

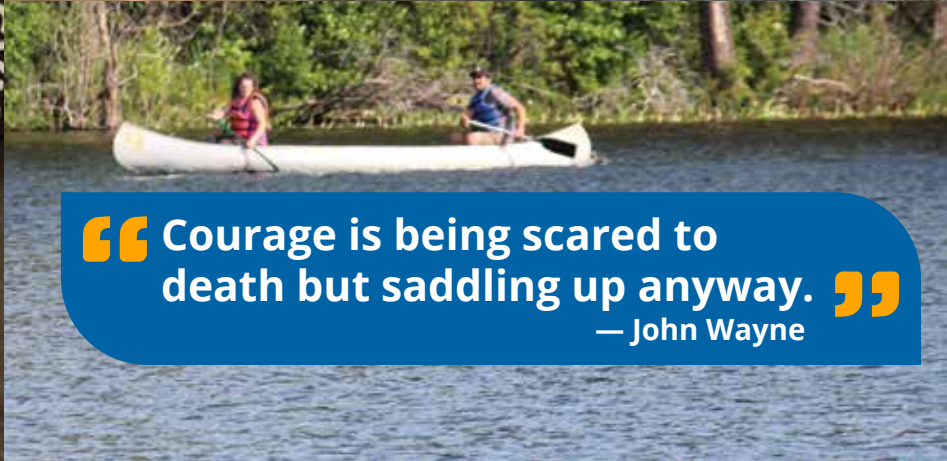
BIO MATRIX

NEWS



**DEDICATED
TO MAKING
A DIFFERENCE**

**SPRING 2020
VOLUME 15 | ISSUE 2**



“ Courage is being scared to death but saddling up anyway. ”
— John Wayne

ABOUT BIOMATRIX

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

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

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

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

MISSION + VISION

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

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

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

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

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

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

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

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

FINE PRINT

Editor-in-Chief: Maria Santucci Vetter

Editors: Susan Moore and Justin Lindhorst

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

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

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A NOTE FROM THE EDITOR

Dear Readers:

Surreal... that's the word I feel most aptly describes the situation our country and the entire planet finds itself in as we collectively battle the coronavirus. Every morning when I wake up, I have to remind myself that our current state is not just a vivid, unsettling dream.

At BioMatrix, our hearts go out to everyone who has been physically, emotionally, or financially affected by this threatening virus. Our pharmacies continue operations, keeping our patients appropriately stocked with medication and supplies. We are so thankful for all who are working every day to keep essential services up and running. During these challenging times, we all need to do our best to support, lift each other up, and show kindness.

This is something our close-knit community knows how to do well. We are resilient. Our history has proven that.

In light of our current "social distancing" protocols, we find it especially important to be an easily and readily available source of information, education, and community news. To accommodate our growing audience, one change you will see in future issues is the addition of advertisements. We plan to keep the ads limited and will also include space for other community partners such as national non-profit organizations.

Let's continue to do all we can to help each other stay well. We will come through this together!

Maria Santucci Vetter
Editor-in-Chief, *BioMatrix News*
maria.vetter@biomatrixsprx.com

Virtual Webinars Available From BioMatrix!

COVID-19 Crisis: The Impact on Bleeding Disorders

Get up-to-date facts on COVID-19. Understand how the crisis impacts bleeding disorders. Learn ways to keep you and your family safe. Be empowered to weather the crisis with confidence.

It's Okay to Not Be Ok

Hear about a community member's struggle with depression. Learn how they were able to overcome challenges by accepting their shortcomings and are pushing forward through the toughest times, including COVID-19.

No Need to Bleed: Making Joints Last a Lifetime

Review hard-hitting data that challenges bleeding disorder patients to invest in a lifetime of joint care. Understand what hemophilic arthropathy is, how it damages joints over time, and what happens if you don't take charge of your condition.

Health Insurance Basics: Everything You Didn't Know You Need to Know

If you've ever faced insurance challenges—dealt with prior authorizations, been denied a drug due to step therapy, told you have a copay accumulator adjustor, or had a claim denied for any reason—this program is for you. Learn about insurance policy-making and how to appeal decisions made by your health insurance plan.

Putting the Mask on First

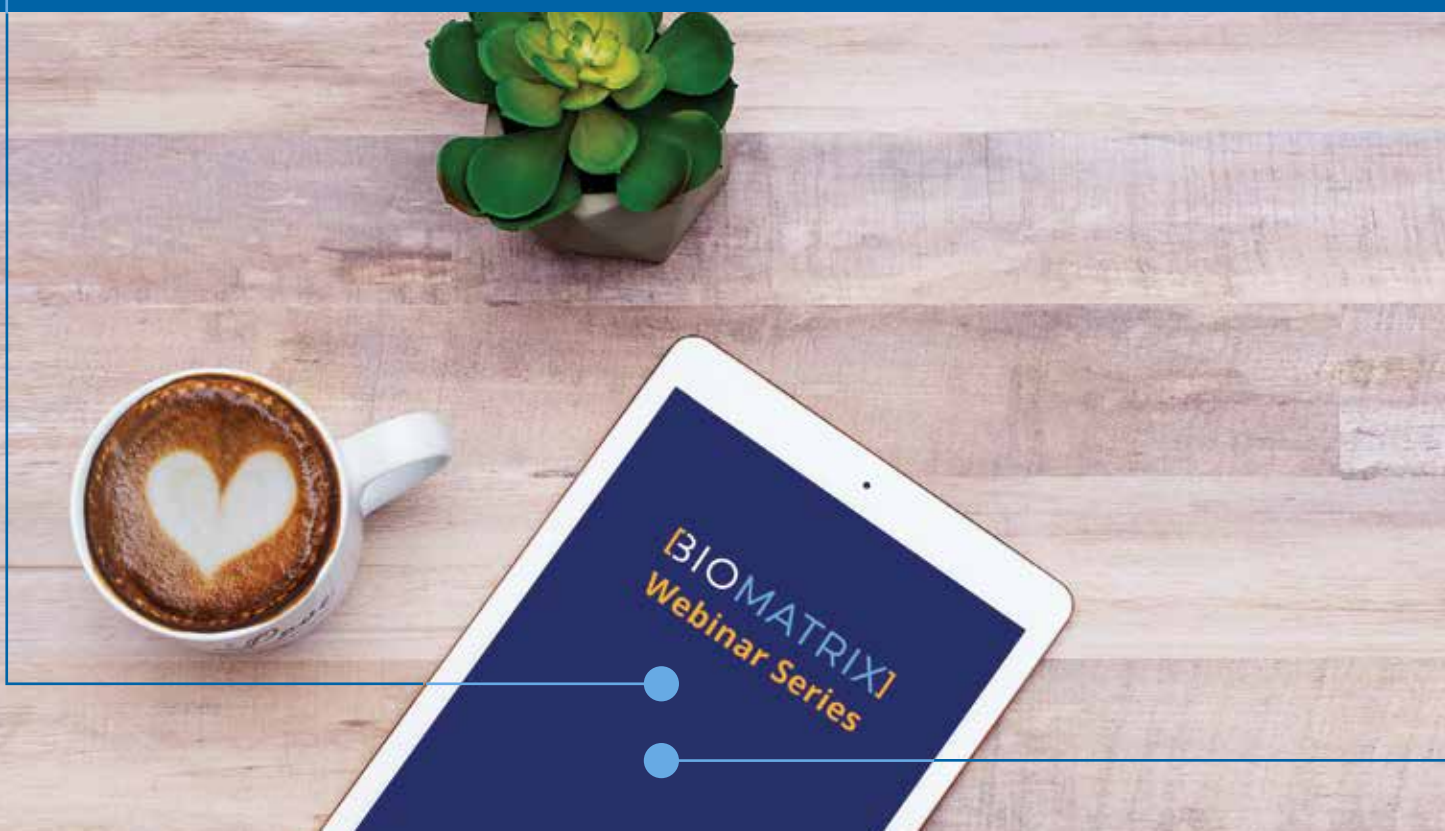
If you are a caregiver for someone with a bleeding disorder, this is your program. Learn how to take care of yourself while you take care of a loved one.

Bleeding Disorders Educational Games!

Play bleeding-disorders versions of Jeopardy, Wheel of Fortune, and Family Feud! Play these educational game versions with us individually or as an add-on to any our other programs! We have adult and kid versions! What are you waiting for?! Solve the puzzle! Spin the wheel! Win your daily double with BioMatrix!

To get set up with our virtual webinars, contact your RCC or email us at:

education@biomatrixsprx.com



CORONAVIRUS

IN OUR BLEEDING DISORDERS WORLD

BY: SHELBY SMOAK, PH.D.

At this time of writing (April 22, 2020), there is little doubt of COVID-19's grave impact on the United States and the world. The concussive force it dealt to our lifestyle, our economy, our jobs, our family, our community is inestimable and will be the thing we work through over the coming months and years. We have had to embrace social distancing, which is hard in ordinary lives, but in a bleeding disorders community that depends upon outreach and social support, it is even more difficult as more and more events are postponed or canceled. Our distance from one another may feel like a chasm. How do you navigate the physical and psychological burdens of a bleeding disorder in a world that seeks to separate everybody and tells us we are better alone than together?

WHY SOCIAL ISOLATION?

With a virus as virulent and contagious as this, social isolation is a primary defense to control its spread and is something everyone can do. To survive, a virus like COVID-19 needs new hosts. Once a person is infected the timeclock is on. Eventually, a person's immunity will fight off and kill COVID-19; some will present no symptoms, while others will endure varying degrees of sickness, and sadly, a small percentage will succumb to the virus. In every scenario COVID-19 does not live, except if it jumps into a new host.

MATH EXPLAINS SOCIAL DISTANCING

To help understand the potent virulence of COVID-19 and why social isolation is necessary, let's compare it to the flu. According to NPR, a person suffering from the flu will infect about 1.3 people. If you carry that out 10 transferences (person 1 infects person 2 who infects person 3, etc.), that 1 infection will potentially infect about 14 people. In contrast, a person with COVID-19 will infect around 2.5 people. That may not seem like a big difference; however, if you carry that across ten transferences, that 1 case of COVID-19 would potentially infect almost 9,000 persons. Compounding the problem of increased transmission is also the fact of coronavirus's higher fatality rate. About 1 in 1000 (.1%) persons infected with the flu die, while, in contrast, about 10 in 1,000 (1%) succumb to COVID-19. That's why we must protect each other by isolation.

THE FUTURE

At this time, too many uncertainties exist about COVID-19 to make any clear judgments about the future, except to say that this period of social isolation will end. We cannot suffer isolation; it is not in our nature. However, how COVID-19 will look in the future is yet unknown. COVID-19 could mutate itself out of existence as did SARS; it could become part of our general healthcare lexicon in much the same way we talk about the flu, with concern and with precaution, but without daily disruption; or

COVID-19 could still be with us enough to generate increased sanitary conditions and heightened social awareness behavior like handshakes and hugs. The good news is COVID-19 is not forever; and, likewise, social isolation is not forever. But for now, it is the thing we must practice so that we can keep ourselves and our community safe.

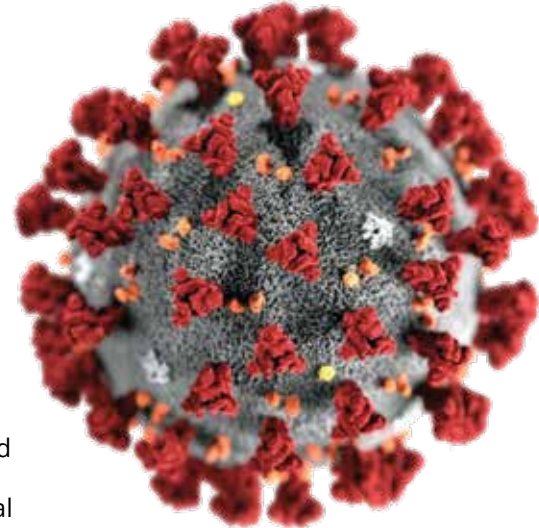
SO HOW DO YOU NAVIGATE SOCIAL ISOLATION?

In many ways, we have already moved to a culture predisposed to social isolation. Think about all the communication technologies that more or less keep us together but apart: text, FaceTime, Google Hangout, etc. Similarly, our community is going to have to figure out how we can be together, apart. Chapters and organizations are already organizing meetups, webinars, and chat sessions. Join these! BioMatrix is working on ways to bring our empowering educational programming into your homes. Invite us in, virtually!

Will these connections be the same as before? Well, no. As social creatures, our preference will always lean towards face-to-face meetups. But these kinds of connections will be meaningful; they will give us the information we need to maintain our bleeding disorders' health and will be an outlet for community support. So for now, embrace the change. Hug from afar. Share your story, your struggle, and your life, but from a distance. For now, COVID-19 has made it necessary to socially isolate. Remind yourself that social isolation saves lives, perhaps your own. That's how we get through this, together.

HELPFUL LINKS

- HFA has a dedicated link for the latest COVID-19 updates: <https://www.hemophiliafed.org/news-stories/2020/03/coronavirus-covid-19-what-hfa-is-doing/>
- MASAC, NHF's medical advisory council, provided coronavirus guidelines <https://www.hemophilia.org/Newsroom/NHF-Community-News/MASAC-Letter-to-the-Community-Regarding-the-Coronavirus-Disease-2019>
 - Maintain monthly supply needs but avoid stock piling factor as this unnecessarily stresses the supply system
 - Manufacturers do not anticipate product access disruptions
 - The Plasma Protein Therapeutics Association (PPTA) does not hold coronavirus a threat to plasma and plasma-derived products. The large size of the virus and its lipid envelope make it susceptible to processing steps involving virus inactivation and removal
- The CDC provides a daily update: <https://www.cdc.gov/coronavirus/2019-ncov/index.html>



OVERCOMING ADVERSITY:

THE ULTIMATE HEMOPHILIA CHAMPION

BY: BRANDON OLMEDO

Hemophilia and cage fighting have absolutely nothing in common. Or do they?

Growing up I remember watching the first *Ultimate Fighting Champion* – *Forrest Griffin*. The amount of heart and sheer will Griffin and his peers showed intrigued me. Their willpower, determination, and grit to pick up and keep moving even after being knocked down reminded me on some levels what it is like to live with a bleeding disorder. I might not be fighting in a cage, but sometimes my body sure felt like it was in one.

I began to learn more about other fighters and their stories. Many faced challenges, hurdles, and adversity requiring major adjustments before being able to realize success. My fight is with hemophilia and like Griffin and his counterparts, I faced a journey before emerging victorious.

Living with severe hemophilia is not easy. To be completely honest, I let it beat me down for a while. I was getting knocked down a lot, and not only from bleeds. Dealing with depression and anxiety that can accompany hemophilia is tough! There were some very difficult days where I felt mentally and physically exhausted.

I realized I needed to learn how to better deal with stress and take action in order to improve my health and make the most out of my situation. I made the decision that I would no longer be held back by the challenges of hemophilia. I knew I would never be fighting in a cage, but I decided to start training like a fighter. At 25 years old, I decided martial arts would be the vehicle I would use to better myself and take my life back.

Learning jujitsu really helped things fall into place for me. In jujitsu, the object of the sport is to force the opponent to submit, just like life, pain, depression and anxiety tried to force on me. In this sport you learn that even in bad situations there's always a way out, a way to turn the tables against your opponent, even if they are bigger or stronger. It teaches you to see through the challenges



and turn a bad situation into a good one. This translated so well for me because of my own challenges with hemophilia.

Training days start at 5:40 am with an infusion before class. One of the most important lessons I have learned is to stay on the ball with my infusions and to work my prophylaxis routine in with my training. When I was younger, I was very hardheaded about taking my infusions and I'm suffering for it in some ways now. For the love of martial arts, I've learned to stay on top of it.

Maintaining your treatment regimen and working with your healthcare team is important before you start any training routine. If I could express anything to the younger people with a bleeding disorder, it is to stay on top of your treatment plan! It will improve the quality of life you have today and set you up for less pain in the future.

In addition to staying on top of my prophylaxis game, I knew I had to be willing to



make certain adjustments and adaptations to keep myself safe while training. My gym, the MMA Institute in Richmond, Virginia, and my coaches Brian and Rick have been amazing.

My coaches and peers are aware of my bleeding disorder and everyone has been incredibly supportive. I think it's very important to find coaches and mentors who are willing to learn and adapt their teaching style and movements to accommodate the needs of their students.

Love holds no obligations, but fear holds plenty.

Working with my healthcare team was instrumental in keeping myself safe while training but aftercare matters too! After a hard day's work, I make sure to get plenty of rest. I recently started using sensory deprivation tanks with Epsom salt so I can rest my body and mind. Taking care of your mental health is every bit as important as taking steps to prevent bleeding. Put together a plan that will work best for your specific situation and stick to it!

Living with a bleeding disorder is challenging. Let my story be an example that by identifying and pursuing your passion, little by little, things gets better! It's a journey that looks different for all of us but never give up in finding and going after something you love. Love holds no obligations, but fear holds plenty. Don't fear your disorder. Find ways to work with it. Love yourself and chase what you love!

In jujitsu, missing one small detail can allow your opponent to find your weakness and use it against you, just as life tries to do. Life will throw things at you but learning how to focus and adapt will make your future brighter. I learned how to pay attention to myself and my surroundings – the little things, the small details I previously overlooked.

I realized my biggest reward came from challenging myself physically and mentally. With a little extra work and effort to accommodate my bleeding disorder, jujitsu became the perfect vehicle for me to realize that reward and overcome many of my personal and physical challenges.

People living with a bleeding disorder should not be cage fighters, but that doesn't mean we don't know how to overcome challenges. We might not always outwit our opponent, but we always have the choice to rise up and push back. Working with my healthcare team and through very careful training with my coaches, I found a way to compete competitively in jujitsu. It's important we know and understand how to best manage our condition. Life with a bleeding disorder can be tough but taking the best care of ourselves can lead us to better health and open doors you may have never thought possible.

Choosing to stand against adversity is always a victory. Keep trying, keep moving things forward even when things are difficult, and I promise you will grow strong because of it.



Brandon with his children, Grayson and Annabell



Brandon shows Grayson the ropes

HACA

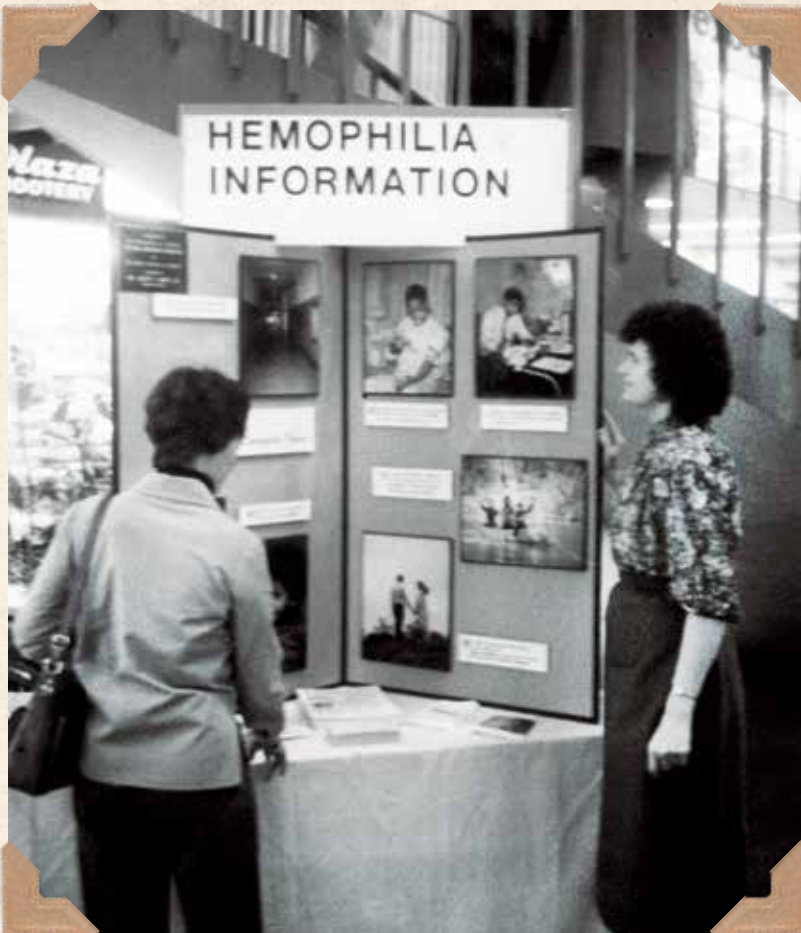
The Hemophilia Association of the Capital Area

A Legacy of Leadership and Advocacy

BY: TERRY STONE

The Hemophilia Association of the Capital Area isn't the largest chapter by far. Nestled right in the middle of the Virginia Hemophilia Foundation and the Hemophilia Foundation of Maryland, it serves patients and families living with a bleeding disorder in Northern Virginia, the District of Columbia, and Prince George's and Montgomery counties in Maryland. It's smaller than the others, but oh so mighty!

You could say it's the little chapter that could... and DID! In the shadow of the nation's capital, its humble beginnings and tenacity to make life better fueled the passion and strength this organization would need to lead locally through some of the community's most difficult and dark days.



The kitchen table – it's not just for meals and family game night, but also where important business transpires. It's the place where decisions are made, worries are addressed, and plans come together. In the early 1960's before there were hemophilia treatment centers, before HFA was created and while NHF was still growing, there were a few parents of children with hemophilia who gathered around a kitchen table to support one another. They discussed their children, how life was going, treatments, bleeding episodes and how to connect with more families and patients dealing with the same struggles. So began the humble grassroots of the Hemophilia Association of the Capital Area.

Known as the Washington, DC Chapter of the National Hemophilia Foundation, the chapter was started in 1964 by Navy Admiral Gordon Nagler and Margaret Graham, who both had children with hemophilia. Realizing they were not the only families in the area navigating this life of bleeding episodes, fragile veins and hospital stays, they wasted no time. They wrote letters to more than 28 regional hospitals and many local school districts to search for families like their own. And thus, a chapter was born! Before long and thanks to this monumental outreach, a chapter emerged with a growing group of 62 families!



Admiral
Gordon Nagler



Margaret
Graham



Now that area families were connected, fundraising was the next step to fuel their efforts and help their mission to unite families, share their journeys and somehow improve medical care. Donation canisters were displayed at local stores and tickets were sold for an opera performance with funds going into the newly created budget.

Ann Walsh, a parent and former chapter Board Member, stepped in and helped the chapter organize new advocacy efforts, which looked much like the current Washington Days facilitated by NHF. NHF worked with major congressional players to ensure funding protection for HTC's when President Reagan consolidated disease related legislative programs into a block grant.

The undertaking was as grassroots as their days at the kitchen table - these families simply wanted to link families and enhance the care for their sons. Remember, back in those days, only boys were diagnosed with a bleeding disorder. And there was no such thing as home care. What quality of life could be had if a person with hemophilia had to be admitted to the hospital, typically in much pain, every time a bleed presented? However, that was the norm and resulted in a challenging life for patients and families.

The undertaking was as grassroots as their days at the kitchen table.

Margaret Graham assumed the role of president and was the driving force of tireless fundraising not only for the chapter, but also to fund a much-needed specialized clinic for hemophilia patients where they could receive quality care and support. One of the first basic care centers to open was the pediatric hemophilia clinic in Bethesda's Suburban Hospital in 1970. It featured a blood bank for producing and storing cryoprecipitate (blood plasma rich in factor VIII and fibrinogen), which was the best way to treat bleeding episodes before factor concentrates were introduced and made available. The Bethesda clinic was a welcome relief to those who needed specialized hemophilia care.

In 1981 the HTC Program became part of the Title V Maternal & Child Health Program where it still resides today. HACA's membership welcomed specialty care access at two HTC's, Georgetown Hospital and Children's National Medical Center, with more opening their doors across the country. As comprehensive clinics welcomed patients with full teams of care, the good times would be overshadowed by the dark days of HIV/AIDS and the hepatitis (HCV) crisis ahead: HACA rose to the call for action.

In 1973, the National Hemophilia Foundation (NHF) began their efforts to create federally funded, comprehensive hemophilia treatment centers (HTC) across the country. When an HTC was established in the area, the Bethesda clinic staff knew their primary mission was complete and with satisfaction, closed their doors, knowing new doors with an expanded comprehensive care model opened.

As the chapter tucked in the shadow of our Nation's Capital, HACA was positioned to take on a leadership role in the bleeding disorders community and NHF joined to bring forward the Ricky Ray Hemophilia Relief Fund Act of 1998. A united effort swelled across the country and the message was clear - a demand for safer blood supply and financial compensation for bleeding disorders patients who contracted HIV/AIDS through tainted clotting factor. HACA's Executive Director at the time was Sandi Qualley, whose tenure spanned a respected 21 years of service. Although not personally affected by hemophilia, it was Sandi who led with action and navigated HACA through the challenges of the HIV/AIDS era and learned how to provide meaningful support, while advocating for the needs of all.

When the Ricky Ray Act passed and was fully funded in 2000, Sandi moved into creating a unique newsletter offering current community events and important



Sandi Qualley and Val Bias 1998



HACA Picnic 2004



HACA Walk 2013



HACA Moms 2014



Brenda Bordelon and Michelle Stielper 2013



Terry Stone and Miriam Goldstein 2013



updates on HIV/AIDS and HCV. As time passed, her role transitioned to a liaison between NHF and disenfranchised community members who felt NHF was slow to react when the community was getting sicker. Times were heartbreaking – so many stories, so many emotions, and so many lost while the lives of survivors were changed forever. Sandi helped bridge leadership and community, connecting families to offer fellowship and healing.

In the years to follow the chapter experienced robust growth and new members were readily welcomed. When Sandi retired in 2011, her departure was well deserved yet bittersweet. Karen Krzmarzick stepped into position moving HACA forward with her expertise in technology. She fine-tuned communications between the chapter and its members and updated policies and procedures in the process.

When Karen accepted a new position out of the area, Brenda Bordelon, former Chapter Administrator under both Sandi and Karen, was rehired as Executive Director in 2016. She is wholly devoted to HACA and its membership. Under her leadership, the chapter continues to grow, bringing new and innovative programming to the community with active participation skyrocketing. With 300 members, this chapter is one big ole HACA family!

Brenda knows each family well, is always looking for and open to new ideas for events and education all while stretching HACA dollars in exciting new ways. Partnering with the Board of Directors, Brenda has brought the chapter full circle. HACA hosts events that people really love. Favorites include the summer family picnic, events for women with bleeding disorders, exciting teen programming, joining forces with the Virginia Hemophilia



HACA Walk 2016

Foundation for state advocacy Days, and other special events connecting members across the state.

It's hard to believe this chapter has been serving our community more than 55 years! This year will bring new advances in treatment and more opportunities that will make living with a bleeding disorder even easier. Have no fear, however, as HACA will continue to be a leader in advocating for this community and will remain on the beat in America's hometown. As they say in the real estate business, its location, location, location! HACA serves its membership well, and as it is just a metro ride away from Capitol Hill, will be first to hop the train when duty and advocacy calls!

Fifty-five years and still going strong! Yes... HACA is indeed the little chapter that could, and can, and will still answer the call for action. The chapter's strong legacy continues brightly into the future.

2020 BLEEDING DISORDER CAMPS ACROSS THE NATION

For well over a decade, we have dedicated the Spring edition of our newsletter to provide a nationwide summer camp listing. Bleeding disorder camp programs create opportunities for youth to connect with others who share their diagnosis, to learn positive self-management skills, to develop independence, and to enjoy the great outdoors. This Spring, we continue that tradition.

At the time of publication, billions of people across the world are hunkered down and practicing social distancing in an effort to stop the spread of COVID-19. The novel coronavirus is already impacting summer camp programs. Some have postponed or canceled given the unprecedented situation the world finds itself in today. As such, we made the decision to remove the annual summer camp program listing from our newsletter.

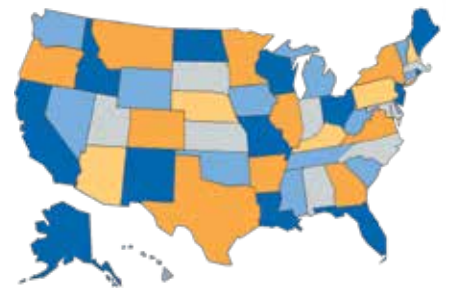
Instead, we will offer the Camp Directory online and will do our best to keep up with date rescheduling and cancellations as we collect information from the host organizations.

To view the 2020 Camp Directory, please visit:

<https://www.biomatrixsprx.com/bleeding-disorders-camp-directory>.

Though we are not including our camp listing in print, we still feel it is important to include related stories and experiences. The spirit of camp will help see us through these challenging times. The bleeding disorders community is resilient. We are experienced with facing and overcoming adversity and together we will see this through.

May the weeks and months ahead bring health, healing and hope for all.



**THE COALITION FOR HEMOPHILIA B
PATIENT ASSISTANCE PROGRAM**

“
**ONE OF THE MOST
IMPORTANT THINGS YOU
CAN DO ON THE EARTH
IS TO LET PEOPLE KNOW
THEY ARE NOT ALONE.**



SHANNON L. ALDER

***BCares Patient Assistance Program* provides short-term, limited financial aid to our hemophilia B community members who encounter unforeseen emergencies, including COVID-19 related hardships. The charity and compassion of our BCares partners make this critical funding program possible. Thank you for your support.**

The Coalition for Hemophilia B is a national nonprofit serving the hemophilia B community for 30 years.

LEARN MORE hemob.org/bcares

PLEASE DONATE hemob.org/donate



HOW CAMP HELPED PREPARE ME FOR A PANDEMIC

BY: JUSTIN LINDHORST



Many things I need to know about living through a pandemic, I learned from summer camp. Camp is a rite of passage for the bleeding disorders community. Memories made and lessons learned around the campfire rings, quiet wooded trails, open fields and cozy cabin common areas of our nation's bleeding disorder summer camp programs last a lifetime. As summer approaches, I've been reflecting on my own camp experiences and how they've helped me deal with our current circumstances.

WE'RE NOT ALONE

In grade school, I remember feeling like the only child in the world who had to deal with infusions, bleeds and frequent trips to the hospital. Explaining to other kids why I was on crutches and could not join the fun at recess was challenging. I remember feeling so frustrated when I had to miss gym class or other activities. I found myself frequently questioning, "Why me?"

The first time I met another kid with a bleeding disorder was at camp. By the end of the week, I had a group of friends that like me, understood life with hemophilia. It was then I knew I belonged to a community. Back at school, I would practically count the days when I'd be able to return to camp again. When I started to feel alone or isolated because of my bleeding disorder, I remembered my friends from camp and knew I was not alone.

Dealing with the coronavirus has left many of us feeling isolated. Daily routines have been upended. As plans are canceled and frustrations rise, it can be easy to forget that billions across the globe are dealing with the same challenges and emotions. We're all in this situation together. Connecting with my blood brothers and sisters at camp helped me understand that even when we feel extremely isolated or alone in our circumstances, even as we feel the weight of challenges outside our control bearing down on us, we're not alone.

GROWTH THROUGH CHALLENGE

Arriving at camp each summer was an experience I can still very distinctly remember. To this day, I can easily recall that feeling of nervous excitement every single time my parents pulled onto the camp grounds. I can still smell the summer air, hear the tires crunching over the gravel road and feel the butterflies dancing through my belly.

I loved camp from day one, but that did not change feelings of nervousness as I left my routine, my whole world behind for a week without my parents, siblings and my beloved Nintendo. Would the kids in my cabin like me? What if I ended up with a bleed? Would my counselor be cool?



Camp teaches us lessons by challenging us to step outside of our comfort zone. I learned independence by overcoming feelings of homesickness. I learned to enjoy vulnerability by "letting go" and singing that camp song from the rooftops. I learned the value of working together and the importance of trust through teambuilding exercises. I learned the sweet taste of victory through conquering my fears on high-ropes courses and other (appropriate) physical challenges that initially seemed absolutely terrifying.

The current situation with COVID-19 pushes us outside our comfort zone in so many ways. It's uncomfortable. It's unsettling. It has thrown the entire world from regular routines. It's not easy and certainly not what any of us wanted, but I'm positive that as we navigate the challenges brought on by the coronavirus, we will emerge wiser, better prepared and ready to rise against future challenges.

CARE FOR YOURSELF, CARE FOR OTHERS

Camp teaches valuable lessons in self-care. It's where many of us begin to learn self-management skills to effectively control our bleeding disorder. Beyond infusing myself independently for the first time, camp helped teach

me to take the best care of myself to ensure I could perform at my best and not miss out on activities. If I wanted to participate in that game of capture the flag, to not miss a day at the pool or the lake, I knew I needed to take care of myself first.



Camp also teaches us the importance of working together to care for others. Camp is structured entirely around "safety first." Camp counselors, medical staff, leaders in training and other volunteers work together to make safety the number one priority. As an adult, I am now a Camp Director, and I'm keenly aware of the many hours of preparation and the extensive resources that go into making sure campers stay safe. Planning a successful camp program starts long before the first campers arrive. Keeping campers, staff and volunteers safe and healthy is a full-time, group effort that takes commitment from everyone.

As we battle the coronavirus together, caring for ourselves and caring for others is more important than ever. Practicing good self-care keeps us and those around us healthy. It ensures we're able to function at our best so we can be there for our family, friends and others who we love. Coming through this time successfully means we're all going to need to do some extra planning and collectively commit to putting "safety first."

Many things I need to know about getting through this pandemic, I learned at summer camp. As I pen this article, I am physically separated from those I care about – but I know time and distance will not break our bonds. The weeks ahead remain full of uncertainty – yet through the challenges, I will strive to find wisdom and strength to overcome future adversity. As new directives, guidelines and public health initiatives emerge as a result of the coronavirus, I understand my individual responsibility to keep myself and others healthy.

All these lessons and many more began over thirty years ago as an 8-year-old boy with severe hemophilia stepped outside of his comfort zone to begin a journey that continues to this day.



Assisting Educating Advocating For The Bleeding Disorders Community.



GOING TO CAMP

BY: MAX FEINSTEIN



Life with a bleeding disorder has many complications. While the most obvious may be the physical ailments, we have been documenting and improving discussions regarding mental health. Mental health can vary from person to person, but hemophilia is certainly a burden to live with. While a child is simultaneously learning how to use their body, they are also learning high-level medical concepts that go along with managing their bleeding disorder. Though this may make a child a great advocate for

themselves in crisis, it also makes for a very specific kind of upbringing that can make a young person feel at emotional capacity, as if their disease is dominating their lives and isolating them from childhood.

As a child, I had the opportunity to attend various camps for children with bleeding disorders. Camp allowed me the opportunity to get some distance from my parents, who in their infinite love could feel overprotective to my developing sense of autonomy, while still ensuring my safety should my blood fail to do the thing it normally fails to do. The camps I attended differed from conventional camps to those that confronted hemophilia head-on through educational efforts and infusion training. They let me mingle with other kids and feel like a "normal" kid, and that's something very important for a child with a bleeding disorder. As your child grows up, be sure to find a camp near you.

MY BEST SUMMER



BY: BEN HICKS


I've been a camp counselor for the past two years. It's been a great experience to be around people with the same disorder. You meet lifelong friends that understand what you're going through. Going to camp is a way for me and the other kids to get away from our disorder so we can have fun doing different activities. I remember my first year as a camper - it was the best summer I've ever had. It made me want to become a camp counselor and get more involved with the Louisiana Chapter.



Thanks to a generous grant from Octapharma, the National Camp Exchange program was created for bleeding disorder camps and staff to share their expertise, foster new ideas and share best practices. Through this program bleeding disorder staff travel to other camps across the country and cultivate a bright future for the bleeding disorder camp community.

- An opportunity for camps and future leaders to learn from one another on how best to improve camp and share best practices.
- A forum to pass along traditions and build community for those with bleeding disorders nationally and internationally.
- A chance to give back to the developing camps and expand bleeding disorder camps across the globe.
- NCE is accepting 2020 applications from individuals and camps. We match qualified volunteers with approved camps, pay for travel, and share lessons learned with participating camps!



 LIKE US ON FACEBOOK! National Camp Exchange

CAMP LEADERS

Have you volunteered as a cabin counselor, activity leader, camp director, waterfront staff or camp medical staff? Does your camp need more staff and new ideas?

- Gain valuable experience!
- Get the help you need for camp this year!
- Bring new idea to camp!
- Share your best camp practices!

MEDICAL STAFF

Are you an experienced camp nurse? Does your camp need infirmary staff?

- Travel to exciting new camp!
- Get medical staff help for your camp program!
- Gain new experiences!
- Share ideas with other camps!

LEARN MORE!

Contact Arizona Bleeding Disorders for more

information, staff and camp/chapter applications and guidelines: Chelsea Guffy, Development

- chelsea@arizonahemophilia.org
- 602-955-3947
- Website: arizonahemophilia.org



SEA OF LOVE

BY: ELI NOBLES

A roar of cheers rolls down the valley, so progressively until it's undeniable in presence. It's like the boldest of crescendos. A sea of love is fearlessly ready to greet you in abundance at the door of the car or bus as your excitement builds. Lights! Camera! Action! The doors open and so the show begins. The absolute best week of every year for many youths living with a bleeding disorder. A place where differences bring us together and being weird is encouraged.

The first time stepping into that abundant sea of love at the tender age of 5, I can honestly say that the young me had no idea how camp would shape my future and ignite a passion in me that can never be taken away. Camp cultivated a vast variety of experiences for me. Having the privilege to understand camp and grow as a camper gave me an advantage that I would take back to the world outside the walls of camp. At a super young age, I witnessed what it meant to be kind, empathetic, courageous, and most of all, genuine. Being able to see true equality in its unadulterated purest form is a lesson that I hold dear to my heart and have kept all the way through graduating at 16 years old from the traditional camp experience.

At age 18 with little world experience and huge curiosity, I was afforded an opportunity that would change the landscape of what life could have been for me. Being



invited back to the place that taught me how to be strong in so many ways was already surreal. Being in the position to learn how to highlight the strengths of others was the next level. From the summer of 2014 to the summer of 2018, I have been blessed to spend my full summers contributing to giving truly amazing individuals from all around the world the best camp adventure possible, all while being alongside the best humans mankind has to offer who also chose to use their summer to do the same thing.

From who you are to who you would like to become, so much is learned at camp. The opportunity to face challenges alongside beautiful teams of people and the many facets of camp - families, campers, medical personnel and leadership - make for a truly intimate and unique experience. Camp means so much to so many, but to sum it up in just one word, it would be **CAMP!**



JUST GO!

BY: EVAN KERSTETTER

I'm your average 22-year-old who happens to have severe hemophilia A. When I was young, I remember going to my yearly hemophilia treatment center appointment where one of my nurses spoke to me about attending bleeding disorders camp. Since I didn't know what it would be like, I told my mom I was hesitant about going and traveling so

far. However, my chapter friends convinced me to go, so at 8 years old, I gained the courage and am so thankful that I did! Double H Camp at Lake Luzerne in New York was a blast! I met a bunch of kids with bleeding disorders from other states, chapters, walks of life... you name it.

I love camp for so many reasons, but one of my top reasons is because the counselors help you feel like a regular kid and help you forget you have a chronic illness. I have great memories of participating in kayaking, horseback riding, climbing, fishing, boating, archery, and many more fun activities!

Camp quickly became a home away from home and I always eagerly looked forward to it every summer. I have been fortunate to stay in touch with my buddies who I met at camp and know I can call them anytime. We understand each other on a different level than with friends who do not have a bleeding disorder. Every child with a bleeding disorder should attend camp at least once to be able to experience making new friendships and creating lifelong memories.

Camp can have such a positive impact on a young kid's life and I'm thankful to have had the opportunity to be part of it. I plan to continue being an advocate for it. Lastly, camp has had a huge impact on how I looked at my bleeding disorder. Camp helped me learn NOT to let my hemophilia control me!



CAMP FOSTERS HEALING, FRIENDSHIP, AND PLAY

BY: STEPHANIE SHEA

Last year, we had the opportunity to attend CHES' *After the Shock*SM inhibitor camp. Although my 5-year-old son Dakota's inhibitor isn't currently active, we decided to attend and am so glad we did. One of the biggest blessings we found on our hemophilia journey has been the community and the love and support we get through our involvement.

At times, we felt isolated among the "normal" hemophilia population. Not all, but many who I've connected with seem to infuse factor prophylactically with no issues and have been fortunate not to experience any major traumas.

Those of us who have experienced inhibitors know it's an entirely different ballgame. Although Dakota's inhibitor has been considered partially tolerized for almost 2 years, his half-life is very short, so he still needs daily infusions, aka, needle pokes. Daily infusions can take a toll on a family, not to mention the task of emotionally healing from past traumas (head bleeds, prolonged bleeding from ports, joint bleeds, etc.). Most families with inhibitors know this path all too well.

On day one of camp we learned that every family was assigned a camp "buddy" who would stay with the kids for most of the day while parents went to educational classes. On that first day my husband and I were on the tennis



court watching Dakota and his little brother, Phoenix, "play" tennis. We started talking with a father whose son is several years older than ours. Dakota and Phoenix wanted to run to the fields to play soccer with their camp buddy. The father we were speaking with could clearly see the anxiety on our faces as we have very rarely let Dakota out of our sight. He shared his own experiences with anxiety and encouraged us to let go and trust that Dakota would be ok without us. During the conversation, my husband and I both teared up and were greatly touched. It set the stage for us to loosen our grip for the rest of the weekend and it felt like a turning point in both of our healing journeys.

Everyone in the inhibitor community seems to just "get it." They get we've all seen our children in pain, we've all seen them suffer and we've all been through a lot of trauma, which often results in fear and anxiety.



Aside from the immense emotional value we received from talking and sharing with other parents, the camp itself was incredible. Set on a lake in Pennsylvania's Pocono mountains the scenery of Camp Zeke is breathtaking. Surrounded by lush green trees and grass, it was so calming to be immersed in nature. The kids were able to be how kids are meant to be – running carefree and playing in nature. Even when



in educational sessions, the rooms have huge windows overlooking the lake and giant trees, giving us the sense that we were in a forest.

There's so much to do at Camp Zeke - never a dull moment! There is the lake, of course, and all the activities that come with it - kayaking, fishing and swimming. As if that weren't enough, we enjoyed an outdoor pool, nature trails, a full theater, art studios, and so much more!



The educational sessions were great too! In addition to *Current Treatment of Inhibitors* and separate rap sessions for moms and dads, there was also *Aqua Therapy* and *Yoga for Relaxation*. My personal favorite though was *The Bio-Psychosocial Effects of a Chronic Condition*. The speaker was knowledgeable about trauma as well as the intensity and daily challenges that come with managing a chronic condition. I feel both my husband and I greatly benefited from this session. We took away tools and techniques that have enhanced our lives, especially in times of stress and anxiety.

When recalling the time spent at After the Shock, there was a special incident that stood out for me. Dakota wanted to play basketball, but a group of older kids were in the middle of a game on the court. Dakota just hopped on and started "playing." Instead of having him move off the court and wait for a turn like many kids their age would, they slowed the pace of their game and included him. Witnessing this, my heart burst with emotion and I teared up. I know most kids with hemophilia and inhibitors have probably been excluded at some point in their lives and instead of doing the same thing to a younger kiddo, they made a point to be inclusive. Every child at camp seemed to exhibit such kindness and compassion and it made me so grateful to be a part of this community.

With a talent show and a wooden wish boat launch to close out the weekend, the final night was special. My boys have already asked when we can return. And they're not the only ones. I can't wait until next year!

GROWING A KINDNESS GARDEN

These days, the world can feel like a pretty stressful place. When people are stressed it's hard to remember how important it is to be kind, and how being kind can make a huge difference in our lives.



Lilly and Austin show off the beautiful garden they grew!

To help campers at New York's BDAN Family Camp re-connect to the power of kindness, we grew a kindness garden. The idea is simple. We started with a canvas backdrop of grass and sky. Then we asked people to watch for acts of kindness around them. If someone was kind to them or they saw someone be kind to another, they wrote it down on paper cut in the shape of a flower, a tree, a butterfly or a bird. Then we added all the notes to the backdrop to create a picture showing how every act of kindness, both large and small, made the world a nicer place to live.

Some schools and workplaces have adopted similar ideas as a way to help people remember how they can make life better for everyone just by being kind. You can do this at your camp too. All you need are some simple materials and a little time each day to ask campers to share the kindness they see!



TAKE A CHANCE TO HELP YOUR CHILD GROW

BY: SUSAN MOORE

Visualize the day your child is making new friends, singing camp songs, trying new things and playing outside. They feel included. They're very well cared for. They're expanding their world. For many parents of children with a bleeding disorder, this vision might seem impossible. You ask, how could your child be safe without you? How do you find a camp that fully understands bleeding disorders, supports your child, and makes you comfortable? Have no fear - these special camps do exist - magical places where campers can learn, grow, and just have a good time.

WHY SEND YOUR CHILD TO CAMP?

Camp is so much fun! Games, songs, new friends, group activities, learning about their bleeding disorder, social interactions, discovering new skills, problem-solving and building confidence – camp has it all! In other words, your child is going to build independence and learn not to rely on or look at mom and dad for direction.

In addition to all these benefits, camp might also be the first place where children with a bleeding disorder get to:

- Meet others with a condition like their own
- Practice making choices in a safe environment
- Bond with other children while practicing social skills
- Learn new group activities and share with peers
- Enjoy being outside with nature
- Learn to self-infuse with medical supervision

Everyone can likely agree that it is often difficult for children with health concerns to get these experiences in their day-to-day lives. They might not meet other children with the same diagnosis in their school or town. Giving your child the freedom to attend camp may be their first taste of independence; their first opportunity to view the world outside of home, school, and church. It will help them realize that it is alright to try out new things, which is a vital step in growing up and making the transition into adulthood.

Camp provides a unique opportunity for your child to grow. Building independence isn't an overnight accomplishment; it's a practice-makes-perfect process. Not only will your child be enriched by camp, but you will feel content knowing the successes your child will achieve. And yes, camp gives parents and caregivers respite, a much needed, but infrequent occasion. Maybe you use that chance to spend time alone with your partner, other children, or friends. Read a book, see a movie, tackle a project... the options are many!

FINDING A CAMP

In addition to the annual BioMatrix News list of camps, check with your hemophilia treatment center, local chapter, or reach out to your BioMatrix Regional Care Coordinator for help in locating a camp near you. Many camps allow siblings to attend as well! If your camper is a newbie, or too young for summer camp, a family camp weekend experience is another great way to introduce camping. Remember, it is never too early to begin thinking



about camp. The process begins early – often by January or February with applications often available online. Slots fill up quickly, so be sure to submit your registration as soon as possible to secure a spot. Plus, most bleeding disorders camps are at no cost to you!

CAMP PREPARATION

When completing the application, have the following information available:

- Insurance information
- Contact information for your child's doctor and treatment center
- Medical history and a complete list of your child's medications
- A current physical exam and updated vaccine record
- Your main phone number and a secondary contact person and phone number



AVOID SEPARATION ANXIETY

Because they're having so much fun, most campers are not homesick after the first day. Parents often seem to have a much harder time than the kids! Here are some ideas to help alleviate the separation for both you and your child:

- **Involve** your camper throughout the process, from the very first conversation to packing, and all things in between. This gives your child a voice and ownership.
- **Discuss** your child's feelings about going to camp without judgment. Stay positive and discuss how there may be some unfamiliar feelings of homesickness and anxiety. It's important to let your child know these feelings are very normal and talk about ways to deal with them if they occur.
- **Talk** about the many activities that may be available (check with your specific camp).
- **Do sleepovers**, slumber parties with cousins, neighbors or friends. It is not unusual for first-time campers to

have never slept away from home before. Sleepovers are good practice for dealing with that unfamiliar feeling before the first night at camp.

- **For the parent or guardian:** Plan how you will spend your time away from your child. Consider taking a special trip, reading that book you've been meaning to, having special time with your spouse and other children, or focus on a project to help keep your mind off of worrying about and missing your child.



SHORTLY BEFORE CAMP

- **Review** camp rules with your child and discuss the campers' responsibilities.
- **Prepare** pre-stamped and addressed postcards for your child to send you from camp and pre-write letters and send them ahead of time for your child, if allowed by the camp program
- **Go over** camp lists and pack appropriately. Label all clothing and items. Follow the camp's rules regarding what to pack and what to leave home.

ARRIVING AT CAMP

The bags are packed, and the big day arrives:

- Make the drop off short and sweet. Once your camper visits their cabin, chooses a bunk, and starts activities, he/she will meet new friends, start having fun and will begin to experience the magic of camp.
- Leave happy – make things easy for your child. Clinging or crying about how much they will be missed will leave the child unsettled. Depart with confidence so your child does not feel scared or worried.



RETURNING FROM CAMP

- Your child may want to share and recount all of the experiences right away or may take time over weeks sharing parts of camp. He or she may feel conflicted – happy to see you and eager to get home, but also homesick for camp and missing the new friends they have made.
- Know that your child's bag may smell funny and nothing will be as neat as when you first packed it! I suggest unpacking it in the garage.
- Welcome your child home with their favorite dinner
- Encourage your child to write a story about what camp meant to them. Submit the story and a photo to us at *BioMatrix News* and we'll print it in next year's camp edition!

As a parent who encouraged her son to attend camp many years ago, here is my best advice: The first year out is the hardest. Sending your child the second year is much easier, honest! Time flies and children grow up way too fast. Feel good about helping your child grow and develop into a happy, independent, confident adult!

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LEVERAGE: WALKING THE LINE

BY: GABRIEL ANSPAUGH



When I was 15 years old, I was diagnosed with an inhibitor. Up until that point, I lived my life pretty normally. Yes, I have hemophilia, but I wasn't going to let it get in the way of how I lived my life.

However, the first bit of time with inhibitors was quite tough on my mental state. What could I do? What couldn't I do? And could I even get back to where I was? As time went on, I again discovered what I could do and what would be more difficult for me.

In February 2018, I was on a slackline at a rock-climbing gym (I know, a hemophiliac with an inhibitor at a rock-climbing gym - sounds like the beginning of a bad joke, right?). A slackline is essentially a tightrope that has a lot of slack, so it wobbles more. I was determined to prove that I could do this, but I ended up rolling my ankle pretty severely. This injury put me in the hospital for a week and in a wheelchair for many more. As I was going through this, it was pretty hard for me to look at the positive side of this situation since there really wasn't one when losing the ability to walk.

However, 8 months later there was an upside to my accident. This life lesson came full circle when I attended an educational, adventure camp program for individuals with inhibitors called *Leverage* in Oregon. One activity we did at *Leverage* was a high ropes course. The amazing instructors had suggested that we each find a specific goal to accomplish. I wanted to complete every element of that course.

My first instinct was to go straight for the most difficult ropes course to complete. In my nature of being a very physically active person, these tasks were fairly easy for me. But I knew the last element was going to be a challenge. It was a slackline with ropes hanging at separate points to hold onto. My experience with a slackline less than a year earlier made this the most difficult part to accomplish. It's funny how such an easy obstacle to complete was the most difficult for me to overcome. That horrible fall, the time spent in the hospital and that debilitating wheelchair were all running through my mind throughout the entire experience.

I watched my blood brothers, who I had grown to know and love, accomplish the obstacle with no problem. However, as I stepped out and was about a quarter of the way out, I actually had to stop, take a breath, and wrap my mind around everything.

I knew I couldn't fall because I had a safety line and I knew that the likelihood of another injury was low. Once I caught my breath enough to keep going, I just had to keep my eyes on the trees ahead and try not to focus on the memories of what was the worst injury of my life. Once I got to the next platform, I had to fight off tears as I realized that I just conquered something that had crippled me for a better part of the year.

So, what was one of the biggest things that I took away from *Leverage* 2018? The memory of conquering something that had once been so disabling.

BIOMATRIX ON THE MOVE

TENNESSEE

Cyndy Coors, David Tignor, Leann Wilson

CSL Behring and BioMatrix together hosted a **Holiday Educational Dinner** December 5th at the beautiful DoubleTree Hotel located in downtown Chattanooga. Oh, what fun we had! In addition to an amazing meal, we found ourselves fully engaged as our spectacular speaker, Tim Ringgold, MT-BC, presented *Music Therapy for Stress Management*. The topic proved to be very interactive and informative as we learned how to manage our stress or pain levels better with music! Families enjoyed time socializing while children enjoyed making holiday crafts. An ugly sweater contest was held and wrapping up the evening with a hardy "Ho-Ho-Ho" was a special visitor, Santa Claus!



Twins Dallas and Timothy wish for their two front teeth!



Santa's hands are full with squiggly babies, AnnaClaire and Kenna

NEW JERSEY

Rich Vogel

'Twas the night before Christmas and someone had a bleed. We've all had this happen – the excitement of a holiday causes a bleed. While there is no hard data, there is certainly plenty of anecdotal stories to support this theory. Maybe it's the change of seasons and the atmospheric pressure?

Maybe it's the blood pumping faster because of excitement or stress? Jean Marandola MSN, NP-BC, former clinical nurse manager at Rhode Island Hospital discussed this phenomenon at an **Educational Dinner** December 15th at Sophie's Bistro in Somerset, sponsored by Takeda and BioMatrix.



A Lily among poinsettias

Suzanne Dyer Vogel told her story of what it's like to be married to a person with severe hemophilia and some of the challenges and rewards. She discussed how hemophilia affects our lives but doesn't define our lives. A lively discussion followed as couples, parents and siblings shared their experiences caring for one another. Suzanne, a professional floral designer, then taught the basics of wreath design. Everyone received a wreath to decorate with holiday ornaments and festive bows supplied by BioMatrix. With kids jingle-belling and everyone saying, "Be of good cheer," it's the most wonderful time of the year!

CALIFORNIA

Gabriela Griffin

The **Snowflake Festival** is truly a wonderful way to end the year! Despite the weather being uncooperative, hundreds of Hemophilia Foundation of Southern California community members gathered December 14th at the Santa Ana Zoo where they had the opportunity to socialize, make crafts, decorate cookies, take pictures with the very lovely Frozen movie characters, Elsa, Anna and Olaf, have special animal presentations, and enjoy a delicious lunch.

As activities wrapped up, every child received a holiday gift and most of the families took advantage of the free admission to the 20-acre zoo, home to more than 150 animals including a rescued bald eagle and many endangered species. Thank you very much to the dedicated staff of HFSC for organizing such a memorable and enjoyable event!



Gaby Griffin (center), Jonathan and Elizabeth smile for the camera!



Always in a holiday mood!
Omar and mom Millie

Making holiday memories!
Bob and Pam



Positively festive! Melinda and Dennis, and Kaley and Alex

BIOMATRIX ON THE MOVE

ILLINOIS

Eva Kraemer

Blood Bond Bleeding Disorder Network (BBBDN) celebrated its annual **End-of-Year Business and Planning Holiday Party** Saturday, December 21st at the Hilton Chicago-Oak Lawn. Bleeding disorders community members attended merrily dressed to spread the joyfulness of the season. With holiday music to set the mood, all were able to reminisce about all the delightful programming provided in the year gone by and look forward to the opportunities of the new year. After dinner, Santa stopped by to spread goodwill and presents to children of all ages.



Daniel, Nancy, Emma, Adriana and Omar visit with Eva Kraemer

UTAH

Kelly Gonzalez

A chilly evening brought a small group in the community even closer as they gathered at a small cafe in Salt Lake City to attend an **Educational Dinner** hosted by Octapharma. The topic of the evening was *Advocacy 101*, which I, as an Educational Specialist for BioMatrix, presented. The presentation is a good reminder of the small things you can do as steps for advocacy that can become huge assets should you ever be faced with insurance problems, desire to change regimen, communication with provider, etc. The group was wonderfully engaging and asked many questions throughout the evening. Good company, good conversation and good food!



Smiles from Robin and Kelly

NEW MEXICO

Felix Garcia

BioMatrix teamed up with Octapharma and Aptevo January 17th at ABQ Axe in Albuquerque to host a Sangre de Oro, Inc. **Breaking Blood Men's Group**. Steve Caldron of Aptevo and Lynn Barker of Octapharma kicked things off with presentations highlighting their respective products, including a discussion with Octapharma patient presenter Dave Alderete, who spoke about his personal experiences. I also took a moment to speak to the group about the services offered by BioMatrix explaining our hands-on approach and heart of the organization.



Let the competition begin Eli, Hiram, Chris, Lynn Barker of Octapharma, Josh (center) and Felix Garcia (front)

Skilled axe throwers! Felix Garcia, Hiram and Donald

Everyone was then invited to join in exciting axe-throwing led by Coach Sage of ABQ AXE. *Almost* everyone joined in, but *everyone* had a great time! Some found it therapeutic while others just thought it was a blast to take aim and get the axe to stick in their target. As a true Cowboys fan, I had to live up to a friendly bet made with diehard Patriots fan Hiram M. This being the first chapter event since that tragic day when the Cowboys lost to the Patriots, I had to wear a Patriots jersey to our get together. It was humiliating. The day brought about a ton of laughs and good sportsmanship with good friends and blood brothers!

NEW MEXICO

Felix Garcia

As much as we all love the large community gatherings, there is certainly a place for smaller, more intimate gatherings. This is especially true when it's a gathering of factor 9 families. Aptevo's Steve Calderon joined with BioMatrix to host an **Educational Brunch** for a few families with a special invite to Sangre de Oro board members January 18th.



Gary unrolls for prizes while Steve rolls for doubles!

Everyone in Albuquerque knows El Pinto Restaurant is a great family-owned restaurant worth visiting anytime you can. While they served up delicious food, Steve offered an Ixinity product presentation and I made sure everyone was up to date on the services available from BioMatrix. To add a bit of entertainment to the mix, Steve and I put together a Saran Wrap Ball Game - we wrapped little prizes and candy with 200 ft. of Saran wrap.

Each person had to try to unwrap the ball to get prizes while the person next in line rolls 3 dice to get a set of doubles. Once doubles are rolled, it's the next person's turn to unwrap. What makes this even more fun is it that the person unwrapping the ball has on an oven mitt. It was

hilarious watching everyone trying their hardest to win some of the Aptevo and BioMatrix goodies. It was all in the name of fun and I'm sure many will be repeating this activity at their next family gathering!

Everyone learned something new, and even more importantly, we shared special factor 9 time with one another. The success of this brunch is measured in smiles, laughter and unity!

NEW MEXICO

Felix Garcia

What better way to kick off the new year than coming together with your bleeding disorders family at a fabulous restaurant and reinforcing how to be the advocate you already are and how to care for yourself while caring for others. Our friends at Octapharma couldn't agree more and joined BioMatrix to host an **Educational Dinner** January 30th at Hibachi One in Albuquerque.



Selfie time with Felix Garcia, Christian, Alfonso and Alex



Mary, Jose, Joshua, Noah and Brandon enjoy the show

With over 30 attendance including Sangre de Oro, Inc. board of director members, the meeting was a huge success. BioMatrix Education Specialist Kelly Gonzalez gave a heartfelt presentation titled *Putting Your Mask on First*. Kelly shared intimate details of her family's health challenges, how she tried to be strong for everyone, how she failed to care for herself, and the lessons she learned from the experience.

The audience was moved – not a dry eye to be seen, not even the big strong dads who were used to being tough for their families. Everyone appreciated the program as it brought attention to an important matter. After the presentation, we were ready for dinner – well, watching the Hibachi chefs was more of a dinner show! Those chefs have some awesome skills! Even after dinner wrapped up, many community members stayed to network and share.



Felicia, Jessie and Bernadette

Carla, Gary, Tice and Isabel

These dinners are more than just education and food, they are an opportunity to connect with others in your community who understand the shoes you walk in. The next time you get a chance to attend a BioMatrix dinner, do what you can to be there – it's worth the experience!

ARIZONA

Felix Garcia

We at BioMatrix were so “axecited” to team up with Elizabeth Pulley of Octapharma to host a fun **Educational Dinner and Activity** at Lumberjaxes in Tempe February 4th. It was an intimate group who gathered to learn about *Joint Health* and the importance of adherence and prophylaxis in today's hemophilia world. We realize we have a long life ahead and we need to take care of our joints. Everyone enjoyed and appreciated the program presented by BioMatrix's Director of Education Terry Rice who spoke about his challenges as a man living far beyond original expectations. When Terry pulled up his pant leg to show us the scar on his knee, we also realized that people from Maine don't get much sun in the winter like they do in the Phoenix area (thanks, Terry!).



Michelle, Martha, Marco and Jennifer



Back row: Jennifer, Ken, Terry Rice, Hector, Martha, Michelle, Marco
Front: Felix Garcia and Elizabeth Pulley

Those in attendance may have thought the idea of axe throwing at a bleeding disorders' event was a little out there and a few admitted being a bit scared. Once the coaches demonstrated a few techniques and shared the rules, you would've thought we had a league going on! All in all, everyone had a great time. Everyone managed to hit the bullseye and posed for their glamour shots. Our “family” came together to learn, share our scars and connect as a community, and in my book, was a total success!

FLORIDA

Peggy Klingmann and Marcy Foertsch

On the evening of February 5th, BioMatrix and Takeda came together with members of South Florida's USF Health Treatment Center and members of the bleeding disorders



BIOMATRIX ON THE MOVE

community at Coopers Hawk Winery and Grill in Tampa for an **Educational Dinner**. Presented by Senior Patient Educator, Erin Weigel, RN, the discussion centered on Takeda's clotting product, Adynovate, and included a general overview of hemophilia as well. Social worker, Brenda King was on hand to answer questions regarding BioMatrix's specialty pharmacy services.

VIRGINIA

Terry Stone and Michelle Stielper

BioMatrix was honored to present **Specialized TRICARE Programming** for families in partnership with Octapharma February 5th at McCormick & Schmick's Seafood and Steaks in Arlington. BioMatrix Education Specialist Shelby Smoak, Ph.D. provided a detailed account of the many tools and programs military families can access to help them live their best life as they navigate caring for a family member with a bleeding disorder.



Presenter
Shelby Smoak

More than 20 attendees learned new information and were actively engaged in discussing their challenges and experiences. Topics of discussion included learning about various TRICARE coverage options, particularly as the military member of the family moves through their career. They also discussed the role of the Exceptional Family Member Program and the support services this division provides during a PCS transition.

UTAH

Kelly Gonzalez

Outside Salt Lake City's The Wild Rose Restaurant, South Jordan was covered in fresh snow as cold winds blew through the air February 6th. Yet walking into the restaurant for an **Educational Dinner** where BioMatrix partnered with Octapharma, we were greeted by a beautiful warm and calming ambiance. The theme of the evening was one of self-care as I, a BioMatrix Education Specialist, spoke on *Putting the Mask on First*, which focuses on caregiver burnout. The audience was empowered to be healthier, happier caregivers. Thank you to the Utah Hemophilia Foundation and Octapharma for their support of the community and to everyone that came out on a brisk wintry evening!



NEVADA

Kelly Gonzalez

Nevada Chapter of the NHF held their 5th annual **Winter Wine Fest & Silent Auction** at the stunning Brio Town Square in Las Vegas on the perfect Friday evening of February 7th. A community favorite, this event creates an opportunity for all community members and their

supporters to gather for conversation and camaraderie while raising funds to meet their goals.

Guests who purchased special tickets to Octapharma's VIP Sponsor tent were treated to high-end hors d'oeuvres enjoyed around a fire pit while winemakers poured and educated partakers about their wines. On the other side of the open-air patio, Bayer sponsored their own cozy fire pit with a comfortable seating area for guests to relax and visit.

All participants went home with a specially etched wine glass. Community participation was high and support from the sponsors was generous – over \$30k was raised to support the many chapter programs! This event is still being talked about!



Escorted by Papi Joe, patient Maddie solicited for the NHF camp program. The cost to send a child to a medically supervised camp for 5 days/ 4 nights is approximately \$500. Camp is free for our young patients and their siblings because NHF NV covers the cost. Fundraisers like this can send 60 kids to camp. During Maddie's 20-minute fundraising walk, folks generously donated enough to send 1.5 kids to camp! Thank you, Maddie!

MARYLAND

Terry Stone

What better way to start off 2020 than to come out of the post-holiday recuperation period, formerly known as January, join together and see friends and family at the Hemophilia Foundation of Maryland's (HFM) **Annual Meeting & Educational Dinner** at the Four Seasons Hotel Baltimore February 8th.



Sweet daughters Chioma and Amarachi with dad Felix

This evening is always such a joyful event. Members arrived and had the opportunity to mingle and stroll through the exhibitor booths while catching up on the latest news. Soon everyone took their seats to enjoy dinner while hearing chapter updates and a year of

accomplishments and outreach in review. Lastly, Keynote Speaker, Shannon Paoletti, Ph.D., engaged the audience with an upbeat and exciting interactive program called, *The Science of Connection, Strengthening Relationships in Time of Change*. Thanks to HFM and Genentech who sponsored Dr. Paoletti and this engaging program.

VIRGINIA

Michelle Stielper

Women gathered at Kingsmill Resort in Williamsburg February 8th-9th for the Virginia Hemophilia Foundation's **Women's Retreat**, a coveted annual event. Back in colonial days when women congregated, they made quilts or cooked, but not these women, oh no! These modern-day ladies were treated to a day full of specialized women's programming, spa, and meals NOT cooked by them!



The ladies of VHF share their hopes, dreams and goals in a moving art session with Michelle Stielper

I was honored to present the *Vision Mirror Program*. After a short presentation of the importance of the power of positive thought, the ladies were inspired to create a physical representation of their own personal vision. For some, their vision frame reflected personal goals, aspirations for self-care, or realizing that they are enough. For others, their vision represented the goals they wish to achieve and the experiences they want to work toward.

Crafting was followed by the ladies sharing their vision with one another. There were happy tears, applause, laughter and camaraderie among the group in support of each another. Congrats to Program and Communication Director Heather Connor and the on-site facilitator as well as VHF Executive Director Kelly Waters and Development Director Megan Schowengerdt for providing such an enriching weekend!

NEW JERSEY

Rich Vogel

Pain relief without narcotics? That's the question. Some living with a bleeding disorder experience physical pain every day. February 9th at Spanish Tavern in Newark, BioMatrix hosted an **Afternoon of Learning Alternatives to Narcotics** to reduce pain and stress, sponsored by Aptevo and Octapharma. This interactive day of learning began with Aptevo speakers Dezar



John and Vincent



David keeps the beat

Tate, RN and community member Myles G., who each spoke about the impact pain can have on individuals and families and touched upon complementary therapies that may help.

Mark Zatyorka, community member and co-owner of Insa, a dispensary in Massachusetts, discussed how medical marijuana

helped eliminate his addiction to pain medication. Lisa Black, outreach and training coordinator for Insa, explained the various components of medical marijuana that target pain, stress, anxiety, etc.

Octapharma educator Janella Swartz explored the importance of exercise to maintain a healthy mind and body through various types of low-stress exercises including yoga, Pilates, and stretching activities. The afternoon ended with music — Shelby Smoak, Ph.D., community member and BioMatrix Educational Specialist, uncovered the healing power of music and its effects on the brain. This hands-on portion of our program included an open mic where talented community member Maxwell played and sang along with Shelby to their favorite 'feel good' original songs. Tambourines and egg shakers were handed out to the attendees so they could feel the beat and join in!

As we left this fun, unique day of good food, camaraderie and education, I can assure you no one was feeling much pain!

FLORIDA

Peggy Klingmann and Marcy Foertsch

It was time to throw axes and feel good about it! On the evening of February 11th, BioMatrix and Octapharma partnered to host an **Education Event and Activity** at Axe Throwing Tampa. While dinner was served, BioMatrix's Education Specialist Kelly Gonzalez presented *It's Ok Not to be OK*, in which she speaks candidly about her mistakes in managing her health and that of her family and offers up coping mechanisms. The presentation was very well received by bleeding disorder community members.



Steve and Devi with son, Kavish



[BIOMATRIX] ON THE MOVE

A lively discussion followed, and the group continued to the activity arena where we were led by trained coaches on the finer points of marksmanship with small axes and tomahawks and engaged in a friendly competition to test our newly acquired skills. A wonderful family-friendly evening was had by all!



Octapharma's Sherri Rohjani and Ivan Seda ham it up

FLORIDA

Justin Lindhorst

BioMatrix and Octapharma teamed up February 12th to host an **Educational Program** at the Saltgrass Steakhouse in Pensacola. BioMatrix educator Shelby Smoak, Ph.D., presented *No Need to Bleed*, and Octapharma presenter Martina Willis-McCullough, RN, presented *Microbleeds*. Both programs illustrated the negative effects of bleeding episodes on the joints and demonstrated the need for therapy adherence and access for all people with a bleeding disorder. Participants enjoyed both programs over a delicious meal. BioMatrix looks forward to returning to the Pensacola area for additional programs. Be on the lookout for your invitation!

OHIO

Love was in the air February 14th as BioMatrix and Bayer sponsored a **Couple's Event** for the Northern Ohio Hemophilia Foundation. A night at the Brew Garden in Strongsville seemed to be the perfect place to mix romance and fun for 25 couples. The evening began with a game of skill and trust as brave couples raced to move



Starr and Tony

Andrew and April



Sweethearts, Fred and Rosemary

tennis balls to jars without using their hands. Each couple wrote out "How we met" and the group tried to guess who wrote the story. It was a great opportunity to reminisce and get to know each other. A buffet dinner was served but didn't slow down the conversations and storytelling.

A rousing round of *Valentine Trivia* ended the evening, and everyone left with a chocolate heart and a big smile on their face as well as in their heart.

MARYLAND

Michelle Stielper and Terry Stone

If consuming mass quantities of food and beer on tap is your idea of a good time, then you just missed the best fundraiser of the year! Tickets were highly coveted for the Hemophilia Foundation of Maryland **Bull & Oyster Roast & Shrimp Feast** adult event and sold out quickly. Very hungry family and friends of HFM gathered February 15th at the



Michelle Stielper surrounds herself with friends and family, Robb, Stephanie, Dave, Matt, Terry, and Autura

UAW Hall in Baltimore but left with full stomachs and full hearts as the event raised much-needed funds that will help HFM carry out their mission. There were raffles, a cakewalk, and auctions... oh my! There were so many ways to be a winner! Folks walked out with all kinds of treasures won at the event. Congrats on another successful fundraiser feast!

ILLINOIS

Eva Kraemer

Let's face it, life can be challenging and learning how to better navigate those challenges can help us be more peaceful. BioMatrix and Octapharma hosted an **Educational Dinner** February 19th, at Murray Bros. Caddyshack in Rosemont. Octapharma's Edgar Martinez talked about modern-day life and how we can manage by planning ahead, writing things down and setting priorities. Another way to navigate challenges in the life of a person with a bleeding disorder is understanding that with the therapies offered today, there is a higher likelihood of avoiding bleeds.



Octapharma's Edgar Martinez takes an all-inclusive selfie!

BioMatrix Director of Education Terry Rice expounded on the fact that unlike any time before whether a person is mild, moderate, severe, Type I, II, or III, more therapies are available to help avoid joint damage and living life to the fullest. Lots of discussion was had making this type of interaction uniquely beneficial. BioMatrix is pleased to support networking for members of the Illinois bleeding disorders community.



Kevin and Malachi

FLORIDA

Peggy Klingmann and Marcy Foertsch

Maggiano's in Brandon was the place to be February 20th for an **Educational Dinner** hosted by BioMatrix and Bayer! The evening began with a presentation by Bayer's Educational

Speaker Linda Peacock, RN who gave an overview of Jivi®. BioMatrix Educational Specialist Shelby Smoak, Ph.D. followed with an engaging and informative presentation on the importance of advocacy in the bleeding disorders community. The evening ended with a question and answer session, and as always, reaching out to offer our exceptional support and service to the community we are proud to serve!

FLORIDA

Peggy Klingmann and Marcy Foertsch

Octapharma and BioMatrix partnered together once again to present an **Educational Event** to the bleeding disorders community in Orlando! Hosted February 22nd at Ferris and Foster Chocolate Factory the topic of the evening, the importance of surviving life's impediments, was presented by Octapharma's Educational Speaker, Seth Rojhani. After the presentation, attendees delighted in creating chocolate culinary confections and taking home a few to share!



Seth Rojhani and his proud mom, Sherri

Sweet smiles from Herman and Nicole

PENNSYLVANIA

Tina McMullen

Pins were flying at all 24 lanes during Eastern Pennsylvania Hemophilia Foundation's **Bowling for a Purpose** held February 22nd at Devon Lanes in Devon. The event began with the opportunity to visit the exhibit area, preview the unique raffle items, and of course, bowling. Everyone enjoyed sandwiches, pizza, snacks, and refreshments. It was a "strikingly" fantastic event for community members!



Strike throwers! Tommy, Jake, Gianna and Bella

NEW JERSEY

Richard Vogel, Carolina Luna

Members of the Hemophilia Association of NJ made their way to iPlay America in Freehold for **Winter Gathering** - education and a little fun February 29th. During a continental breakfast, attendees gathered information and visited with exhibitors. A choice of breakout sessions followed and offered something for everyone from self-infusing, branded sessions, and sessions in Spanish.



Juan and Iomara

Leonardo, Adrian, Marlen, Carolina Luna, and Adriana

The morning went quickly and after a buffet lunch, families had more opportunity to network, parents attended education sessions while children and young adults played at one of NJ's largest indoor amusement parks. They were able to choose from rides, bumper cars and typical boardwalk games made famous by the Jersey Shore. As Bruce Springsteen says, "*Down the shore everything's alright*" and it certainly was on this beautiful extra day in February.

CALIFORNIA

Gabriela Griffin

Hemophilia of Southern California (HFSC) Executive Director Michelle Kim gave a warm welcome at the **SoCal emPOWERment Forum** February 29th at Pickwick Gardens in Burbank. Community member Anna Clark followed with *Friendly Feud*, a fun ice breaker.

Kicking off the educational sessions was *Estate Planning for People with Chronic Disorders* presented by Cynthia J. Waterson and in Spanish by Steven P. Beltran and an *Access to Care Panel*, with Terri Cowger, Elizabeth Stoltz, Dr. Doris Quon and Paul Clement, in Spanish with Erika Bocanegra, Cynthia Chavez and Oscar Horta. Following a lunch break, *Weaponless Self Defense and Active Shooter Training* by instructors Nelson Carter and Richard Moreno became an instant favorite with its easy explanation and interactive exercises.

Afterward and to the excitement of all, the Avengers made their glorious entrance, and everyone had the opportunity to take pictures with their favorite heroes. To end the event on a high note, the **Bloody Hot Salsa Challenge 2020** ensued, and we were able to taste the truly most delicious hot salsas. Every salsa was unique and exceptionally enjoyable. Congratulations to all the winners! Thank you again to The HFSC for another great event!



Gaby Griffin with Rocio and Gerardo



Jeff Johnson with Alex, Dwayne and Aaron



Kyla, Michael and Huxley visit with Kelly Gonzalez

IDAHO

Jeff Johnson

Families gathered at Smoky Mountain Pizza in Boise for a community Dinner and Presentation hosted jointly by BioMatrix and Takeda March 5th. Guests enjoyed some of Boise's finest pizza while learning from Education Specialist Kelly Gonzalez on *No Need to Bleed*, and from Takeda presenter Aaron Smith, who spoke about his experiences growing up with and overcoming the challenges presented by hemophilia. The following day, local ladies attended the Idaho NHF Chapter's Victory for Women conference.

They were delighted to hear another presentation from Kelly, as well as visit the BioMatrix booth for goody bags and to learn about BioMatrix services.

VIRGINIA

Terry Stone

The Virginia Hemophilia Foundation held its **2020 Medical Symposium** at the Richmond Marriott Short Pump Hotel in Glen Allen March 7th-8th. Due to last year's popularity of this program, VHF presented it again and brought in physicians and other industry leaders to provide consumers with topics as *Emerging Therapies, Product Safety, Mental Health* and offered round table discussions from which to learn. VHF also reminded us all that March is *Bleeding Disorders Awareness Month* and presented fun activities for kids and teens.

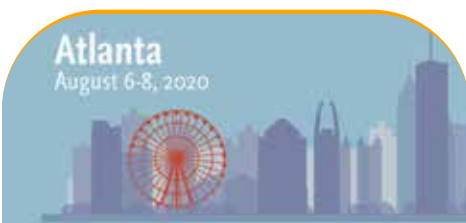
BioMatrix' own Michelle Stielper presented an art project for the teens. They were asked to reflect on what encourages them to advocate, then choose a word or two that represents their reasoning. After writing their word(s) on a stone and decorating it, their Mandala stone will be a visual reminder as to why they choose to advocate for themselves and others. The teens allowed their creativity to flow and enjoyed the process!



Elsa and Kierra enjoy painting Mandala stones

UPCOMING EVENTS

Due to the coronavirus pandemic issues throughout our country, most upcoming events have been canceled or are being rescheduled for later in the year. Please check directly with the host organizations to verify conference and event dates. We hope to have this page in *BioMatrix News* issues filled to the brim with new events soon!



NATIONAL EVENT!

AUGUST 1-8, 2020

VIRTUAL CONFERENCE

National Hemophilia Foundation

212-520-8272

72nd Bleeding Disorders Virtual Conference

Visit www.hemophilia.org for updates!



NATIONAL EVENT!

AUGUST 24-26, 2020

BALTIMORE, MARYLAND

Hemophilia Federation of America

202-675-6984

Annual Symposium "Charting Our Future"

Hilton Baltimore Inner Harbor

Visit www.hemophiliated.org for updates!



NATIONAL EVENT!

OCTOBER 2-5, 2020

ORLANDO, FLORIDA

The Coalition for Hemophilia B

212-520-8272

Annual Symposium

Renaissance Orlando at SeaWorld

Visit www.hemob.org for updates!



Now Accepting
Applications for the
2020/21 School Year!

BIOMATRIX MEMORIAL SCHOLARSHIP PROGRAM

APPLY ONLINE!

<http://bit.ly/BioMatrixScholarship>

BioMatrix offers six \$1000 educational scholarship opportunities to students diagnosed with hemophilia or von Willebrand Disease, and in the case of two of the scholarships, immediate family members may also apply.

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

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

Apply online by visiting:
<http://bit.ly/BioMatrixScholarship>

The application may also be accessed by visiting:
<https://www.biomatrixsprx.com/bleeding-disorders-scholarships> or
scholarships@hemophiliafed.org



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



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



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



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



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



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

THE ULTIMATE KIDS' GUIDE TO THE NEW CORONAVIRUS

HI KIDS!

Every day, we have been hearing news about the coronavirus pandemic. But what is it? We hope this article will help explain the coronavirus, why everyone is being asked to stay home and wash our hands, and why we are seeing so many changes in our communities. Don't be afraid — Be informed!

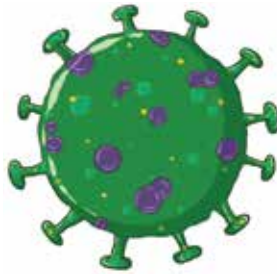
WHAT IS A VIRUS?

A virus is a teensy, tiny germ, way smaller than anything you can see. Viruses can make us sick, but they can't do anything on their own – they need to live inside another creature (their host) to survive. To do that, they have to get into our cells.



WHAT IS THE CORONAVIRUS?

You may have noticed lots of adults talking about a "coronavirus." There is a new kind of this virus spreading around the world. It's called a coronavirus because "corona" means "crown" in Latin. And the virus looks like it's wearing a spiky crown.



Mostly, it makes people cough, feel tired and have a fever. But older people and people who have other conditions can get very sick from it. The disease the virus causes is called COVID-19.

WHERE DID THE CORONAVIRUS COME FROM?

The virus was first found in a city in China, called Wuhan, last December. But we think the virus actually comes from bats. From there, it hopped into another type of animal, who gave it to humans. No one knows for sure what this mystery animal was, but some people think it might have been a pangolin, a scaly animal that eats ants.



HOW DOES THE VIRUS GET INTO CELLS IN THE BODY?

The virus enters cells using a special "door" on the outside of human cells. The new coronavirus also needs a "key" to get into cells.

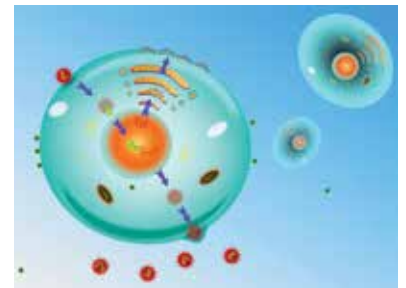


In this case, the coronavirus has a special "spike" on its surface that it uses as a key to open the door.

Once inside cells, the virus makes lots of copies of itself. Those copies break out of cells, then infect other cells. At a certain point, there are so many virus particles being produced that our normal cells can't work properly ... and we get sick.

HOW DOES IT MAKE PEOPLE SICK?

Viruses make people sick by killing human cells or making them not work properly. Like we said, the new coronavirus uses a special door to get into cells. Those special doorways are on cells in the nose and lungs. If the virus grows too much in the lungs, it can make it hard to breathe. That is called pneumonia.



Luckily, your body has an army to fight germs like the coronavirus. It's called the immune system. When a virus enters your body, the immune system attacks the virus. You know how you can get a fever, headache or runny nose when you're sick? That's caused by the immune system, and it's good! These yucky symptoms are signs that your body is fighting the virus.

Most people who get COVID-19 just have symptoms like a cough, fever or runny nose. Doctors are not sure why, but some people get really sick. Some peoples' immune systems may not fight hard enough. Other peoples' immune systems may fight too hard, hurting their own cells. Both of these things can make people sicker.

HOW WILL I KNOW IF I GET IT?

There's a special test to see if you have COVID-19. If you feel sick, tell your parents. They will call your doctor to see if you need the test. It's just like a flu test; they stick a Q-tip up your nose and test your snot for the virus. The results come back a day later.



WHAT CAN I DO TO HELP?

You can help stop the virus by washing your hands. This means sudsing up with soap and rubbing your hands together to clean all your fingers, under the fingernails and between the fingers. You can sing the ABCs or come up with another tune that lasts about 20 seconds.



Also, try to keep your hands off your face, so no rubbing your eyes or nose or putting your hands in your mouth. That way, if there is any of the virus on your hands, you won't give it a way to enter the body where it can make you sick.

And remember to cough or sneeze into your elbow (like a vampire!), and stay home when you're sick.

SHOULD I BE WORRIED?

There's no need for you to worry, because adults are working very hard to keep kids and other adults safe. Even if you do get this virus, kids usually don't get very sick from it. It's more like a mild cold.



But you still have a special role to play in protecting others! Older people, like grandparents, need your help to stay healthy. That means washing your hands and staying home if you're sick. It may also mean skipping your activities or not going to school if your principal and other grown-ups in charge decide that's best. That can slow down the spread of the virus and protect older and sicker people.

WHAT IS BEING DONE TO KEEP US SAFE?

Doctors and government officials are working hard to make sure families stay safe. That's why they may ask people to cancel activities, like sports events. They may close schools to stop the virus from spreading. They may tell you to keep your distance from other people when you're out. All these tricks make it hard for the virus to jump from one person to the next. If the virus can't spread, fewer people get sick.



Doctors are also working hard to care for sick people. Scientists are trying to make a coronavirus vaccine — kind of like the shots you get at the doctor's office. Others are trying to make medicines to help sick people get better.

WILL MY SCHOOL CLOSE?

Each school may make a different decision. Schools may close if there are lots of cases of COVID-19 in your area or if someone at the school gets the virus. But it's not easy to close schools. There are many things to think about before doing that. For example, some children eat school meals and may not have enough food at home if schools close. And parents who work in hospitals may not be able to care for sick people if they need to stay home with their children. Parents, teachers and principals probably won't decide to close a school on their own. City leaders will help make the decision.



If your school does close, they may teach your classes online. Or they may send home workbooks so you can still learn.

WILL I BE ABLE TO SEE MY FRIENDS?

It may be harder to see your friends if you are told to stay in your home. However, there are lots of great ways to stay in touch online. You probably already know about these, and you can also get creative! There are ways to play games and have fun with friends, even if you're not able to see them in person.



If you can meet with friends, you'll probably have to keep the group small. So, no birthday parties for now. Meeting in large open spaces like parks, where you can keep lots of distance, is probably the best choice.

WHEN COULD THE CORONAVIRUS OUTBREAK END?

We don't know for sure. (I know, not what you want to hear!) But using math, we can make educated guesses. Left on its own, the virus would take many months to spread all around the world. But that doesn't mean your city would be affected for that long. And a vaccine could stop the virus sooner — if scientists can create one.



Some scientists think that the virus will go away when the weather gets warm. That's what happens with other coronaviruses and the flu. Lots of viruses like cold, dry air. But we don't know if that is true for this new virus.

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"The Ultimate Kids' Guide to the New Coronavirus: 'Will School Be Closed?' and 'Should I Be Worried About Getting Sick?'" Live Science. 11 Mar 2020. <https://www.livescience.com/coronavirus-kids-guide.html> (Images credit: Shutterstock)

[BIOMATRIX]

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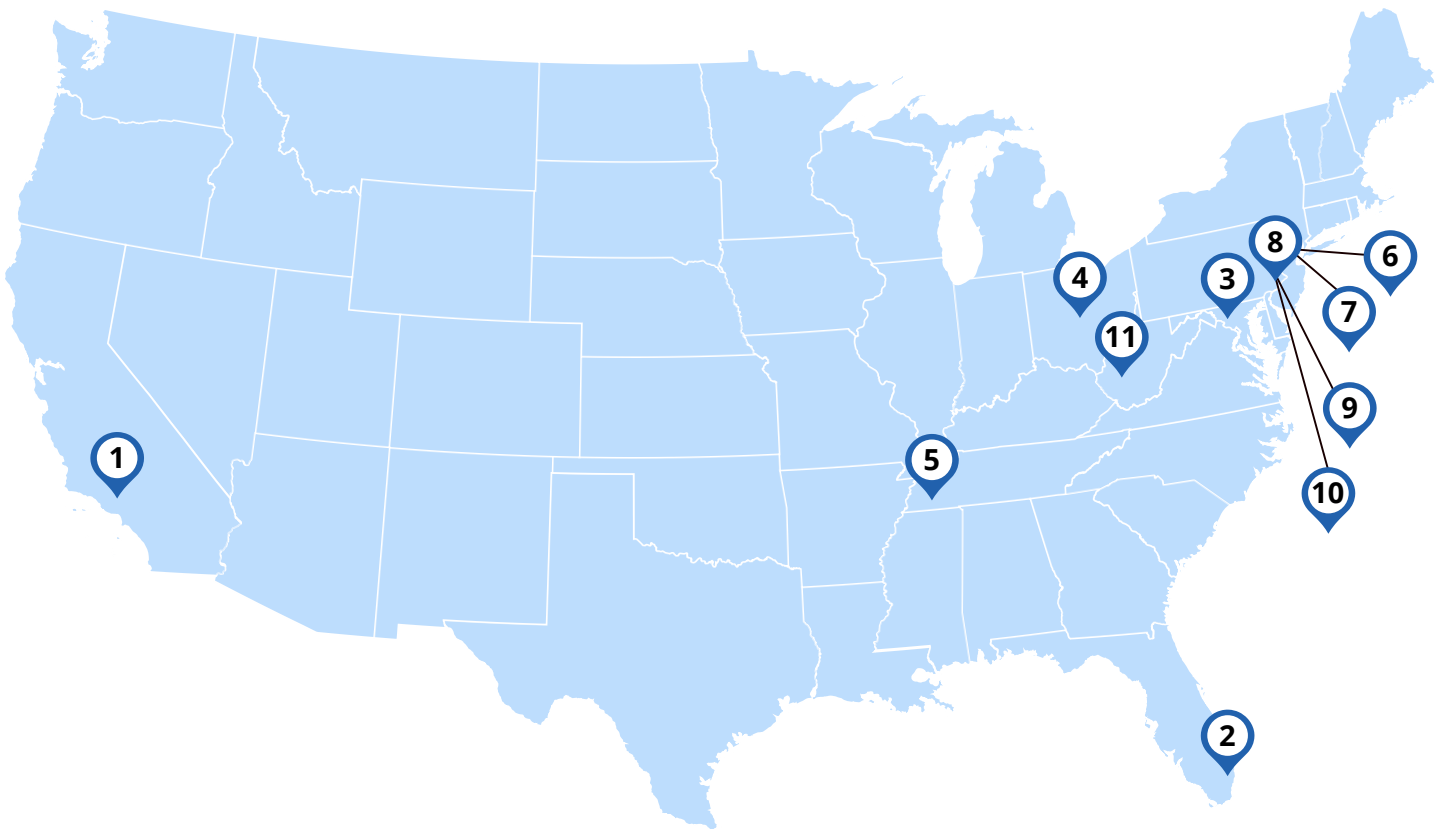
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Pharmacy Locations



1. Canoga Park, California
2. Weston, Florida
3. Columbia, Maryland
4. Dublin, Ohio

5. Memphis, Tennessee
6. Glen Rock, New Jersey
7. Totowa, New Jersey
8. Garnet Valley, Pennsylvania

9. Lima, Pennsylvania
10. Media, Pennsylvania
11. Charleston, West Virginia