebook has recently been fined $5 billion for privacy violations. For a company worth $138 billion, that is hardly a slap on the wrist, but it does send a message that all may not be safe. A loose coalition of patient advocacy groups led the charge against Facebook privacy issues claiming that "Facebook deceptively solicited patients" to use Groups "to share personal health information about their health issues," and that information (which was disclosed in closed, supposedly anonymous and private Facebook groups) was then exposed. The problem the coalition had, however, was that they could not charge Facebook with a HIPAA (Health Insurance Portability and Accountability Act) violation even though Facebook posts contain personal health information (PHI).

> **As a Facebook user, you don't always have control over your private information.**

Facebook is not nor does it have to be a HIPAA compliant company. HIPAA was created to protect a patient's PHI for medical entities like health plans, physicians and pharmacies that conduct transactions electronically. According to an article in *HIPAA Journal*, "Facebook is not bound by HIPAA rules, so the sharing of any personal health information with advertisers would not be a HIPAA violation." Facebook's business model is to get users to share information and then to sell that information to other businesses, so if it's your PHI they are selling, they are not breaking any laws.

Most Facebook users will acknowledge that Facebook posts are public. Once posted, it is readily available to be seen by another Facebook user. Even if a person is posting to "Friends Only," the information is seen by Facebook, data-mined and shared with its advertisers who will use it to market their products. Have you ever made a post on Facebook about something and then in the following days seen an eerily specific advertisement pop up in your email or online feed? That's Facebook data mining.

More concerning perhaps is the Closed and Private Facebook groups. **Let me be clear: These groups are not Closed nor Private.** But many believe they are safe spaces. And many people reveal sensitive health information in these groups. The case is especially true for those with a chronic illness who may be seeking help or better care for their condition. The $5 billion fine handed down from the FTC was due to false advertising of these groups as "closed" and "private."

Fred Trotter, leader of the advocacy complaint group, was able to download information of 10,000+ members of a closed and supposedly private breast cancer Facebook group by using a Chrome extension app. The HIPAA Journal elaborates: "In addition to real names of members, Trotter was also able to download email addresses, the cities where members are located," as well as employer information.[2] More disturbing, Facebook uses an individual's information to nudge them into joining these Closed Facebook patient support groups.

If you are participating in a closed Facebook group, here are some things you should know:

1. Facebook requires you to use your real name. There are no aliases or screen names allowed. Having your name posted within the group can make you vulnerable for searches by insurers, employers, or anyone else. Essentially your participation in a group is not private but is public.
2. Any user within the group can take a screenshot of your posted page. At that point, the screenshot can be used in whatever manner the individual wants, including reposting to their own public Facebook page. To quote Trotter's letter to the FTC, "Facebook's current policy explicitly permits the taking and re-publishing of screenshots.[3]
3. The Group Administrator will have access to your information and posts. You must ask yourself to what degree you know and trust the Group Administrator with your information.
4. Many Closed Groups are hosted by Administrators with industry ties. You should understand that you

may disclose health information that could be used to market a service or product to you. Research the Closed Group's Administrator and make an informed decision about their disclosure and/or withholding of information regarding their Closed Group.

5. As a Facebook user, you don't always have control over your private information. For example, another user can suggest you as a Group "Add" without your consent or knowledge. Let's say User A is part of an HIV closed group. User A knows you are HIV positive and "adds" you to the group. At that point, the Group Administrator then has access to your information to approve or deny the request. If the request is denied, you won't even know it was put in motion nor that your information was shared. If the Add request is approved, however, you will receive a notification, in which case you can "click here" if you do not want to be added to the group. Yet, even if you decline the group request, Facebook has already collected and stored that information, and the Group Administrator will also have been privy to your information.
6. Some members of the Closed Group may only be there to gather information instead of participating in the actual support the group may offer.

The appeal of Facebook has always been its ability to connect persons with family members, friends, and lost acquaintances. The new appeal through Closed Groups is allowing persons to connect with others with shared traumas or experiences. Even the best coffee shops can't connect you to somebody several hundred miles away who is going through exactly what you are going through right now. Facebook can. And Facebook Closed Groups *can* be a very supportive environment. But you should know that your name, your condition, your posts, your hobbies, your likes and your other personal information is not private.

Only post what you are comfortable with having the world know, and you can keep the rest private in an old-fashioned way—by making a phone call to a true friend.

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8-BALL, CORNER POCKET:
A WINNING SHOT FOR STRESS RELEASE

BY JUSTIN LINDHORST

"I started playing pool when I was 15. I thought the game was interesting and challenging, and I enjoyed practicing to get even better."

Now an adult, Will is definitely playing better. The South Florida native has competed and earned the top spot in numerous tournaments, and consistently challenges himself to improve. "My greatest success was winning a trip to Las Vegas last year for the American Pool Association's (APA) national tournament," he shares. "I had to beat a lot of good players to win, and it put me on the radar as one of the best players in the APA in my area."

Will's talent on the pool table is the result of many hours of practice, but it's not the only skill set that took time and effort to develop. Will was diagnosed with severe hemophilia A at birth. Like many in the bleeding disorders community, Will had to learn how to manage infusions, bleeds, trips to the HTC, insurance issues and everything else that comes with having hemophilia.

He never let it stop him from pursuing his ambitions, even at the young age of 15. "I won a trip to the Junior Nationals tournament in Chicago not long after I started playing when I was 15. We had to do a lot of planning and preparation to best manage my bleeding disorder on the trip. We figured out the hemophilia part just fine, but in the end, I did not play very well in Chicago. It was a great learning experience that motivated me to push myself further."

When he has free time, you can find Will relaxing, honing his skills at his favorite spot to shoot pool in West Palm Beach, *Grover's,* and preparing for that next tournament. "I've been playing there since I first started at 15. They have nice tables, a good atmosphere and a lot of good players," he notes.

According to Will, playing pool helps relieve some of the stress that can come with hemophilia. "Pool helps because it's an activity you can participate in without being hard on your body. It's a game that requires focus and concentration, but it's relaxing! It's great for taking your mind off the daily activities of living with a bleeding disorder."

Will encourages others in the bleeding disorder community to find their passion as well, "Enjoy your life, have fun and don't let hemophilia stop you from doing what you want to do. Take care of yourself, focus on education and believe that you can do whatever you want in life."

PRESERVING CONTINUITY OF CARE FOR MILITARY FAMILIES

BY MARC STRANZ
CHIEF CLINICAL OFFICER, BIOMATRIX

Continuity of Care (COC) is a concept centered on the quality of care patients receive over time. Unfortunately, some populations are predisposed to issues with continuity – including those serving in our armed forces.

Frequent moving, prolonged separation and challenges related to military health benefits can impede the continuity of care for members of the military and their families. One analysis found that 44% of military families caring for children with special healthcare needs did not receive assistance coordinating care across providers.[1]

Military families have also reported approval delays and issues related to receiving prescription medicine or special medical equipment for their child.

Though military families face COC challenges, specialty pharmacies are uniquely poised to help navigate these issues – preserving continuity and improving health outcomes.

Studies show when continuity is high, outcomes improve.[2] Fewer emergency room visits, increased adherence to therapy, improved patient satisfaction, and lower overall healthcare costs are just a few of the documented results when continuity is present.[3] Continuity of care was rated as a top priority by patients and caregivers dealing with chronic health conditions.[4] Though the importance of COC is widely acknowledged, maintaining it in a fragmented health system can often be difficult.

Specialty pharmacies play an important role in continuity of care. Medication therapy management (MTM) is one of the primary tools a specialty pharmacy wields to positively influence COC. The American College of Clinical Pharmacy defines MTM as, "A distinct service or group of services that optimize therapeutic outcomes for individual patients." Broadly speaking, this involves tailored clinical assessments, focused patient education, and interventions designed to promote adherence, reduce side-effects, and avoid negative drug interactions. A well-designed MTM program provides patients the tools and knowledge to effectively manage their condition based on individual circumstance. Over time, clinical assessments, dispensation, and utilization data provide a comprehensive view of patient response to prescribed therapy.

[Specialty pharmacies play an important role in continuity of care.]

Experienced specialty pharmacies understand high levels of patient engagement are required for MTM programs to be effective. Through ongoing communication, clinical and support staff at the specialty pharmacy develop a detailed understanding of the day-to-day challenges faced by patient and caregiver. For military families, this could mean proactive planning with the pharmacy before a move or deployment to avoid interruptions in care. Working together, pharmacy and patient anticipate and mitigate potential disruptions to therapy. Beyond filling a monthly prescription, the specialty pharmacy becomes an advocate and partner in the ongoing management of chronic health conditions.

Patients access healthcare and medication across a range of disciplines and locations. This is especially true in populations that move frequently and with individuals who have chronic health conditions. Coordinating care across healthcare access points is another way specialty pharmacies impact COC. Leveraging detailed clinical knowledge with individualized patient information, pharmacists help providers fine tune treatment plans and promote communication across healthcare channels. Highly trained care coordination teams including billing and intake support clinicians in promoting continuity. These professionals promote COC by helping patients understand their coverage, coordinating complex health benefits, securing prompt authorization for prescribed therapy, and providing access to resources reducing barriers to care. Using a collaborative approach, the specialty pharmacy team proactively coordinates services between patient, provider, payer, and other community-based resources to overcome challenges, maintain continuity, and promote safe, effective care.

Continuity of care is a critical component of quality healthcare for all consumers. Specialty pharmacies with a well-defined MTM program and high levels of patient engagement are well equipped to maintain COC in the complex and ever-changing healthcare environment. By tailoring programs to meet the unique needs of specific populations predisposed to continuity challenges – such as military families – specialty pharmacies are bridging gaps, promoting communication, and ultimately helping to produce the positive outcomes continuity of care is best known for.

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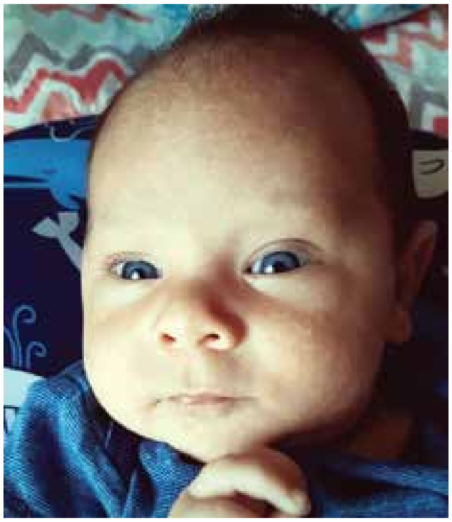
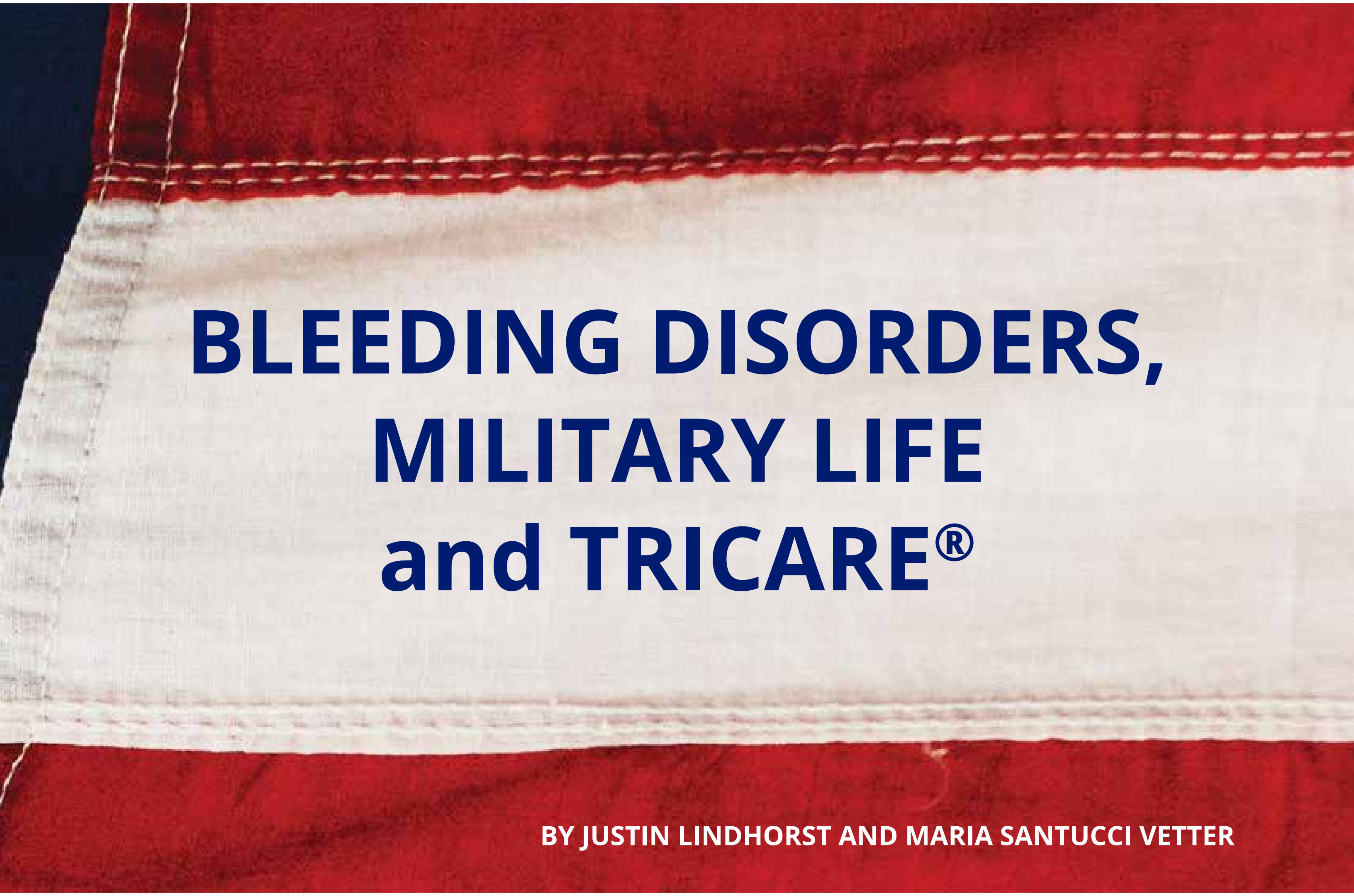
UNITED STATES AIR FORCE





BLEEDING DISORDERS, MILITARY LIFE and TRICARE®

BY JUSTIN LINDHORST AND MARIA SANTUCCI VETTER

Members of the US military dedicate their lives to service. And for that, we give our sincere thanks to every member of the military, as well as their families!

Part of that commitment means being ready at a moment's notice to pick up and move to a new city, a new state, or in some cases, a new country!

For active duty service members raising a family, deployment and frequent moves can be challenging – especially for those raising a child with a bleeding disorder.

Studies have shown that military family life includes prolonged separation, frequent moves and facing multiple stressors in a short time.[1] Further, families with military health insurance have been shown to experience access to care issues when compared to other medical benefits.[2]

This interview explores the challenges of military life from the perspectives of two families in the bleeding disorders community. We spoke with moms Kalee and Denise, and their spouses and active duty service members, Ryan and Jon. Their candid responses show what raising a child with a bleeding disorder in a military family is like.

FIRST, LET'S GET TO KNOW YOU A LITTLE BETTER. WHERE ARE YOU AND YOUR SPOUSE FROM, WHERE DID YOU MEET AND HOW LONG HAVE YOU BEEN TOGETHER? WHAT IS YOUR SPOUSE'S SERVICE DIVISION, RANK, AND CURRENT LOCATION?

Kalee: I am from Wisconsin, a little town called Mauston. My husband is from Palatine, IL a Chicago suburb. My husband, Ryan, and I met in college in Milwaukee, WI. We've been together since 2007 and married for 10 years. Ryan is in the United States Air Force based at Scott AFB, Major (O-4), currently deployed to Kuwait.

Denise: Jon and I are both from Fresno, California. We met while working at a hotel restaurant in Fresno. We dated for a year and have been married almost 15. My husband is in the Army, E7, currently stationed at Scofield Barracks in Hawaii at Division Artillery doing many jobs. His main position is as a nurse, but he has done other tasks including running the ER in Kuwait and drill sergeant at Fort Benning Georgia, to name a couple.

WHAT WERE YOUR FIRST THOUGHTS OR CONCERNS ABOUT BECOMING A MILITARY SPOUSE/FAMILY?

Kalee: I was too young and naive to know what the military was all about. To my 22-year-old self, I was in love and it was an adventure. It still is!

Denise: My hubby joined the army young. Looking back, we may have chosen differently but we are very thankful for the army healthcare.

TELL US ABOUT YOUR FAMILY. WAS THERE FAMILY HISTORY OF A BLEEDING DISORDER?

Kalee: We have 2 children, Penny almost 4—carrier status unknown, 2-year-old Henry who has severe hemophilia B, and we have a baby boy on the way due in January. We had no bleeding disorder history whatsoever.

Denise: Jacob is 13 years old and has severe hemophilia B, 9-year-old Cora has mild hemophilia B and is a carrier, 7-year-old Ava and 3-year-old Emma are not affected, and our youngest, 3 month-old Brody, has severe hemophilia B. I am a carrier and my levels put me in the mild range as well. Since I was adopted my parents had no idea my factor level was so low and looking back so many instances make much more sense.

HOW WAS YOUR CHILD WAS DIAGNOSED; HOW DID IT AFFECTED YOUR FAMILY?

Kalee: Henry was diagnosed 2 days after his birth when his circumcision would not stop bleeding. At first, it really shook our family. As time has gone on it has made my husband and I even closer. My son's hemophilia has made me step back and really appreciate the important things in life. It is still so new to us and we are constantly learning, but I feel like it has made us slow down, smell the roses and be more patient parents.

Denise: Jacob wasn't diagnosed until 6 months old during a routine heel stick that bled excessively. We ended up in the ER where he was tested. We were able to get the girls tested about 2 years ago as part of a case study. Jacob's diagnosis was such a shock. Even worse, right after we found out, my husband had to deploy for the first time. I ended up going home to my parents to have additional help while he was gone. It was very hard for my hubby and me. We knew he was going to be gone for a significant amount of time – it ended up being 15 months in Iraq. When Brody was born, we knew what to prepare for and had him tested right away. At 8 days old we confirmed that he has severe hemophilia.

Jon: The initial unknown regarding what to expect from day-to-day was hard. It was very difficult to send my wife and newborn child to her mother's as I deployed to Iraq. I worried tremendously but did feel good that they were in the hands of other family members while I was away.

HAVE YOUR FEELINGS ABOUT YOUR CHILD'S DIAGNOSIS CHANGED OVER TIME?

Kalee: In the beginning, the devastation of not having a, "healthy newborn," was overwhelming. It took about a year for us to really catch our breath. There was so much to learn and at first, the scary stuff was front and center in our brains. As soon as Henry went on prophy, our lives changed. Things shifted back to normalcy. Other than some extra work with infusions and give or take some hard days, bad infusions, or emergencies, we feel we are in a really good place with the diagnosis.

Denise: The shock gives way to acceptance and things do get easier. Self-infusion has been a game-changer for us. Jacob infuses himself (with us there) and that has been a big confidence booster. He also no longer has a port, so fevers don't scare me as much as they used to. At times, Jacob doesn't realize how various situations can affect him compared to kids who don't have hemophilia. Things have gotten easier since the initial diagnosis, yet there are always times of worry and concern, though those times have become fewer and further. With Brody, the whole process is starting again.

Jon: For me, it hasn't changed too much really. Especially after we received additional diagnoses for my oldest daughter, my wife, and now my 3-month-old, the challenges take on different forms as time goes on. I've extended my military career in part to make sure my family retains access to care.

> **"We are having to slow down and really think through our major life decisions."**

MILITARY LIFE:

HOW OFTEN HAS YOUR FAMILY EXPERIENCED A PCS (PERMANENT CHANGE OF STATION) AND WHAT HAS THAT EXPERIENCE BEEN LIKE WHEN CARING FOR A CHILD WITH A CHRONIC HEALTH CONDITION?

Kalee: We have moved 6 times, but only once since Henry was born. Moving has been tough, time-consuming and emotional. Organizing everything, speaking with new people and explaining the diagnosis is the most exhausting part so far. For example, our last pediatrician was in the know about sub-q options for vaccinations. Getting the new pediatrician on board took about two weeks because he did not take my word for it. I had to drag both kids to the appointment, have the sub-q vaccination request turned down, contact the HTC, get the okay from the HTC, get in contact with the pediatrician to discuss, then have the pediatrician go to the immunization clinic in the military treatment facility (MTF) to explain the reasoning for the sub-q vaccinations.

Ryan: I was actually supposed to deploy approximately 30 days after Henry was born. Due to the challenges and stress associated with his diagnosis, combined with the support my family needed during this time, the military deferred my deployment. This was immensely helpful to get a handle on the situation and come to terms with what Henry's care and medical needs would be. I eventually deployed when Henry was closer to 2 years old. While it was indeed stressful for my wife to handle Henry's needs on her own, his diagnosis has become a normal part of our lives and we are comfortable with the situation at this point. It's a process for many things. Getting

> **"Moving and being on the road for months at a time can be tough. We stay in a lot of hotels.**
>
> **My mom helps a lot. She makes sure the space to infuse is as clean as it can be but when we're not living in a house it can be difficult! It's hard also for our pets. We recently lost one of our dogs and that was very hard.**
>
> **I like being able to travel but wish we wouldn't move so much. I'm looking forward to not having to move again. Changing schools and leaving friends is hard."**
>
> **Jacob – Son of Denise and Jon**

new care providers is also stressful. We were very comfortable with our caregiver in New Jersey but having to search and find a new one is time consuming, stressful and repetitive.

Denise: We've moved a lot. Officially, we have PCS'd I believe 7 times, but we have moved for one reason or another about 14 times. Moving and re-establishing care is always an issue. First, we have to get the move approved by the Exceptional Family Member Program (EFMP). Once we move, we have to see a primary care physician before we receive a referral for the hematologist. We have faced challenges where the people we're working with have a hard time understanding the nature of hemophilia because my son does not appear to be "disabled." Once we had to stay in a hotel for over two months while we waited for a more permanent residence. At the time, with 4 kids and 2 big dogs, being stuck in a tiny room was pretty tough, to say the least. We basically have to make sure we always have the medications and supplies on hand to prepare for the move until we can get to the next semi or permanent address.

WHAT HAS BEEN YOUR GREATEST CHALLENGE AS A MILITARY FAMILY RAISING A CHILD WITH A BLEEDING DISORDER?

Kalee: Our greatest challenge has been the medical side of it all. In the military, your doctors can be deployed, or PCS'd and you find yourself starting from scratch with someone new. In the 3 years we were on the East Coast, I alone had 3 different primary care physicians. Henry has already had 2 different primary physicians. Also difficult is receiving medical care when traveling away from the home station. When my husband is gone for long periods, it makes more sense for me to stay with my family. This can create challenges for receiving medical care. Making sure we have a treatment center and infusion options while not at our home station has been challenging.

Ryan: Being geographically separated from extended family is the greatest challenge. It would be far easier to have grandparents, aunts and uncles nearby to help with support when we need to do infusions or ER visits, etc.

Denise: I would have to say the greatest challenge is the constant moving and trying to re-establish medical care. When my husband is awaiting orders, we have additional screening to go through to make sure our placement includes access to the medical professionals required for our family. Every move requires finding a new primary care provider, then we are referred to a hematologist. We do our best to make it through these "in-between" times, but sometimes the wait conflicts with our needs – especially if a factor script expires or we get low on product before we can secure an appointment.

HAVE YOU EXPERIENCED ANY ISSUES ACCESSING CARE OR SERVICES?

Kalee: Our spouses can be gone for long stretches for training and deployments. During those times, being alone and away from family is difficult with small children. Especially if you just moved to a new place and haven't made good friends yet. This is my current situation. I haven't had the chance to really make solid friendships where you can ask them for family-style favors (i.e. drop kids off in an emergency). I am currently alone as my spouse is deployed and my family is 5 hours away. It's easier for me to drive and stay with my family and have help for an extended time; however, there are hardly any nearby TRICARE military treatment facilities where my family lives. This means we have to rely on out-of-network care and getting that approved is hard, especially because I'm told it is my choice to go stay with family, which is true, but it's not my choice to have my spouse gone and not have any local help.

Ryan: Another issue is explaining Henry's diagnosis to new doctors, nurses and medical insurance coordinators every time we move or switch primary care providers. Most general care practitioners seem to have limited knowledge of the specific needs and we have to do a lot of educating to be given referrals and proper attention.

Denise: For the most part we've been very fortunate and have not experienced too many problems accessing care or services other than those I described earlier. I remember one time the pediatric hematologist we were seeing closed his practice. It was quite a scramble to find another physician versed in hemophilia and then obtaining a new referral. There was a lot of back and forth on the phone, and when we finally got things settled, the hospital was over two hours away. That was definitely challenging!

> **"Henry's diagnosis was at the forefront of the military's consideration when I was last re-assigned to a new installation."**

HOW HAVE YOU WORKED TO OVERCOME OR MITIGATE ANY CHALLENGES?

Kalee: I have focused on getting involved in the hemophilia community and meeting other families. It has helped me to talk out any challenges with other experienced parents. I reach out to get their perspective and advice. I have attended a couple of educational dinners and the Coalition for Hemophilia B Symposium this last March as well as their Meeting on the Road in St. Louis. I also joined the St. Louis Gateway Hemophilia Foundation. I find that the more I attend and the more hemophilia families I meet, the more I learn!

Ryan: To help educate providers and advocate for Henry's needs, my wife keeps meticulous records of all doctor visits, medical records and infusions. The military ensures family members who need special medical services are prioritized and considered to determine an optimal balance between the military member's career path and the family member's medical needs. Working together helps minimize challenges. Henry's diagnosis was at the forefront of the military's consideration when I was last re-assigned to a new installation. We were very fortunate that the assignment I was given provided excellent care for Henry and was also my top choice for career goals.

Denise: We are very grateful for the care we receive through TRICARE. I always try to do my homework to minimize the impact of all the moving around. I am very persistent when it comes to my kids and their care. As soon as we move, I quickly set up all the required primary care appointments so we can get the appropriate referrals in. That's one thing I do wish was different – for those with lifelong chronic illnesses, requiring a primary care appointment for a referral to a specialist can create setbacks and delay our access to care. Hopefully, one day, that will change.

WHAT HAS BEEN YOUR GREATEST SUCCESS?

Kalee: So far, our greatest success is doing home infusions with a nurse once a week. We were not sure how Henry would react and were told if it didn't go well, we would need to have a port placed. I worked with him on play therapy and tried to stay organized with infusions and make it a family event. We usually do popsicles or suckers and get pizza and wings. It's now a family affair - we all help. Our daughter Penny is our bandage girl, my husband and I prep the medication with Henry and let him pick which spot he wants his infusion. He's come a long way from being burrito wrapped and needing 3 people to hold him steady - now it takes just 2 and Henry mostly sits still.

Ryan: Generally speaking, our biggest success with Henry's diagnosis has been learning to understand hemophilia and coming to terms with how manageable it is. Once we realized children who grow-up with hemophilia today live very normal lives with proper care, it made the scope of what we were dealing with seem much easier to handle. The care and consideration we have received from the military with Henry's diagnosis has been excellent.

Denise: Everything we've gone through has made us stronger and the ability to adapt has become one of our strengths as a family. That adaptability has helped us immensely as a family. Another great accomplishment occurred when Jacob learned to self-infuse. He has also loved the opportunity to go to bleeding disorders camp.

Jon: Serving our country and being able to provide my children access to the care and services they need has been my greatest success. It definitely hasn't been easy, but we do it daily and will continue to get through it together.

RESOURCES:

WHAT KIND OF RESOURCES ARE AVAILABLE TO MILITARY FAMILIES? WHAT OTHER ISSUES HAVE YOU ENCOUNTERED?

Kalee: Our main resource has been the Exceptional Family Member Program (EFMP). This program provides advocates to help you navigate parts of the medical system, provides childcare, and has events to connect with other families. I think the military tries hard to take care of their families. The hardest part is taking advantage of all the resources they offer especially when the military member is deployed. We have been able to obtain childcare through the EFMP program. It was a challenge finding the right people, but the option is there.

Many resources exist, but some take a lot of paperwork and a lot of effort to be able to participate. There are always requirements required to be a part of the program. In my case, there always seems to be a missing document. It's never simple and straight forward, there are always a bazillion steps, or that's what it feels like to me. There's a lot of red tape. In terms of support, it all depends on the service member's squadron and whether they have good leadership and value connection. Some really reach out and help each other while

Ryan: There are many resources available. For us, the best resource has been Respite Care, which offers up to 40 hours per month of childcare to help alleviate the challenges associated with military children with difficult medical diagnoses.

Denise: Juggling the medical stuff is a challenge, but school changes for the kids have been incredibly difficult. Two of the 3 who are now in school are having a hard time adjusting and adapting. That isn't because of hemophilia, but because of the military lifestyle. Concerning childcare, since our family is large and we now have 2 with severe hemophilia, I've never had them in childcare. One of our children has severe anxiety so it makes the moves and transitions even harder than normal.

IN CLOSING:

HOW HAS HAVING A CHILD WITH A BLEEDING DISORDER CHANGED YOUR LIFE AND WHAT DOES THE FUTURE HOLD FOR YOUR FAMILY REGARDING CONTINUING MILITARY SERVICE?

Kalee: Before Henry's diagnosis we felt like we knew our path in life. We could see it all spelled out. Now it's just given us pause. We are having to slow down and really think through our major life decisions. We don't know what our future holds for sure. We are grateful we have the option to continue with the military and have very good healthcare.

Ryan: Henry's diagnosis has limited some options. For example, pursuing overseas assignments and certain assignments in remote locations that do not have the appropriate medical support for hemophilia. However, my wife and I decided even before Henry was born that overseas and remote assignments were not something that we were interested in pursuing while raising our children. In the grand scheme, however, the diagnosis has had minimal impact on my personal career goals.

Denise: Even though we think it didn't, our lives have changed so much. My husband always wanted Jacob to play contact sports just like he did, so coming to terms with that reality was somewhat difficult. My husband has 4 more years of service and would love to be able to get out at the 20-year mark, but now with the baby's diagnosis, we are worried about our financial future. With 3 of our children requiring specialty medications, making any change is a little scary.

WHAT ADVICE WOULD YOU GIVE TO ANOTHER MILITARY FAMILY WITH A BLEEDING DISORDER?

Kalee: The hemophilia community reminds me, in a sense, of military families - it is an instant bond that happens because of a shared lifestyle. The advice I would give a new family would be to get out there and join the hemophilia community. I am so glad I did! It has helped me overcome fears. I've learned a ton and have made new friends!

Denise: Staying strong is the hardest, yet the best thing to do. There is always hope and there will always be others who are going through, or have gone through, similar times. Although it's often harder to say than do, reach out for help if you need it!

Resources:

1. Huebner, Chadley. (2018). American Academy of Pediatrics. Health and mental health needs of children in US military families. (143,1) doi: 10.1542/peds.2018-3258
2. Rapaport, Lisa. (2019). Physicians Weekly. US military families face challenges getting healthcare for kids. https://www.physiciansweekly.com/us-military-families-face/

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[BIOMATRIX] ON THE MOVE


BioMatrix Care Coordinator Gaby Griffin and community members Yeni, Andrew and Milton pause for a photo

CALIFORNIA

Gabriela Griffin

Though the start of June 1st was dark and cool – not a typical southern California day – community members arrived at the San Diego Zoo for the ***2019 Family Information Day*** on time and ready to learn! Following a warm welcome by Hemophilia Association of San Diego County (HASDC) Board of Directors President Sean Pentz, three very helpful and interesting sessions were presented:

- Athletic Program Specialist Andres Flores and Physical Therapist Peter Aguero at The Hemophilia and Thrombosis Center at UC San Diego discussed differences between athletic training and physical therapy. Together, they explained how each one can help strengthen muscles, prevent diseases and maintain joint health.
- Dr. Courtney Thornburg, Medical Director of the Hemophilia and Thrombosis Treatment Center at Rady Children's Hospital-San Diego and Director of the Hemostasis and Thrombosis Research Program presented *Treatment Options for Hemophilia in 2019 and Beyond*.
- Amalia Vega spoke about *Mindfulness*. She explained how it can help us navigate through life and its benefits to body and mind to promote a healthier lifestyle.

By the end of the program, the day had brightened up beautifully and community members were able to spend the afternoon exploring the zoo and visit all the fantastic animals. Thank you to HASDC Executive Director Nooshin Kosar and her team for all their hard work in organizing such an ideal event!

OHIO

Shelia Biljes

When life gives you lemons... have lunch with friends! BioMatrix partnered with Octapharma on June 6th at TGIF in Brooklyn to host an ***Educational Luncheon*** for a group of interested community members. Ordering from the menu, everyone chose their favorite dish and, keeping with the lemon theme of the gathering, each meal came complete with personal lemon Bundt cakes and, of course, refreshing lemonade to drink.

Octapharma Nurse Educator, Martina Willis-McCullough provided a fantastic presentation focused on microbleeds. An hour of great conversational exchange followed leaving everyone with newfound knowledge of microbleeds.

OHIO

Shelia Biljes

Together with Octapharma, BioMatrix welcomed over 50 guests to the Ice Cream Parlor party room at b.a. Sweetie Candy Company on June 6th in Cleveland where we met for an ***Educational Dinner***. While we enjoyed a variety of pizzas, Octapharma Nurse Educator Martina Willis-McCullough presented *To Treat or Not to Treat, That is the Question*. Being a mother of four, Martina knows how to foster contributions from children. She had the kids asking and answering questions and being fully engaged. The group involvement was exceptionally rewarding!

An ice cream bar with over 25 flavors of homemade ice cream and 10 flavors of old-fashioned sodas provided an abundance of choices to quench everyone's thirst on such a warm day. For those interested, a round of mini-golf was on the evening agenda. However, the majority preferred to remain in the air-conditioned party room and visit with friends. A sweet time was had by all!


Tyler and Miya - So Sweet!

BIOMATRIX ON THE MOVE


Dan, Axel, Jon and Jim take to the links for BDAI's annual *Driving fore Hemophilia!*

ILLINOIS

Eva Kraemer

Bleeding Disorder Alliance Illinois (BDAI) hosted its 22nd annual ***Driving fore Hemophilia*** golf fundraiser June 17th at Orland Park Silver Lake Country Club. The day was ABSOLUTELY fabulous, being neither too hot nor too cold – just the most perfect day to be outdoors! BDAI's Executive Director Bob Robinson, staff and volunteers provided 18 challenging holes of golf while raising funds for important programs. Later at the clubhouse, we met for food and the raffling of sports paraphernalia, including Chicago Bears and Cubs tickets. Everyone's generosity enhanced the flawless day. BioMatrix was pleased to have sponsored a foursome.

VIRGINIA

Michelle Stielper

The Virginia Hemophilia Foundation (VHF) has done it again! This year's setting for the chapter's ***Annual Education Meeting*** was the beautiful Natural Bridge State Park. Families stayed at the Natural Bridge Historic Hotel and Conference Center where sessions were held Saturday morning on genetics, vWD, and the future of gene therapy and products.

Young community members enjoyed some great time together and entertained us with a silly skit before dinner on Saturday evening. We may have some future Hollywood stars in our midst! After dinner, the families attended the Natural Bridge Drama of Creation light show under the stars – a truly magical experience! Sunday after breakfast families were free to roam the 180-acre Virginia Safari Park where they could take a tractor-drawn wagon ride and feed the animals. More memories made and another unforgettable annual meeting on the books for the VHF!

OHIO

Rania Salem

Family and friends of the TriState Bleeding Disorder Foundation (TSBDF) gathered for another terrific sun and fun-filled ***Family Education Day at Coney Island*** in Cincinnati June 22nd. Enjoying a great picnic-style lunch, visiting industry representatives, and meeting up with old friends while making new ones was only the beginning. Our much loved and now retired hematologist, Dr. Ralph Gruppo, made an appearance! He had always been so dedicated to the families that he cared for. It was a treat to have him with us!


Benjamin, Jackson and Renee enjoy their day at Coney Island!


Is there any doubt that Jackson is having a blast?

Along with being the home of the world's largest Sunlite Pool, Coney Island features classic rides, golf and boating fun on Lake Como! Although rain eventually arrived, it did not dampen the excitement of the day. Thanks to TSBDF for hosting this wonderful family-oriented event!

MISSOURI

Eva Kraemer

Celebrating its 50th anniversary, Gateway Hemophilia Association (GHA) hosted its annual ***Family Education Weekend*** July 12-14 at the Chesterfield Doubletree. From all over the state, several newly diagnosed families joined existing bleeding disorder families for fellowship and support of their chapter. An exciting

array of breakout session activities made for an extraordinary educational experience.
Executive Director Bridget Tyrey and GHA Board President Anne Parrott gave the group a warm welcome. Everyone's favorite, "Big Dog," Pat Torrey talked about finding your Gut Monkey – that thing that inspires you. Debbie De La Riva, LCP, founder of *Mental Health Matters Too*, discussed the connection between mental and physical health as well as resources available for mental health care.

There were several breakout sessions to choose from including *Leading Edge 2019: Making Change When Change is Hard*, *vWD Panel – Ask the Experts*; *Self-Infusion, New Product Update*, *Less Stress – More Living; Impact of Stress on Physical and Mental Health*; *Ways to Manage Anxiety*, *"Let's Talk Period" Mothers and Daughters*, *Be Mindful: Manage Your Pain* and *Stretching Techniques*.

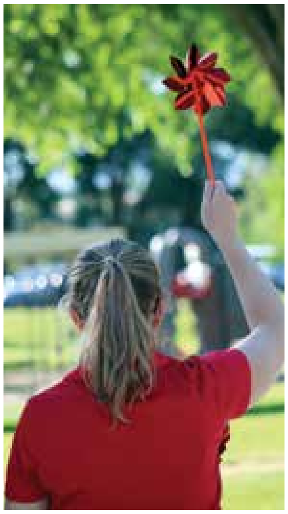
After the sessions, the families gathered for a "dive-in movie" by the pool to view *Smallfoot*. BioMatrix was honored to have participated in such a well-planned, well-attended event!

Celebrating 50 years! Eva Kraemer and GHA Executor Director Bridget Tyrey show off a special "50" comprised of community photos

NEVADA

Kelly Gonzalez

Moms, dads and kids excitedly anticipated the Northern Nevada ***Family Education Weekend*** held every second year in Elko. The evening of Friday, July 19th began with dinner at the Elko Convention Center where an educational presentation was given on accommodation plans in school. The next day brought a robust variety of educational programs including *Back to School*, *Anxiety and Depression*, *Advocacy*, and more. Meanwhile, the younger set was having all sorts of fun! Leaders-in-Training had big plans for fun and excitement including balloons, park time, games and more games!



After the daytime events, the group participated in the ***First Elko Unite for Bleeding Disorders Walk*** and a barbecue in Main City Park, adjacent to the convention center. The fun wasn't over yet! Activities continued at a nearby family bowling center where all sorts of strikes were being thrown!

Sunday's activities were more toned down as additional programs related to parenting and the Parents Empowerment Program (PEP) were held. Thank you to the amazing people of the Nevada Chapter of NHF, the Hemostasis and Thrombosis Center of Nevada, the industry supporters, and especially to the amazing community of Nevada!

Ready to welcome visitors!

Family Tree Project

Kelly Gonzalez presents

Family Bowling was LIT


Carter, Carmello, Cameron, Chardea, Tiffany and Alaina


Colin, DaShawn, Cameron, Bryan and Jordan


Tony and Brooklyn, Lily and Star

OHIO

Shelia Biljes

If you have never been to a ***Flamingle*** you are missing out! In partnership with Novo Nordisk, BioMatrix invited Northern Ohio families to attend their own version of Flamingle July 24th at Strongsville's Brew Garden Restaurant. With over 50 in attendance, it was a sea of pink as everyone reveled in a Flamingo mood!

The evening began with a remarkable presentation life story by Novo Community Advocate Speaker Vaughn Ripley. Brought back by popular demand, this was our second occasion featuring Vaughn, who kept the audience captive as he shared his heart-wrenching life story. Families were eager to talk to Vaughn one-on-one throughout the evening.

After the presentation, we moved on to an amazing dinner featuring lemon chicken, roast beef, mashed potatoes and pasta alfredo followed by delicious desserts. As we enjoyed our meal, everyone learned something new as we played Flamingo Trivia. Did you know that flamingo parents sit on the eggs together? Or that flamingoes are born white and eventually turn pink from the daily crustacean and shrimp they consume? We also learned that a group of flamingos is called a "pat" and that a flock is called a "flamboyance." Just the word makes me smile.

The younger kids tried their hand at ring toss, working to get rings over flamingo necks. The awarding of the hand-crafted Flamingo wreath came next. Very appropriately, the winner was a family from Parma, Ohio, a town historically known for its plastic yard flamingos that were introduced in 1957, as we learned in our round of trivia!

Social time followed, everyone snapped photos, and no one seemed too eager to leave. The weather was gorgeous, and the families gathered on the patio for time to talk and play cornhole. There's nothing more enjoyable than a good, pink-infused FLAMINGLE!


Maddie and Gabby


Kelly and Charlene


Ceiera and DaShawn


Jordan and Jordan!


Hannah Lombardo and Shelia Biljes


Calissa

FLORIDA

Peggy Klingmann and Marcy Foertsch

Together Bayer and BioMatrix partnered to serve Hawaiian cuisine and ***Education*** at Roy's Restaurant in Tampa July 24th. Well attended with community members and staff from the University of South Florida's Adult Hemophilia Treatment Center, Bayer presented a program about Jivi and detailed the recent Kogenate FS recall. Thanks to Dave Lau and Jennifer Harris, RN, BSN for facilitating and making our evening a fun and enjoyable time!

PENNSYLVANIA

Shelia Biljes

Dave & Buster's never gets old when you love gaming! It's was the perfect location for the July 25th Western Pennsylvania Hemophilia Foundation's (WPNHF) ***Annual Meeting*** in Homestead. Over a hundred chapter members attended the meeting to review chapter financials, discuss upcoming events, enjoy a meal together, and finally, PLAY!

Booth visitors shared an hour with industry representatives getting to know their company's products and services. The BioMatrix booth offered fun backpacks for kids to decorate and fruit roll-ups as a snack as we waited patiently for dinner to be served.

During dinner, each manufacturer gave a product update and chapter business was discussed. Each member then received a Dave & Buster's game card to play. Walk teams wore their team shirts and worked hard at recruiting walkers and donations. It was a fun evening for everyone!

Mindy and Steve promote their walk team in style!

Ryker

FLORIDA

Johnny de la Fuente, Hector Heer, Peggy Klingmann and Marcy Foertsch

This year's ***36th Annual Florida Bleeding Disorders Conference*** took place at the Hilton Palm Beach Airport Hotel July 26–28th. As we have delightfully come to anticipate, Executive Director of Florida Hemophilia Association Debbi Adamkin and her dedicated team hosted a spectacular event with a thoughtfully considered agenda. From educational sessions to interactive family activities, everyone came away with a deeper understanding of important information, and of course, many fantastic memories!

The agenda offered a wide array of subject matter ranging from medical marijuana to von Willebrand disease and stress management. Breakout sessions provided valuable information that will continue to improve quality of life. Children and teens living with a parent or siblings with hemophilia were given a platform of creative expression to gain a deeper understanding of the impact the disease has on their daily lives.

Christina V. and Juan Bruno de la Fuente bring on the smiles!

The most popular session focused on *Gene Therapy in Clinical Trials*. Led by Rhonda Fritz, PNP, the session provided an update on the progress being made in gene transfer research as well as gene therapy. With the highlight on the topic of vectors, this session was so popular that people had to be turned away at the door!

Feeling all Hawaiian! Mily, Kim and Myriam with Juan Bruno de la Fuente

In addition to the informational sessions, there was also the opportunity to attend more practical sessions that discussed topics such as insurance and infusions. Much care was given to provide all members of the bleeding disorders community sought-after material. Round table sessions gave patients a unique opportunity to interact one-on-one with a rock star panel of physicians including Dr. Joanna Davis, Dr. Christopher E. Walsh, Dr. Tung Wynn and Dr. Sidonio. These physicians generously gave their time to answer patients' questions and concerns.

The final event was an outstanding Hawaiian-themed gathering for all to enjoy! And enjoy they did with an entertaining deejay, delicious buffet and a fun photo booth to capture and share these memories with family and friends. We look forward to next year - hula skirt optional! Aloha!

NEW MEXICO

Felix Garcia

Saturday, July 27th was a great day for the New Mexico bleeding disorders community! A happy group of nearly 60 people gathered at Lucky 66 Bowl in Albuquerque for Sangre de Oro's (SDO) annual ***Back to School Event***. This is one of SDO's favorite places to gather since it's right across the street from the office. SDO likes to make the most of every opportunity to educate the community and this was no exception. Yes, there was bowling involved… it came after the education. Yes, there was pizza involved… it came during the education, and yes, there was fun and camaraderie… it was everywhere the whole time!

Thumbs up from Patricia, Felix Garcia and Sandra!

Focused on how to prepare for and speak to school staff about bleeding disorders, Takeda provided a great program for parents of elementary-age children. Programming also touched upon 504s and IEPs. Middle and high school students enjoyed a presentation sponsored by Bioverativ, which focused on preparing for the future and how to take control of situations that may arise at school when parents aren't around.

The sun still shines hot in New Mexico, but the days of summer vacation are winding down. Students will soon be back in class with sharpened pencils in tow. Sangre de Oro made it a bit easier by providing backpacks filled (and I do mean filled) with school supplies for each child in attendance. With bookbags ready, minds opened and hearts filled, everyone came away from this event ready for the next school year!

SOUTH DAKOTA

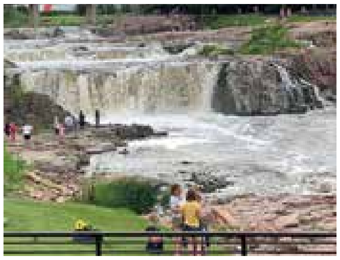
Shelia Biljes and Eva Kraemer

The weather was perfect for Hemophilia Foundation of Minnesota/Dakotas to host their ***Education Event*** at the Great Plains Zoo July 27th in Sioux Falls. The Delbridge Museum was the perfect location for over 75 members to first gather for a fun, picnic-menu lunch.

Shirley and Tom have fun exploring the museum

Presentations from two well-received speakers were featured. First was Nathan Anderson, Social Worker at Sanford HTC In Sioux Falls began with updates and ended with a humorous poem he created right on the spot that brought a lot of laughs. He was followed by HTC pediatric physician Dr. George Maher, who opened with funny animal jokes and continued with a very informative talk on new treatment techniques and gene therapy.

The children were in full concentration as they colored designs on backpacks found at the BioMatrix booth. Chapter Director Jim Paiste wrapped up the event with chapter updates, information on the new walk location and a warm welcome to the many new families. As wrist bands for the zoo were handed to attendees, some families said goodbye while others decided to tour the zoo together. The weather thankfully cooperated, and everyone had a great time!



IDAHO

Jeff Johnson

The Idaho Chapter of NHF held its annual ***Education Conference*** August 2nd-3rd at the Boise Riverside Hotel, next to the Boise River. Twenty-five families from southern Idaho gathered to learn about the latest advancements in treatment for bleeding disorders and how to manage bleeds by properly wrapping joints and self-

infusing. They also learned how to manage insecurity when dealing with the psychological and emotional challenges that come with bleeding disorders, and how to lift yourself and those around you up when life and bleeds get you down. A *Blood Brothers* breakout session, as well as sessions for teens and parents, provided everyone an opportunity to share experiences and gain valuable insight from others walking in their shoes.

The weekend ended with dinner together, followed by having fun and splashing in the pools and waterslides at the Roaring Springs Water Park. It was a refreshing way to cool off from the hot summer sun! Many thanks to the Idaho Chapter team for organizing this popular event!

CONNECTICUT

Cheryl Ashmore

As midsummer in New England reached its peak the first weekend of August, more than 40 women from 6 states met August 2nd–4th to recharge spirits and renew friendships. The New England Hemophilia Association sponsored this popular ***Women's Retreat*** at the Guest House Retreat and Conference Center in the small, quaint village of Chester. The property's quiet, roomy spaces and beautiful, shared guest rooms fostered both a sense of introspection and an opportunity to create new friendships.

Facilitator Kelly Gonzalez and NEHA Program Director Heather Case added even more significant programming to an event already known for its value to the community. The weekend was a time for connective bonding and nurturing activities, each creating thoughtful, deliberate space for the women to stretch out, put their busy lives aside and add to the strong foundational network of NEHA women.

Beginning with a customized group-focused icebreaker early Friday night, Kelly and Heather gently guided the women into thought-provoking sessions and semi-structured free time that brought a balance of laughter and tears, and at times dug deep into the rawness and anxiety that comes with being affected by a bleeding disorder. Educational session topics were relevant and impactful, including workshops on mindfulness and meditation, *Tools and Tips for Self-Care*, *Strength Through the Struggle*, and *It's Ok to NOT be Ok*. Lighter activities were scheduled throughout the weekend to encourage conversation, laughter and creativity. Attendees made bracelets and candles and enjoyed a pajama party complete with '80s movies and manicures.

A young mom and first-time attendee summed it up perfectly: "I never expected to be a part of anything like this. Deciding to attend was far out of my comfort zone, and the fast camaraderie and supportive community came as a total surprise. I am grateful to be moving forward in life with this amazing group of women!"

OHIO

Rania Salem

Todd, Abigail and Amanda enjoy a beautiful day at FAMOHIO!

The first weekend of August is always an exciting time for Ohio families affected by bleeding disorders! FAMOHIO Bleeding Disorder Safari took place August 2nd–4th at the Dublin Marriott NW. The Family Annual Meeting of Ohio is a much-anticipated event for folks from all 5 Ohio chapters to gather under one roof to share stories, hang with old buddies, meet new families and learn the latest about bleeding disorders. This year's theme was *See Us Soar – Hear Us Roar*, and whether learning about new products hitting the market, the future of hemophilia or navigating insurance, there was something new for everyone.

The weekend began Friday evening with dinner followed by the annual fitness walk, cooling off with a trip to the famous ice cream truck and hanging out with friends. Saturday was a day for a little fun and a lot of education. Session titles included *My Bleeding Disorder*, *Exercise for Everyone*, *Medicare 101*, *Choose to Take Control*, *Medical Marijuana*, and my favorite session, *New Products and the Future of Hemophilia Treatment*. Dr. Riten Kumar did an amazing job recapping where we've been and where we are heading. It is always fascinating to see year-after-year how much we have advanced in the bleeding disorder world.

After a productive day of learning and meeting with industry representatives, families filled up buses and headed to the Columbus Zoo! With zookeepers on hand for animal presentations, families walked around the exhibits at their leisure and enjoyed dinner and s'mores before heading back to the hotel.

Abigail visits the elegant pink flamingos!

The next morning was time for breakfast, a wrap-up and a special viewing of *Bombardier Blood* depicting the adventures of real-life hemophilia hero, Chris Bombardier. The film captures Chris' journey through Nepal where he summited the world's tallest peak, Mount Everest. Chris partnered with fellow hemophilia filmmaker Patrick James Lynch and Executive Producer Alex Borstein for this extraordinary documentary that brought both tears and smiles to the audience.

A special "thank you" to FAMOHIO for another outstanding event!

TEXAS

Richard Lopez

Care Coordinator Richard Lopez staffs the BioMatrix booth

Gathering to show strength in the El Paso Community, over 180 attendees participated in Hemophilia Outreach of El Paso's (HOEP) annual ***Back to School Education Event*** held August 8th at the El Paso Embassy Suites. Getting students back to school informed, empowered and in style were the anchoring goals for this well-planned event.

Families garnered an overwhelming amount of support and school supplies from industry partners and the HOEP team. Each of the 50+ students was provided with a book bag loaded with supplies to help ready them for the new school year.

Backpacks all filled and ready!

Presenting sponsors BioMatrix and Octapharma hosted breakout sessions and a plentiful dinner. Nearly 200 people filled the room to near capacity and energy was at a peak, but soon the attention of the crowd turned to listen to Fernando Reyes, Octapharma Education Specialist, and Kelly Gonzalez, BioMatrix Education Specialist.

Fernando's session was given in Spanish and shared an informative message on *How to Identify and Prevent Bullying in School*. Fernando facilitated an interactive discussion helping adults identify if a child is being harassed and shared practical examples of how parents and students can better communicate with each other and with the school administration to help prevent bullying.

Students and parents were treated to another important topic as Kelly Gonzalez gave a compelling presentation on *Transition to School* highlighting the importance of 504 Education Plans for students ages 3-22 with a chronic illness. Kelly did a fantastic job engaging the audience as she presented information on how to develop and implement a 504, knowing which accommodations to ask for, and empowered parents and students to feel prepared in making their requests. Kelly likened a 504 plan to a safety net for a trapeze artist, "You wouldn't want your child-acrobat to be practicing without a safety net and potentially having a fatal fall." She asked, "Why wouldn't you consider having a 504 plan in place as a safety net should your child's chronic illness interrupt their academics to a serious status as well?" Parents were very eager to continue the discussion and eagerly ask Kelly more 504 Plan questions.

Especially so soon after the August 3rd shooting rampage at an El Paso Walmart, we were inspired to see our community come together to support one another. Thank you to HOEP and industry sponsors for making this event possible! We at BioMatrix look forward to our continued support of the El Paso bleeding disorder community.

OHIO

Shelia Biljes

Where has summer gone? It's time to send the kids back to school so BioMatrix took part in the ***Family Education Day*** hosted by the Northern Ohio Hemophilia Foundation (NOHF) to help prepare families. It was a great turn out August 10th at Cleveland's Great Lakes Science Center. The weather cooperated, giving beautiful views of the city skyline and Lake Erie's horizon! Sponsoring exhibitors' booths welcomed community members, readily providing information regarding products and services offered by their company.

Akron Children's HTC Social Worker Doug Palmer met individually with families to determine if any assistance was needed in setting up a 504 Plan for school-age children. Chapter member and employee of Cuyahoga Community College Danielle Schwager was available to assist older students with college resource needs. Meanwhile, NOHF Board Member Bob Scaccia was kept busy on his computer signing families up for the upcoming Unite for Bleeding Disorders Walk September 7th at the Akron Zoo.

Boxed lunches were served at noon and then families were off to visit the many exhibits at the Science Center. It was the perfect way to get the kids back into the learning mode and excited for school to be back in session!

The BioMatrix booth draws lots of visitors!

Colin, Calessa and Diane concentrate on their creative designs

Korbin and Caleb prepare to pitch

TENNESSEE

David Tignor

For 13 years straight, Shane and Kelly Wood, with the help of a great team of volunteers, organize a much-anticipated event in honor of their son, Caleb, who lives with von Willebrand Disease. Centennial Park in Crossville was the place to be Saturday, August 10th for the "Pitchin' for Caleb" Cornhole Tournament.

Prior to the tournament getting underway, participants were able to practice tossing bags. Teams of two were randomly assigned and play was underway for the 15 competing teams, with an excited audience observing from the bleachers. Teams played hard then broke for lunch, provided by local community members, Scotty and Ronnie Webb. After the nourishing meal came the elimination tournament. When the final scores were tallied, winners were announced and awards presented.

Participants and attendees enjoyed this exclusive fundraising event where funds help support the Tennessee Hemophilia and Bleeding Disorders Foundation Camp Freedom! BioMatrix was a proud sponsor of this tournament and we look forward to participating again next year! To learn more about "Pitchin' for Caleb" and the Tennessee Hemophilia and Bleeding Disorders Foundation please visit: https://www.thbdf.org/pitchin-for-caleb

BIOMATRIX ON THE MOVE

Douglas Estrada,SW Nicklaus Children's Hospital, with Hector Heer

FLORIDA

Hector Heer

Heavy rains August 11th diminished attendance, yet over 80 people showed up for Foundation Hope & Life's ***6th Awareness Event - Back to School*** held at the Royal Palace Ballroom in Miami Lakes. After time to visit industry exhibit booths, Executive Director Ana Calero welcomed everyone and introduced an informative session on *Back to School – Safety and Bleeding Disorders* led by Samantha Blain-Maiza, RN, BSN. Her session covered everything from backpack safety, educating school staff and individual healthcare plans to playground safety and psychosocial support. Samantha was joined by three young community speakers. Ten-year-old Leo spoke about school bullying, 15-year-old Karol discussed drug issues and 17-year-old Jocsan talked about toxic friendships. These were very impressive young people!

The children each received brand new backpacks brimming with all sorts of school supplies. It was fun to see them so excited and looking forward to the start of school. Thanks to Ana and her team for organizing this brilliant event!

TENNESSEE

Cyndy Coors, David Tignor, Dave Burgeson

Keep It Moving - Bleeding Disorders Don't Run Us, They Run with Us! was the inspirational theme of this year's Tennessee Hemophilia and Bleeding Disorder Foundation's (THBDF) ***49th Annual Meeting*** August 16-18 at the Holiday Inn Downtown Knoxville.

Bright eyes and a pretty smile, here's Temperance!

This well-attended meeting is a wonderful opportunity to catch up with folks in the community you might not get to see very often. Year after year, people are spotted greeting one another with big smiles, enthusiastic handshakes and warm hugs, much like an extended family. Activities kicked off Friday evening with hors d'oeuvres, time to meet with industry and a variety of rap sessions for men, women, parents and teens to attend.

TN BioMatrix Team - Regional Care Coordinators LeAnn Wilson, David Tignor, Cyndy Coors and Region Manager Dave Burgeson

BioMatrix Terry Rice presents *It's Ok NOT to be OK*

The next morning brought insightful sessions that included a von Willebrand Patient/Caregiver Panel, *Kinesio Taping, Bleeding Disorders in Children with Special Behavioral Needs* and *Exploring Emotional Well-Being in the Hemophilia Community*. In the meantime, children headed out to the Knoxville Zoo while teenagers worked their magic in film making and cinematography.

After lunch, special awards were presented to community and industry members. BioMatrix was proudly recognized for being a 2018 Gold Sponsor. Sessions followed into the afternoon including discussions on *Trough Levels*, *Gene Therapy*, *Microbleeds* and *Legal Rights for Bleeding Disorders* just to name a few. THBDF's business meeting was up next where chapter business and 2020 plans were discussed. The afternoon wrapped up with BioMatrix's Terry Rice presenting *It is OK not to be Ok*, a valuable presentation focusing on speaking with healthcare providers about the management of pain, depression and anxiety.

After dinner ended with exciting raffles, everyone had the opportunity to explore downtown Knoxville. Popular to visit was the 1982 World's Fair Park, where the Sunsphere, an iconic feature of the city skyline could be appreciated up close and personal, and folks could cool off at the park's water fountains and splash pad.

Sunsphere

As twilight transitioned into night, it was wonderful to see community members congregating in the common areas of the hotel as hardy laughter from grown-ups and children alike rang through the evening air. There is something to be said about the simplicity of community members enjoying each other's company and sharing their commonality of living with bleeding disorders. In

2020, THBDF will celebrate its 50th Annual Meeting. BioMatrix is looking forward to helping sponsor and celebrating this ground-breaking event!

VIRGINIA

Terry Stone and Michelle Stielper

Before theme parks and paintball and Chuck E Cheese, where did families go for some summer fun? If you lived in the country, you'd probably say, "I'll meet you down at the swimming hole," right? Well, nothing beats some good ole fashion fun, so that's exactly where the Hemophilia Association of the Capital Area (HACA) held its annual ***Chapter Picnic*** at The Water Mine Family Swimmin' Hole in Reston on a warm, sunny August 18th.

The Picnic Trio:
The Newlywed, the Kidd and the Legend - Spencer, Matt and Ed

Families were thrilled that the rains and downpours of last year stayed away. What a fantastic reunion of friends over barbecue and brisket and some home-cooked sides that gave granny's famous potato salad a true contender! Everyone had a plan, some stayed at the pavilion and caught up on life's happenings, while others had lunch and hit the water park, and oh, what a water park it was. THIS PLACE… is not your daddy's swimmin' hole of yesteryear. Oh no, this is a supersized place with so many places to splash, slide and swim. Everyone had a wonderful time, and I am sure that all the kids slept well that night after a full day in the water! HACA says, "You're welcome!"

Picnics and waterparks go together like good food and great friends. Many thanks to HACA for another great family day for which BioMatrix was delighted to be one of the sponsors.

KENTUCKY

Rania Salem

Family and friends of the Kentucky Hemophilia Foundation gathered at the Hyatt Regency Hotel in Louisville for its August 24th ***Summer Family Event*** (Annual Education Meeting, Post-Meeting Social Activity, and Walk Kick-Off Lunch). We began the day with a scrumptious breakfast buffet. During the keynote session, special guest Judy Saltzberg, Ph.D., spoke on *The Science of Optimism*. Other educational sessions for the day included *Carrier Barrier-Women with Hemophilia* and *Factor Fingerprint*.

The Annual Education Meeting is a chance to reflect on years past and to get updates on future plans. Past board members were honored as new board members were welcomed. It was also time to kick off the foundation's *Annual Walk*. Winning teams from last year were honored as new teams were encouraged to sign up. To highlight the day…it was all aboard the Mary M. Miller Riverboat for a delightful harbor cruise along the Ohio River.

All Aboard! Sierra, Hunter, Shannon and Marissa stop to smile for the camera before boarding the Mary M. Miller Riverboat

A huge thanks to the Kentucky Hemophilia Foundation for another job well done. Special kudos to Executive Director Ursela Kamala as we honored her for 25 years with the chapter. We love you, Ursela!

NEVADA

Kelly Gonzalez

Picturesque Nevada Beach at Lake Tahoe was the setting for the annual ***Northern Nevada Family Education and Beach Day***. The temperature of August 24th was a breezy 95 degrees, the water was sparkling blue and so clear the sand base could be seen, and the beach began filling up with community members of the Nevada Chapter of NHF.

Gathering for empowerment through education, attendees came to hear presenters Stormy Johnson of Aptevo and Amber Federizo of the Nevada Chapter discuss women and bleeding disorders and encourage the crowd to take control of their health. After the presentation, the group picnicked on a generous spread of fresh fruits, veggies and sandwiches before having fun on the lake with canoes, kayaks and paddleboards.

Emily is with Kelly Gonzalez as they hide away in the shade

We at BioMatrix are proud to have teamed up with Aptevo in support of this Nevada Chapter community event!

BIOMATRIX ON THE MOVE

PENNSYLVANIA

Shelia Biljes

"Be Prepared" is more than just the Boy Scout motto - it's a responsibility to your family and yourself! The Western Pennsylvania Chapter of NHF invited its members to Erie's Ambassador Banquet & Conference Center August 24th for a ***Summer Program***. The morning started with social time as the families were invited to visit exhibit booths and speak with industry sponsors. Lots of goodies were available at the BioMatrix booth and community member Devin proclaimed, "BioMatrix always has the best snacks!" We aim to please!

Devin enjoys
"The best snacks!"

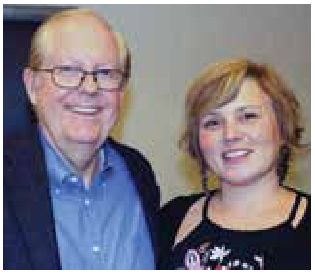
Ashley and Weston

Brunch was served as everyone settled in to hear Sharon Meyers, MS CFRE, Vice President of Development at Hemophilia Federation of America, as she spoke on *Don't Be Scared, Be Prepared: Creating an Emergency Plan*. Her presentation focused on managing an unexpected emergency, such as a snowstorm or flooding, with information specific to bleeding disorders. Children were present at the session with their parents so that everyone could engage in making a family plan to use in case of an emergency situation. The event ended around noon with plenty of time for families to proceed with the rest of their Saturday activities.

ILLINOIS

Eva Kraemer

Bleeding Disorders Alliance Illinois (BDAI) Board of Directors and Executive Director Bob Robinson hosted the 2019 ***Board of Directors Annual Meeting*** August 26th, at the Burr Ridge Crowne Plaza Hotel. Board President Michael Towner opened with a report on the state of the organization, touching on endeavors for 2020. Keynote speaker and member of the bleeding disorder community, Eldon Ham, Esq., spoke about the adversity he faced growing up in an age when modern treatments were not available. Eldon talked about getting out there and getting started with what you want to achieve. He emphasized, "Just get started, see where things go. You can't get lucky if you're not out there!" His speech resonated with every single one of us, inspiring us to take a chance on what we want to accomplish in life.



Eldon Ham and Eva Kraemer

BDAI Executive Director Bob Robinson and
Board Member Michael Towner present the
25th Anniversary Award to Lily Schwartz, Associate Director.

The *Anniversary Award* was presented to Lily Schwartz, BDAI's Associate Director, for 25 years of service with the organization. The *Bradley Krueger Scholarship* was awarded to 2 deserving recipients for the 2019-2020 school year. Motivated by Mr. Ham, everyone left the meeting eager to start something new and see where it can lead. We look forward to another great year with BDAI!

CALIFORNIA

Gabriela Griffin

Familia de Sangre, the 3rd annual statewide conference for those with bleeding disorders presented in Spanish, with English translation available, took place September 6th–8th at the Anaheim Marriott. In addition to families arriving from all over California, this year brought families traveling all the way from Arizona, Nevada and Illinois. This wonderful event was a great success thanks to endless hours of work and the collective effort from the staff of the Central California Hemophilia Foundation, the Hemophilia Association of San Diego County, the Hemophilia Foundation of Northern California and the Hemophilia Foundation of Southern California. Thanks to all four organizations for the great choice of topics and speakers, many who traveled long distances to share their experiences and knowledge with us all. Familia de Sangre not only gave the bleeding disorders community a wonderful opportunity to learn important

BioMatrix Spanish speaking
team - Gaby Griffin, John
Martinez and Hector Heer


Gaby Griffin (lrft) chats with Emily and Maria

information about their condition but also facilitated new relationships with other community members who will eventually be a valuable resource of support and encouragement for each other.


Fel and Laura visit with Gaby Griffin

VIRGINIA

Terry Stone

Quickly becoming a coveted weekend away with our womenfolk, The Hemophilia Association of the Capital Area has created, and shall I say perfected, a recipe for a rich and nourishing ***Women's Retreat*** that was enjoyed in the pristine countryside of Middleburg the weekend of September 6-8.

The recipe, you ask, is a treasured HACA family recipe that Executive Director Brenda Bordelon is eager to share. First, have your ladies gather at Meadowkirk at Delta Farm and breath in that clear country air. Next, sprinkle in some meet-and-greet time and snacks and beverages. Add in some talks about self-care, the 101s of adopting, relationship do's and don'ts, great meals, and s'mores by the fireside, and stir gently. To make it all come together, add a pinch of craft time led by BioMatrix's own Michelle Stielper and voilà! You have a perfectly brewed weekend full of flavor, nourishment, and even something to take home in the way of a beautiful fall candle centerpiece.


One craft., 28 interpretations!

Until next year, remember the goals you set, close your eyes, see yourself crossing the finish line, and know… together we are stronger!

NEW YORK

Richard Vogel

September signals the end of summer and back to school. While many don't look forward to the end of summer, bleeding disorder families do look forward to New York City Hemophilia Chapter (NYCHC) ***Bilingual Back-to-School Event*** held September 8th at the NY Marriott Downtown.

Rich Vogel


Mark P. and Kelly Gonzalez flash big smiles!

Education began early with families gathering information from sponsor exhibits. Opening sessions included *Transicion a la escuela y planes 504* (*Transition to School 504 plans*) by Kelly Gonzalez, BioMatrix Education Specialist. Kelly presented the program in Spanish and English covering what a 504 Plan means, who's eligible, how one is set up and what accommodations to request. This was the perfect program for this time of year. Simultaneously, *Infusion Training* was presented in English and Spanish in another ballroom.


Kelly Gonzalez presents

Welcome remarks by NYCHC Executive Director Jeremy Griffin was followed by lunch and a panel discussion from various perspectives regarding *Participation in Sports*.

Beautiful smile from Alaina

Afternoon sessions included *Maintaining a Healthy Diet at School* and *Evaluating Your Health Insurance Options* - both offered in Spanish - and *The Science of Hemophilia: A Changing Landscape*, *Making the Grade*, and two workshops for children and teens; *Robotics Model Building with LEGOS* and *Improvisation Show with Deb Rabbai.*

Continued on page 35

OHIO

Shelia Biljes

September 7 was a gorgeous day at the Akron Zoo as Northern Ohio Hemophilia Foundation hosted the Unite For Bleeding Disorders Walk. With more than 300 in attendance, everyone enjoyed winding their way throughout the zoo, a 50-acre park - home to more than 700 creatures! There was so much to see! The Pride of Africa, a realistic lion habitat, was a crowd-pleaser as the King of the Jungle paced in front of visitors to show off his beautiful mane. Meanwhile, a bald eagle recognized a couple of family members on the other side of the glass.

The event wrapped up as everyone completed their walk and gathered at a pavilion for lunch at noon. As the general public entered the zoo, our Unite For Bleeding Disorders shirts drew attention and many of us found the opportunity to share our story and define our community to curious zoo visitors. The chapter exceeded its goal, raising over $46,000. Thanks to the hard work of the chapter and board members for another fantastically successful walk!


Making friends at the Bald Eagle exhibit

NYCHC events are always well attended because Jeremy and his staff do a great job in making sure there is something for everyone, from patients to caregivers, teens to children and for those whose first language is Spanish. BioMatrix is proud to be a sponsor of this popular event.

PENNSYLVANIA

Tina McMullen

Golfers and volunteers could not have asked for a more flawless day Tuesday, September 10th for Eastern Pennsylvania Hemophilia Chapter's Golf Classic. This annual scramble is held at the beautiful Rivercrest Golf Club and Preserve in Phoenixville. Before the shotgun start, 17 foursomes began the day with a buffet lunch. This popular event included contests for Men's and Women's Longest Drive, Putting Contest and Closest to the Pin with exciting prizes for the winners including various TaylorMade items such as a sand wedge, M6 Hybrid club and a golf bag.

Jessica and Steven give up looking for Tina McMullen's lost golf ball

Fantastic Foursome! Steve, Tom Sr., Elizabeth and Tom Jr.

The day concluded with a fabulous dinner and the ever-popular Drone Drop. Everyone had the opportunity to purchase a numbered golf ball that was placed in a basket and lifted high into the air by a drone, then released. The owner of the ball that drops closest to the pin is the winner of the 50-50 raffle.

Thank you to Curt Krouse, Executive Director, and his staff Lindsay Frei and Kat Kocsi for a perfect day!

Illinois

Eva Kraemer and Maria Vetter

Music makes everything better, which is exactly what we learned from Pete Dyson and Shelby Smoak at an ***Educational Dinner*** hosted by CSL Behring and BioMatrix September 11 at Paisans' Pizzeria in Berwyn. Pete elaborated on how listening to music allowed him to relax during challenging moments of infusing while growing up. Shelby discussed how music is essentially not needed to survive such as food and water, but how it has always been present throughout history and cultures. He spoke about the use of music to heal, and the release many people find while writing lyrics, singing or just listening to music.

CSL Presenter Peter Dyson, community member Gina W., Eva Kraemer and Shelby Smoak

The real treat came when we had the benefit of a live performance. Shelby sang and played his acoustic guitar while Jim Hurster, CSL Behring, Manager-Coagulation Products, accompanied him on the mandolin. It was a private little concert for those in attendance and BioMatrix was pleased to have played a part in making the music happen!

BioMatrix Educational Specialist Shelby Smoak and Jim Hurster of CSL Behring jam for the audience

FLORIDA

Peggy Klingmann and Marcy Foertsch

Positivity and being proactive about healthcare set the tone of the evening when BioMatrix and Takeda partnered to host an ***Educational Dinner*** at Grillsmith in Lakeland September 12th. The topics of advocacy and self-care presented by Erin Weigel, Senior Clinical Specialist for Takeda. On hand to answer any questions regarding social work was Brenda Montgomery King of BioMatrix. The dinner was well attended by community members who were very engaged throughout the meeting! We very much look forward to our next dinner!

SAVE ONE LIFE:

WHEELS FOR THE WORLD — THE TOUR DIVIDE JUSTIN AND RICH'S EXCELLENT ADVENTURE

As Justin started up his rental car at Newark Airport Saturday, June 22nd, Chuck Berry's *"Promised Land"* was blasting on the stereo.

His own lyrics took over:

Left my home in
'Lauderdale, Florida
Massachusetts on my mind

I straddled that Nissan
And rolled with Rich
Past New York City and on into
Greenwich time

And thus,
Justin and Rich began their
excellent adventure.

BioMatrix Regional Care Coordinators Justin Lindhorst and Rich Vogel were on their way to Save One Life's *2019 Wheels for the World* biking fundraiser to honor Barry Haarde, a beloved community advocate and avid cyclist who passed away February 2018. Barry rode many miles to raise awareness and funds for his favorite charity, Save One Life, and BioMatrix is very proud to be a sponsor of this important event. Though many miles apart, the Save One Life ride was held at the same time as the famous "Tour Divide" – considered the most grueling cross-country mountain bike race in the world.

The first stop of Justin and Rich's excellent adventure was Louis' Lunch in New Haven, CT. Having opened as a small lunch wagon in 1895, Louis' claims to be the first and oldest restaurant to serve hamburgers in the US and is recognized by the Library of Congress as the *Birthplace of the Hamburger Sandwich* made with a proprietary blend of five cuts of meat, ground fresh daily, served on white toast and only offer cheese, onion and tomato as garnishes. As they got back on the road, they turned to each other and said," Dude, you and I have witnessed many things, but nothing as bodacious as what just happened."

Continuing their adventure into Massachusetts, they stopped in Salem. Since 1626, when Roger Conant arrived with the first settlers, Salem has been attracting people from all over, including Rich and Justin. It may be most widely known as the site of the Salem witchcraft trials of 1692, but this colorful, coastal city has much to offer: a culturally diverse population, a rich maritime heritage, an impressive display of historic architecture, amazing stories that span almost four centuries and the Clam Shack, with its gorgeous view and stellar seafood, this shack is a heavenly place to enjoy the warm sunshine. Their steamer clams and lobster rolls are to die for and best enjoyed on the picnic tables overlooking the water.

After a good night's rest, Justin and Rich went to the start of the ride. Riders had the option to complete a 25-mile ride or a 62-mile "Century" ride. Justin insisted on completing the Century, despite more than one plea from his sage colleague to settle for the 25-mile course. In the end, Justin completed well over 70 miles after getting lost in the Massachusetts countryside. Being the last one to roll through the finish line did not prevent his smile, nor the celebrations to follow.

Days later it was announced that Justin and Rich's friend and fellow community member, Chris Seistrup, completed the Tour Divide in the number one spot. His efforts, along with supporters who rode or donated, are keeping Barry's legacy alive. Together the combined fundraising efforts helped Save One Life raised over $30,000 — all of which will be put to good use helping individuals with bleeding disorders in developing countries.

Be excellent to each other!

UPCOMING EVENTS

OCT. 17, 2019 FLORIDA
BioMatrix and Bayer
Contact Peggy Klingmann
864-275-0246
Education Dinner
Maggiano's Little Italy Restaurant
Tampa

OCT. 18, 2019 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Autumn Wine Auction and Dinner
Columbia Yacht Club; Chicago

OCT. 19, 2019 OREGON
Hemophilia Foundation of Oregon
541-753-0730
hemophiliaoregon.org
Shooting for the Stars Auction
Vitalidad Movement Arts and Events Center; Portland

OCT. 19, 2019 TEXAS
Texas Central Hemophilia Assoc.
972-386-3865, texcen.org
DFW Walk
River Legacy Park; Arlington

OCT. 19, 2019 WASHINGTON
Bleeding Disorders Foundation of Washington
206-533-1660, bdfwa.org
Bloody Fun Run
Green Lake Park; Seattle

OCT. 20, 2019 CALIFORNIA
Hemophilia Assoc. of San Diego Cty.
619-325-3570, hasdc.com
Unite for Bleeding Disorders Walk
Liberty Station Park; San Diego

OCT. 26, 2019 PENNSYLVANIA
Eastern PA Chapter of NHF
484-445-4282
hemophiliasupport.org
Adventures in Learning
Spooky Nook Sports; Manheim

OCT. 26, 2019 TEXAS
The Lone Star Chapter of the NHF
713-686-6100
lonestarhemophilia.org
Hill Country Walk
Brushy Creek Lake Park
Cedar Park

OCT. 26-27, 2019 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495
bdai.org
Statewide Weekend
Your Bleeding Disorder and Beyond
Chicago Marriott Midway

OCT. 26-27, 2019 RHODE ISLAND
New England Hemophilia Assoc.
781-326-7645
newenglandhemophila.org
Fallfest
Crowne Plaza; Warwick

NOV. 2, 2019 CALIFORNIA
Hemophilia Found. of Southern CA
626-765-6656
hemosocal.com
11th Annual Unite for Bleeding Disorders Walk
Griffith Park; Los Angeles

NOV. 2, 2019 FLORIDA
BioMatrix and Bayer
Contact Peggy Klingmann
864-275-0246
Education Lunch
WonderWorks; Orlando

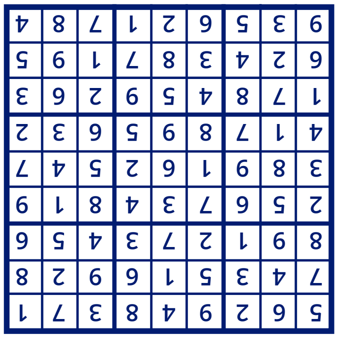
NOV. 2, 2019 MISSOURI
Gateway Hemophilia Foundation
314-482-5973
gatewayhemophila.org
Trivia Night Fundraiser
Jefferson Barracks Park
St. Louis

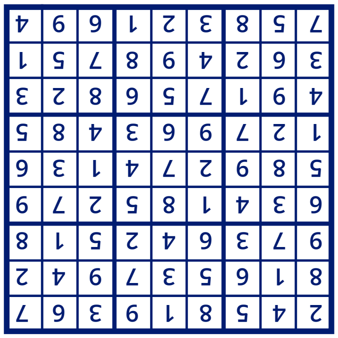
NOV. 8, 2019 OHIO
Northern Ohio Hemophilia Found.
216-834-0051; nohf.org
Annual Meeting
Holiday Inn; Independence

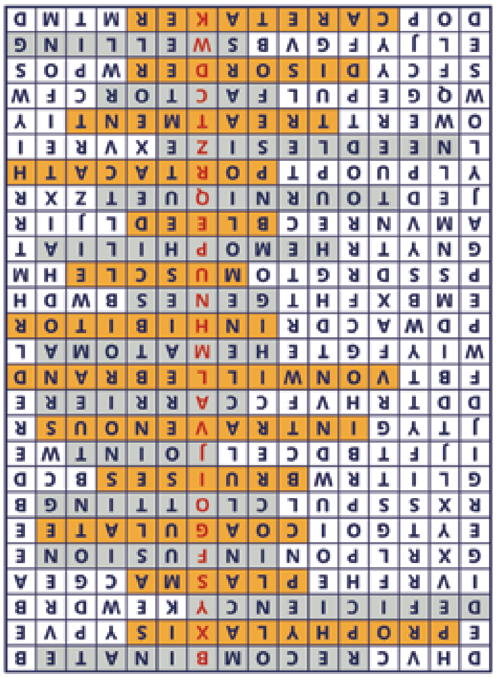
NOV. 9, 2019 NEW HAMPSHIRE
New England Hemophilia Association
781-326-7645
www.newenglandhemophilia.org
von Willebrands Retreat
Sheraton Hotel
Portsmouth

NOV. 9, 2019 TEXAS
The Lone Star Chapter of NHF
713-686-6100
lonestarhemophilia.org
Houston Walk
Houston Zoo; Houston

SOLUTIONS TO PUZZLES ON PAGE 39







UPCOMING EVENTS

NOV. 12, 2019 NEVADA
NHF Nevada Chapter
702-564-4368; hfnv.org
Annual Ely Family Conference and Holiday Celebration
Location TBD; Ely

NOV. 13, 2019 FLORIDA
BioMatrix and Takeda
Contact Peggy Klingmann
864-275-0246
Education Dinner
Maggiano's Little Italy Restaurant
Tampa

NOV. 17, 2019 NEW YORK
New York City Hemophilia Chapter
917-722-3887; nyhemophilia.org
Education Day
Crowne Plaza Hotel; New York City

NOV. 22-24, 2019 NEW MEXICO
Sangre de Oro, Inc.
505-341-932; sangredeoro.org
Annual Patient Education Weekend
Marriott Pyramid North
Albuquerque

NOV. 23, 2019 TEXAS
The Lone Star Chapter of the National Hemophilia Foundation
713-686-6100
lonestarhemophilia.org
Houston Winter Education Event
The Westin at The Woodlands
The Woodlands

DEC. 1, 2019 KENTUCKY
Kentucky Hemophilia Foundation
502-456-3233; kyhemo.org
Year End/Family Information and Support Event
Holy Trinity Clifton Campus
Louisville

DEC. 5, 2019 FLORIDA
BioMatrix and Bayer
Contact Peggy Klingmann
864-275-0246
Education Dinner
400 Beach Seafood Restaurant
St. Petersburg

DEC. 7, 2019 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Holiday Party
William Tell Holiday Inn; Countryside

DEC. 7, 2019 NEVADA
NHF Nevada Chapter
702-564-4368, hfnv.org
Annual Family Day and Holiday Celebration
Orleans Convention Center
Las Vegas

DEC. 7, 2019 OHIO
Northern Ohio Hemophilia Found.
216-834-0051, nohf.org
Holiday Dinner
Stan Hewett Hall; Akron

DEC. 7, 2019 PENNSYLVANIA
Eastern PA Chapter of NHF
484-445-4282
hemophiliasupport.org
Holiday Party
Cannstatter Volksfest Verein
Philadelphia

DEC. 7-8, 2019 MAINE
Hemophilia Alliance of Maine
207-631-7550
mainehemophila.org
Winterfest
Samoset Resort; Rockport

DEC. 8, 2019 TEXAS
The Lone Star Chapter of the NHF
713-686-6100
lonestarhemophilia.org
Hill Country Winter Education Event
Embassy Suites by Hilton Hotel
Conference Center and Spa
San Marcos

DEC. 11, 2019 NEVADA
NHF, Nevada Chapter
702-564-4368, hfnv.org
Elko Family Day / Winter Celebration
Hilton Garden Inn; Elko

DEC. 14, 2019 CALIFORNIA
Hemophilia Found. of Southern CA
626-765-6656
hemosocal.com
Snowflake Festival
Santa Ana Zoo

DEC. 14, 2019 TEXAS
The Lone Star Chapter of NHF
713-686-6100
lonestarhemophilia.org
Valley Walk and Winter Education Event
Dean Porter Park; Brownsville

DEC. 21, 2019 ILLINOIS
Blood Bond Bleeding Disorder Network
773-653-1963
bloodbond.org
2019 End of Year Business and Planning Meeting
Hilton Chicago/Oak Lawn

TIME FOR FUN!

HI KIDS!

Here's a game that is sure to challenge you! Insert a different letter of the alphabet into each of the 26 empty boxes to form words related to having a bleeding disorder. The letter you insert may be at the beginning, the end, or in the middle of the word.

Each letter of the alphabet will only be used once. Cross off each letter as you use it. All the letters in each row are not used in forming the word. Solution is on page 37.

GOOD LUCK!

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

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

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

Sudoku!

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

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

[BIOMATRIX]

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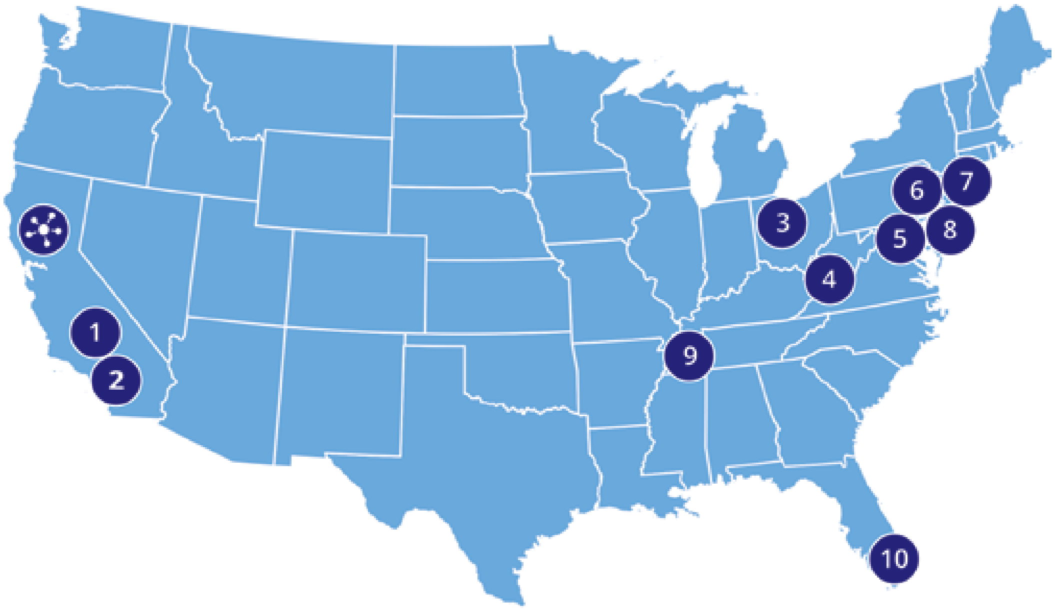

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