

BIO MATRIX

NEWS



**DEDICATED
TO MAKING
A DIFFERENCE**

**SPRING 2022
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“ Tough times never last, but tough people do. — Dr. Robert Schuller ”



ABOUT BIOMATRIX

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

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

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

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

MISSION + VISION

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

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

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

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

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

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

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

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

FINE PRINT

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

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

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A NOTE FROM THE EDITOR

Dear Readers:

Winter is giving way to longer days, warmer weather, blooming flowers, and refreshing spring rainfalls. After a couple of difficult pandemic years, the availability of life-saving vaccines, medical treatment, and relaxed COVID restrictions are creating a growing sense of normalcy.

We are still learning how to best live with this virus, but many are proceeding cautiously back to pre-pandemic activities. An increasing number of bleeding disorder organizations are resuming in-person programming. This Spring brings a sense of renewal and hope that we have left the worst of the past few years behind us.

In this issue we continue our tradition of listing bleeding disorder summer camp programs across the nation. For those who do attend camp this year, please write and tell us about it! We'd love to share your story! Parents - please encourage your young campers as well. This issue also reviews the No Surprises Act, provides tips for successful blood draws, and features Regional Care Coordinator Shelia Bijes in our Meet the Team segment.

As Winter gives way to Spring, we look forward to more sunshine and reconnecting in-person with our many friends and acquaintances in the bleeding disorder community – we hope you enjoy this issue!

Maria Santucci Vetter
Editor-in-Chief, *BioMatrix News*
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BIOMATRIX

Our cookbook brings together recipes from our family to yours!

Our Regional Care Coordinators have provided their very best recipes— from appetizers to entrees and desserts. To get your free cookbook, contact your Regional Care Coordinator or request online:

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





DON'T BE SURPRISED ANYMORE: THE 2022 NO SURPRISES ACT

BY SHELBY SMOAK, Ph.D.

This could happen to you: you're on vacation and experience a terrible bleed in your foot. So tremendous is the pain that you grow concerned it may be a stress fracture. After a night of unrelenting pain, you call a nearby Urgent Care center and confirm they are in-network. No problem, you say. And you go. An X-ray is taken. The foot is diagnosed as not being broken. You go home.

Then the bills come. While all your services at the in-network clinic were covered as in-network costs, the X-ray was sent to a third party for review. And, well, they were out-of-network. Zing! Surprise! This results in a high-cost item not covered by insurance. This is an example of *Surprise Billing*, and renders you helpless to negotiate the cost. There is nothing you could do about it...until now.

In January 2022, the *No Surprises Act* took effect. This bill is meant to end those nefarious charges that appear on the explanation of benefits (EOB) listed as "OON" or Out-of-Network and are the result of care received at in-network facilities. Let's take a look at what the No Surprises Act is and isn't.

What is a surprise bill?

The most succinct answer is that a surprise bill is an unexpected bill, but that could be any bill you hadn't anticipated. Specific to healthcare and this act, a surprise bill refers to a *balanced bill* where a provider bills the patient for the difference between their charge and the amount paid by your health plan.

Why would someone receive a surprise bill?

A surprise bill is more often than not the result of an out-of-network charge. When a charge is in-network, the provider and the insurance plan have a previously agreed-upon arrangement for what the provider will charge and what the insurance will pay. With an out-of-network cost, no such agreement exists: the provider will charge what they feel is appropriate, the insurer will pay what they feel the service is worth. When these two figures do not align, usually with the provider asking for more than the insurer is willing to pay, the patient is billed by the provider for the balance difference, hence *balanced billing*.

In what scenarios might a surprise bill be received?

Numerous situations might lead to a surprise bill, but a majority of these can be related to emergency (ER) services. In these situations, providers often must act quickly. They may not be fully equipped for diagnosis and treatment within the facility and may use contracted help, as exemplified above where the X-ray was read by a third-party source, even though the facility and X-ray technician were in-network at the facility. A blood draw and lab test may be taken where the phlebotomist is in-network, but the sample is farmed to a testing service that happens to be out-of-network.

Another common scenario may involve a procedure where a specialized provider, like an anesthesiologist, may be out-of-network, even though the procedure facility and the primary physician/surgeon are in-network.

How can you determine if your claim was an in- or out-of-network claim?

On most Explanation of Benefit (EOB) claim forms, these are noted or coded as OON (out-of-network), or the insurer's EOB may include a note about the provider being out-of-network to indicate why the full provider cost is not being met. If you are unsure about the explanation on the EOB, you can also call the insurer for clarification.

What does the No Surprises Act cover?

According to the Centers for Medicare & Medicaid Services (CMS), the No Surprises Act provides consumers with "billing protections when getting emergency care, non-emergency care from out-of-network providers at in-network facilities." It also provides out-of-network protections for air ambulance services.¹

What situations do the No Surprises Act not cover?

The Act does not cover out-of-network billing from ground ambulance services. In many cases, a ground ambulance may be contracted with an in-network provider but be out-of-network with your insurance plan, and, unfortunately, the No Surprises Act does not offer patient protections in this situation.

The No Surprises Act also does not protect you if your provider (ER, hospital clinic or other facilities) is out-of-network. *To be applicable, the out-of-network claim in question must have occurred within or at an in-network facility or provider.*

What happens if my emergency care is at an out-of-network facility?

Unfortunately, the No Surprises Act does not specifically address this situation. However, emergency care is provided under the ACA and requires that providers must match in-network copayment and coinsurance rates when care is received at an out-of-network facility, so there would be some leverage for disputing an out-of-network charge in such an event.

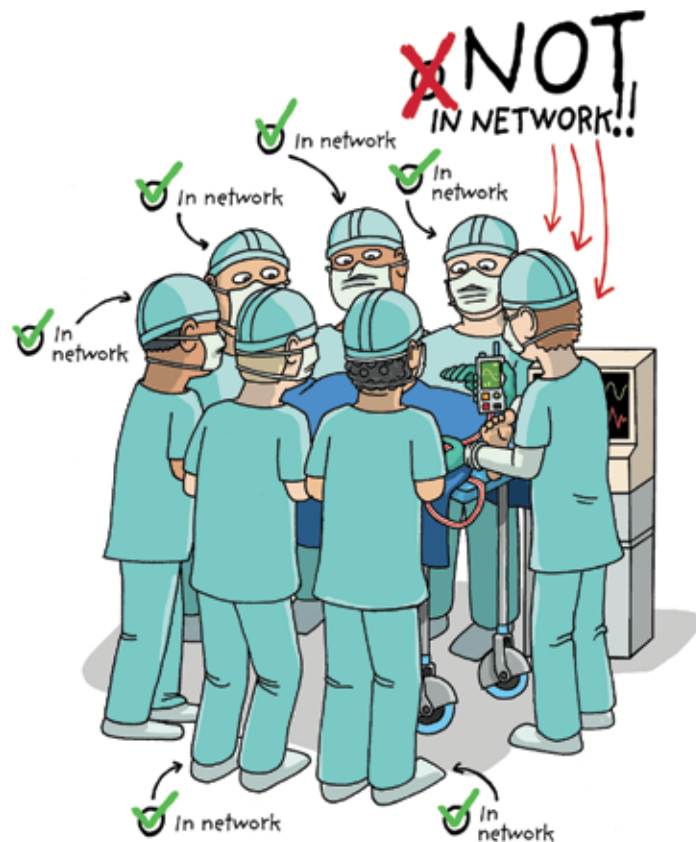
Will the No Surprises Act automatically take effect when I receive an out-of-network bill?

No. The Act provides you with the protection to challenge the charge, but it does not require providers and insurance plans to flag out-of-network claims, nor are they required to determine if one of your out-of-network claims meets the criteria of a surprise bill. *It is the patient's responsibility to read the insurance plan's EOB and determine if an out-of-network claim occurred at an in-network facility.*

How do I dispute a medical claim that I think is a surprise bill?

If you believe you are the victim of a surprise bill, you can challenge the charge with the insurer and provider:

1. Obtain the itemized bill from the provider
2. Obtain an explanation of the charges from the medical provider



3. If you are going to appeal, let your provider know and ask them not to send the outstanding bill to collections
4. Call your insurer to discuss the charge
5. Be sure to document all of your communications with the insurer and provider during this process. Take detailed notes - include manner of communication (email, phone, etc.), date, time, person's name and department. Request contact confirmation numbers when available.

CMS has designated an arbitration process for the plan and provider to work out the charges without your involvement. The important point is that once you receive a confirmation of a surprise bill, you should not be paying an additional fee, or settling the "balanced bill" with the provider.

The No Surprises Act is new to 2022 and is likely to have some bumps, but it's important to know the law and know your rights. If you have any questions, please reach out to your RCC at BioMatrix or our education team at education@biomatrixsprx.com. We hope this helps you stay protected in 2022 and forward.

References:

- i. CMS. "Surprise Billing and Protecting Consumers." 14 Jan. 2022. <https://www.cms.gov/nosurprises/Ending-Surprise-Medical-Bills>.
- ii. Controlling Costly Care: Lawmakers Weigh Surprise Billing, Transparency Legislation, https://cdn.theindianlawyer.com/wp-content/uploads/2020/02/Focus_SurpriseBills_IL021920_BradTurner.png. Accessed 25 Jan. 2022.



BLOOD DRAW *Success!*

BY DAVID TIGNOR AND ROB CARTER, RN

I can't imagine there are many people that actually enjoy having their blood drawn; however, to maintain good health, routine blood draws are often necessary. This article reviews ways to help ensure blood draws are as easy and trouble free as possible.

As a person with severe hemophilia A, routine labs and blood draws are a part of my care routine. On a few occasions, I have experienced bleeds in the antecubital vein (the area in the bend of the arm) as a result of having the venipuncture. These bleeds were most likely due to one or more factors: the gauge of the blood draw needle, the unavoidable movement of the needle in the vein when collection tubes are placed and removed, how the needle is withdrawn from the vein, or even from the post-draw bending of the elbow, rather than keeping it straight, to place pressure after the needle is removed. If you live with a bleeding disorder you may have experienced similar issues. Luckily there are steps you can take to minimize negative effects from an infusion or blood draw.

If you have a bleeding disorder, chances are your veins are accessed on a more frequent basis than most individuals'. As such, it's important to keep your veins happy and healthy. One great way to start well before an infusion is needed is through diet and exercise! Regular exercise will help your veins grow larger and stronger. Additionally, following a healthy diet will ensure your veins recover quickly from frequent pokes and prods. Dietary suggestions include food rich in bioflavonoids (natural antioxidant compounds typically found in fruit), vitamin C, antioxidants and fiber. This will help the elasticity and strength of the vein walls and valves. A healthy diet, plenty of exercise and staying properly hydrated will have a positive impact on your veins and overall health.

We all know that our annual HTC visit will typically require labs to be drawn. Many hospitals and clinics will have a phlebotomist available to administer the blood draw. A

phlebotomist is an individual who is trained and certified to draw blood. Typically, phlebotomists will use vacuum-sealed collection tubes in conjunction with an adapter/holder and a hypodermic needle. The size of a needle is determined by gauge numbers, which refer to the diameter, technically known as the "bore" of the needle. A larger gauge number indicates a smaller needle diameter or bore. For example, the bore of a 23-gauge needle is smaller than a 16-gauge needle (often used for blood donations). For adults, the most common blood draw needle size used to draw blood is a 21-gauge.

There can be a higher risk for those living with a bleeding disorder to have bruising, hematomas, or even a bleed at the venipuncture site when blood draw systems use a larger needle. An alternative for preventing trauma to your vein is to use a butterfly needle. I have found that requesting a smaller gauge butterfly needle for blood



draws has made a huge difference for me. A 23-gauge is the size typically used on children. Anything smaller, the needle would need to be in the vein too long and can cause hemolysis, which is the breaking down of red blood cells causing the release of hemoglobin into the surrounding fluid and may result in a ruined blood sample.

Your phlebotomist can be asked to use a 23-gauge butterfly needle and most of the time they will comply without any issues. However, sometimes they have to follow a certain protocol when drawing blood and are allowed to use the smaller 23-gauge butterfly needles for children, or to control stress placed on small or fragile or rolling veins. If you are an adult and would prefer a smaller needle for your blood draw, talk to your hematologist or doctor and ask them to write, "Please use 23-gauge butterfly needle" on your blood draw orders. This will let the phlebotomist know there is a valid reason an adult with seemingly typical veins requires a 23-gauge butterfly needle for the venipuncture.

Especially for children, a numbing cream can be applied to the venipuncture site to help alleviate the pain of the needle stick. This will require time for the cream to work. Also, an excessively tight tourniquet is not needed and may cause bruising on tender skin. Placing the tourniquet over the sleeve instead of on bare skin can help with this.

It is important to educate your phlebotomist about your bleeding disorder as it relates to the draw and advocate for your specific needs. In my case, I have pretty good veins

and some phlebotomists do not understand why I am requesting a 23-gauge needle. I found it helps to have a quick conversation before the blood draw. Educating them about your condition and the steps that can be taken to minimize any issues is a great way to ensure a positive outcome. If you are not comfortable with their level of experience, you have the right to ask for another phlebotomist.

Phlebotomists have a demanding job and are sometimes rushed to get patients in and out of the lab. Sometimes being in a hurry can result in human error when extracting the needle, such as applying pressure while the needle is still in your arm instead of applying pressure after the needle is completely removed. This can cause unnecessary trauma in the vein. Remind the phlebotomist to remove the needle completely. Once gauze and a bandage are placed over the injection site, place gentle pressure for at least 5 minutes while keeping your arm straight. Bending your arm can cause the blood to pool resulting in a bruise. If certain adhesives cause skin irritation, be sure to remove the tape within 20 minutes. A Coban wrap instead of tape may also be requested.

Healthy veins are important for everyone, but for those living with a bleeding disorder, taking additional steps is key to preserving the access sites we depend on. By eating healthy, staying well hydrated, exercising, and working closely with your physician and the phlebotomist conducting blood draws, you can greatly improve your experience when it comes time to do labs or receive an infusion.



TIPS FOR A SUCCESSFUL BLOOD DRAW

- **Hydrate** – Most important for a successful blood draw is to be hydrated. Drink plenty of water before your appointment to help dilate the veins. Avoid nicotine (cigarettes, vapes, chewing tobacco) and caffeine (sodas, coffee, energy drinks). These will constrict the veins making the draw more difficult.
- **Warm up** – Being warm increases the blood flow and makes the veins easier to find. Take a warm shower before your appointment and keep yourself warm in cold temperatures. Do a few jumping jacks or rotate your arms around to get blood flowing. Hold a warm compress over the injection site for 15 minutes.
- **Use gravity** – Let your arm hang down to increase blood flow. Make a fist or squeeze a stress ball. No need to pump your hand since doing so does not increase blood flow, especially once the tourniquet is on.
- **Relax and breathe normally** – Being tense can lead veins to constrict. Don't watch the venipuncture if it bothers you or makes you feel dizzy.
- **Sit still** – Try to avoid making it more challenging! Hold a small child in your lap and use distraction.
- **Speak up** – If you're prone to feeling dizzy when having your blood drawn, let your nurse or phlebotomist know before starting.



Now Accepting Applications for the 2022 School Year!

BIOMATRIX MEMORIAL SCHOLARSHIP PROGRAM

Each year, BioMatrix offers six \$1000 educational scholarships to students diagnosed with hemophilia or von Willebrand Disease who are pursuing higher education. In the case of two of the opportunities, 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. 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 to manage and administer our scholarship program. This allows us to streamline and enhance our program with an organization that knows and understands the bleeding disorders community.

**Applications will be accepted
through August 1, 2022.**

APPLY ONLINE!

scholarship.biomatrixsprx.com



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



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



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



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



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



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

BIOMATRIX

Meet the Team!

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



Shelia Biljes
Regional Care Coordinator

My advice for newly diagnosed families is to build a support team within the hemophilia community. Get involved, learn all you can, and try everything!

Introducing Shelia Biljes! Shelia, her father, and her son have all been affected by hemophilia factor IX deficiency. These personal connections prompted a journey of service to the bleeding disorders community. Shelia is a tireless advocate, applying her personal experience to help connect, support, educate, and serve people with hemophilia and vWD. Based in the Cleveland area, Shelia primarily works in Ohio and Pennsylvania, but her long time involvement in the community and willingness to serve has led to connections and support for community members across the country. Get to know Shelia!

What brought you to BioMatrix?

For many years I was employed as a medical claims examiner. After my son was born, I volunteered at my HTC to help design educational programs for families with young children. A few years later, my career path turned toward the specialty pharmacy arena. Twenty-one years ago, I began serving patients with bleeding disorders, happily joining BioMatrix as a Regional Care Coordinator in 2017. It's been wonderfully fulfilling!

Tell us about your family and connection to the community?

I was born in Cleveland, Ohio, and have lived in the area my whole life. My father had hemophilia, but I was only vaguely familiar with it growing up. His bleeding disorder was kept quiet because he feared losing his job if he missed work or if attention was brought to the costly treatment.

Becoming a mom was my greatest desire and it came true with the birth of my daughter, Mika, followed by my son, Jordan, and then my daughter Miya. My dream was for a large family, but three babies riding in a double stroller proved to be enough!

During my second pregnancy, as an obligate carrier and knowing the baby was a boy, my doctor took extra precautions with the delivery. My son was diagnosed at birth with 2% moderate factor IX hemophilia. We were referred to a hematologist and put in contact with our local bleeding disorders chapter. The chapter invited us to their holiday party, which was scheduled for the next weekend. That day, Jordan was just 7 days old. I met people who became my second family, one full of love and support. Our friendships continue to this day and I am still very active in my local chapter.



Shelia with husband, Bill



Shelia and son Jordan ziplining and taking in the views of Costa Rica

Our lives have evolved around the joy of raising our kids and it's been an extremely busy journey! We were very involved with school, church, Girl and Boy Scouts, ice skating, baseball games, music lessons and more!

My daughters graduated high school with honors, Miya as Valedictorian and Mika as Salutatorian. My son completed his Eagle Scout and was Senior Class President. All three graduated college and by this summer, all three will have master's degrees. I am so proud of my kids and when I see them using their talents to help in the bleeding disorder community, my heart just swells!

With the kids grown and gone, my husband, Bill and I are empty nesters currently residing in Columbia Station.

What is an interesting or unique fact about you?

In addition to hemophilia, my dad passed on to me his love of antique cars. He left my son a 1928 Model A, which we use to cruise around on Sunday afternoons. We also own a 1976 Cobra Mustang, a 1966 Oldsmobile 442 convertible and a 1971 Kingswood Station wagon. The station wagon inspires many people to approach us and tell stories of trips taken in their family wagons back in the day. The car takes me to the days of being in the back of my dad's wagon with my siblings small enough to sit side-by-side looking out the back window.

Who in your life has influenced you the most?

My father, a much-loved Baptist minister, was a huge influence in my life. He suffered quietly through bleeding episodes and illness caused by hepatitis C. In 2019, he was approved for hep C treatment around the same time a cancer diagnosis was received. Sadly, he lived only a few months longer.

1970 Mom, Gloria

1974 Kindergarten

1987 High school

2004 Busy family days

2012 Jordan becomes an Eagle Scout

2015 Dad, Eddie

2018 in Costa Rica with kids

2018 with derby-driving husband

1975 Siblings Eddy, Joey and Kim

1997 Attending very first FAMOHIO

2001 NHF Annual Meeting

2010 Admiring an antique

2017 Shark!

2017 With husband Bill

2021 sewing party!



Participating in the Northern Ohio Hemophilia Foundation Walk at the Akron Zoo 2015

Describe your most difficult challenge.

One of my greatest challenges was learning to infuse my son. Initially, we only infused for injuries, which always seemed to happen at bedtime, weekends, and holidays. My husband worked and went to college, so I found myself making doctor's office or emergency room trips with all three little ones in tow. When my son turned two, we decided in order to have a more normal life, we needed to learn how to infuse. I was extremely nervous but pushed through the fear for the sake of our sanity and more independence. I encourage new parents to learn to infuse their child just as soon as possible. It makes a huge difference in managing a bleeding disorder.

What advice do you offer new families?

My advice for newly diagnosed families is to build a support team within the hemophilia community. Get involved, learn all you can, and try everything! I also suggest families speak to their HTC or medical provider about infusing before special occasions where a bleeding episode would be especially inconvenient. Keeping with the old saying, "an ounce of prevention is worth a pound of cure," I remind them to slow down a minute and make sure their loved one's prophylaxis has been administered.

before letting the excitement of a moment overshadow the necessity of *taking care of business*. Looking back at my own experiences, we could have prevented some disappointments and extended healing times had we been more attentive to this.

What motivates you – what is your passion?

What motivates me is knowing there are still many families in this community to meet and hopefully provide a level of support. My focus for many years has been on uniting community members and watching friendships grow with every event.



Greta Von Biljes, Nora Jean, Lucy, Codi and Flynn

As a former part-time wedding photographer, one of my passions is taking pictures. With my kids all grown and gone my empty nest is now used to entertain my dogs. We have a Rottweiler named Greta Von Biljes, a pit bull, Flynn and a little beagle, Nora Jean. I often watch my daughter's dogs, another pit bull and a labradoodle. All five dogs are subject to portrait sittings!

Sewing is another favorite pastime. Making quilted bedspreads, purses, totes and table runners takes up some of the time I used to spend running around with my kids. When I make a project, who it is for is decided before I start sewing. As I work, I think about the recipient and fill the quilt with thoughts of love and good wishes. I recently hosted a sewing class for a wonderful group of hemophilia B ladies. It was an event that was so near and dear to my heart! Hopefully, they can use this activity as a future stress reliever.

What is your proudest achievement?

My proudest achievement was during a BioMatrix sponsored event at the Cleveland Aquarium. The topic was getting over the fear of infusing. Having a serious fear of sharks, I've never watched the whole *Jaws* movie. In fact, I won't go into an ocean any further than my knees! However, on this occasion I donned scuba gear and swam in the shark tank. To surpass my greatest fear with the hope of encouraging someone to overcome their fear of infusing was worth it!

How do you feel you are Making a Difference?

By helping families understand overwhelming aspects of insurance and the medical system, I feel I am *Making a Difference*. I try to help patients navigate common insurance challenges and maintain access to care. It's a challenge I enjoy and take seriously.

Every month, I host events for families to provide education and support. Themed events are my favorite to plan, and I try to incorporate education unobtrusively. Also, much of my free time is devoted to helping guide young people in our community into college or their chosen career.



Facing her greatest fear

What is the most cherished part of your job?

What I cherish most about being a Care Coordinator is when I can be a light in the darkness for a family with a newly diagnosed child. I remember the women who showed such compassion toward me at my first chapter event, and I try to make myself available for new mothers as I once was.

I have had the joy of watching many boys grow into amazing young men and am so glad to see women finally beginning to be properly diagnosed. As a woman "with hemophilia," I am excited to have the opportunity to offer education and support to women who have been ignored over the years. Through the patients I serve, I feel I've been given the large family I had always wanted.

To contact Shelia Biljes, call 440-813-1626 or email: shelia.biljes@biomatrixsprx.com



Shelia and son, Jordan



Camp... DEEPER THAN THE SURFACE

BY FELIX GARCIA

Remember when the most phenomenal week of the year began when our feet hit the ground at bleeding disorders camp? For me, the joy of that week seems like yesterday, and at the same time, as if it were a lifetime ago. Those feelings get lost as we grow older – a few of us go back as counselors, but for most, school, jobs, relationships and other grown-up obligations take their place. Those years at camp are precious.

When I was young, there were no camps near where we lived. When I was about 11 years old, my parents contacted the closest HTC in our state and arranged for me to attend. I was blown away! It was the most liberating week of my young life! Every cabin was full of boys just like me. I didn't have to explain my bruises or why I was limping by the end of the day. After all, everyone else was limping too. There was comfort in knowing we were all going through the same challenges in our lives. We were happy to be together. I can't think of a fonder memory than that week and from the start, I looked forward to it all year long.

In my life back home, I was sort of an outcast. Kids looked at me as if I were strange. I was sometimes called a "faker" because I'd arrive at school in the morning just fine but would be in pain and limping by the end of the day. Keep in mind this was before the days of prophylaxis – I infused only when it was needed to treat a bleed. I can only imagine that home life was much the same for my hemophilia brothers.

During my last 2 years at camp, I remember sitting with my cabin mates talking about the HIV/AIDS virus that was running rampant in our community. At that time, we all saw it as a death sentence. Treatment wasn't what it is today. A couple of my fellow campers knew they had already contracted the virus, while many of us had also, but didn't know it yet. We talked about how we were all

eventually going to get it to help our diagnosed blood brothers feel better. Crazy how such a sad thought might bring comfort to someone. At the time, my parents knew I had HIV but kept it from me for a while. Camp was a safe place though - we talk about everything with each other.

As I look back through adult eyes, the camp experience was different then – in some ways better but in others, it was barbaric! To me, the week was more about letting these poor kids have the time of their lives for a few days rather than trying to teach them anything. I can't really say I remember learning much about life skills or how to prepare for the future. My biggest takeaway was learning how to self-infuse though and that was a huge benefit. With a bleeding disorder, our life span was already jeopardized. Once HIV/AIDS entered the picture, we honestly didn't have much of a future to look forward to. With no parents hovering over us in this newfound freedom, we weren't afraid of anything, at least I wasn't. That mentality may have led to my no longer being invited to camp.

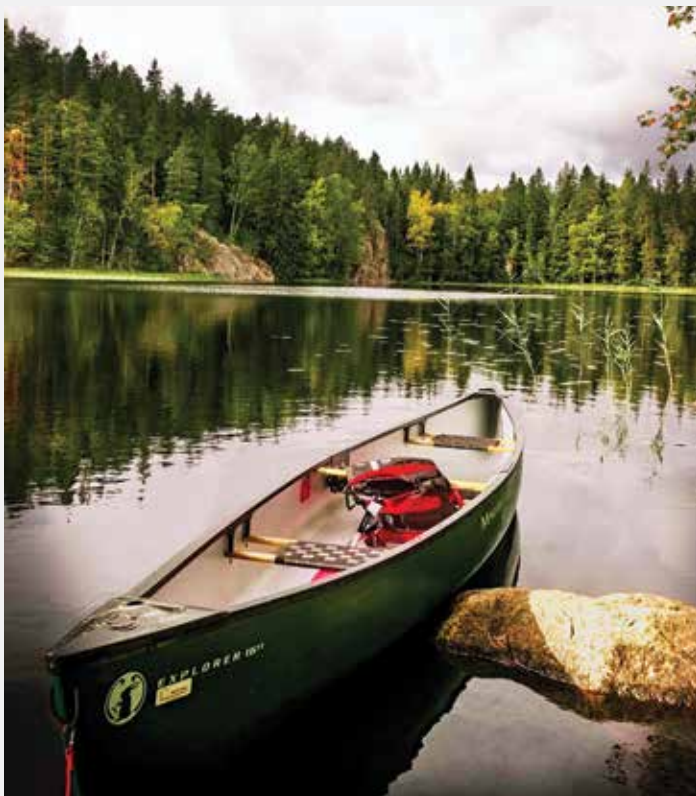
During my last camp year as a 14-year-old, we swam and canoed along a small river where the campground was located. Just downstream was a Girl Scout camp. My cabin mates and I decided to sneak over to visit the girls' camp. Our (untrained) counselors thought it was a great idea and did nothing to stop us – they cheered us on if anything. And so, with another boy and me deemed the ringleaders,

we snuck off in the hush of the dark night in canoes, quietly and covertly passing the security guard... and we got away with it.

I got a kiss on the cheek from a Girl Scout that night. That would have been a sweet, sentimental camp story if it ended there, but of course, it didn't. The next night, our last night, we organized another expedition to the girl's camp. Having heard of our previous adventure, other campers joined us and the group was much larger this time. We couldn't all travel by canoe, so we had to make the trek on foot. This time, however, the whispers, giggles and commotion were much too noisy and we caught the attention of the security guard. Busted! Our adventure failed miserably!

The next morning, eager to avoid my parents learning about the trouble I had gotten into, I waited at the pick-up spot with my luggage. As soon as they drove up, I threw my bags in the car and said, "Let's go!" We left without my parents ever hearing about what happened the previous night. During a post-camp meeting, it was decided the ringleaders – the other boy and I – were no longer to be invited back to camp. In more modern days, camp is an entirely different ball game. Rather than letting kids run around wild, the focus is on developing boys and girls to be productive, responsible adults who can care for themselves and manage their health condition. In addition to all the fun activities, a lot of rules and oversight to keep everyone safe and out of trouble have been implemented.

Busted! Our adventure failed miserably!



I had no idea how much that innocent kiss on the cheek would cost me. It was years before I realized the impact not attending camp would have on me. As a teenage boy with HIV and a debilitating chronic illness in the early 90s, it caused me to lose my support system – I needed my blood brothers. The years that followed were lonely – not a single fellow hemophiliac around. My circle got smaller and smaller as I grew distant from most people. I was a loner who tried to cover my pain with jokes. Those were dark days as the cloud of HIV loomed overhead... I lashed out and my behavior spiraled to the point I became self-destructive.

It took years to eventually find my way out of that place. I had to learn to cope with the fear of death and the guilt of surviving. Since then, I've volunteered as a counselor for years (even at my old camp) and have held various positions within camp committees, always advocating for that one kid who needs more attention or direction.

Once a boy in my cabin acted up and kicked out a window. I fought hard to keep him from being sent home. It turned out his medications had gotten mixed up and he was off balance. His actions were not his fault. He was allowed to stay and was a perfect camper the rest of the week. I do everything I can to help the camp experience be the very best it can be for all children, not just the easy ones.

My experiences have taught me just how important bleeding disorders camp is for our youth. COVID-19 and its variants have, of course, done a number on our whole world, but on a smaller, more personal level, it's been horrible for the young people in our bleeding disorders community. It may seem like just a week of fun, but it has taken away the experience of being with others who walk in similar shoes where no explanations are needed. We won't know the real impact the isolation has on these young lives for years, if ever.

Many organizations understand the importance of camps and have done their best to provide get-togethers in the form of virtual meetings. We all know this isn't at all the same as being on the campground, but if that's all that's available, then let's get the kids to participate! I implore camp staff to keep volunteering – even if it's a corny Zoom session, do it! You may not think so, but it does make a difference!

Make it a goal to reach out to former campers and their parents about attending. If you know of a child who is now of camp age, contact their parents and invite them to attend. Parents, we never know what is truly going on in the hearts and minds of our children. We only get to see the portion they choose to share with us. With fellow campers and even counselors, they may, and often do, share another side of themselves. Encourage your child to attend even if they don't seem interested.

I challenge each of you to share my story and to make the effort to participate in camp. Let's make sure we are here for our youth especially now when they need us most!

#KeepCampGoing

2022 BLEEDING DISORDER CAMPS

Across the Country

Every year, many in our bleeding disorders community eagerly look forward to spending time at camp. It's a magical place where kids make lifelong friends with others who, just like them, live with hemophilia or von Willebrand. It's a place where everyone understands what a young patient or sibling goes through with little explanation needed. It's a place where a child can learn to self-infuse and gain independence and confidence.

With the availability of COVID-19 vaccines and the promise

of a safer future, many camps are moving forward and more confidently booking dates, some are holding virtual camps, while a few have cancelled camp altogether and are not included in our 2022 list.

The decision to hold in-person camp can quickly change given CDC guidelines and specific state-by-state decisions. Please stay in touch with your local camp organization to learn how your camp is proceeding and when registration may take place.

NEHA Camper Testimonial

"When we got to camp last summer, we didn't think Julian would attempt to self-infuse. He has never shown an interest or willingness to try. But things turned out to be different this year. The family-pod model meant he was with his dad during infusion class, which provided an extra level of comfort. Much credit is due to the nurses who provided so much encouragement and refused to let him give up on himself, as well as a small group of peers who intuitively formed a support network for each other's attempts. All of these factors contributed to Julian's achievement of the "Big Stick" and we were completely blown away by his courage and determination. It felt like we were watching an unbelievable developmental milestone (which is about right for a kid with hemophilia), as he took a deep breath and stuck a needle in his vein for the very first time. His "Big Stick" was one enormous feat that is the first step to gaining independence with managing his bleeding disorder and we could not be more proud of that."

— Julian's mom, Ann Marie Minichiello

ALABAMA

1. Camp Clot Not

Date: June 18–23, 2022

Open to: Boys and girls with a bleeding disorder, and carriers
Ages: 6–18

Camp Harvest Family

Date: October 21–23, 2022

Open to: Active HBDA families with a parent or child with a bleeding disorder

Location: Children's Harbor Mariner's Adventure Camp; Alexander City, AL

Contact: Amanda Jennings, 334-478-7822
amandajennings525@gmail.com

Host: Hemophilia and Bleeding Disorders of Alabama, Inc., www.hbda.us



ARIZONA

3. Camp HONOR

Date: July 11–15, 2022

Open to: Boys and girls with a bleeding disorder, siblings and children of an affected parent
Ages: 8–17

Location: Camp Wamatochick Prescott, AZ

HUG Family Camp

Date: Oct. 7–9, 2022

Open to: AZ families with a parent or child affected by a bleeding disorder

Location: Emmanuel Pines Camp; Prescott, AZ

Contact: Vickie Parra
602-955-3947

vickie@arizonahemophilia.org

Host: Arizona Bleeding Disorders
www.arizonahemophilia.org



Camp Honor



ALASKA

2. Camp Frozen Chosen

Date: June 20–24, 2022

Open to: Boys and girls with a bleeding disorder, siblings (space permitting)

Ages: Completed 1st grade through senior year of high school

Location: Birchwood Camp; Chugiak, AK

Contact: Michelle Palmatier
907-229-6017
907-917-9235

alaskahemo@gmail.com

Host: Alaska Hemophilia Association and Bleeding Disorder Center

<https://www.facebook.com/Alaska-Hemophilia-Association-210132535692257/>



Frozen Chosen

ARKANSAS

4. Camp Aldersgate

Date: July 31–Aug. 5, 2022

Open to: Boys and girls with a bleeding disorder, carriers and siblings

Ages: 6–18

Location: Camp Aldersgate Little Rock, AR

Contact: Ian Shuttleworth
501-225-1444 x228

ishuttleworth@campaldersgate.net

Host: Camp Aldersgate
www.campaldersgate.net



5. Camp Nopokamee

Date: July 17–21, 2022

Open to: Boys and girls with a bleeding disorder, carriers and siblings (space permitting)

Ages: 8–18

Location: 4H Club Ferndale, AR

Contact: Angela Hodgdon, 501-428-5754
secretary@arkhemofoundation.org

Host: Hemophilia Foundation of Arkansas
arkhemofoundation.org



Nopokamee



Nopokamee

CALIFORNIA

6. California Camp Hemotion

Date: July 31–Aug. 6, 2022

Open to: Boys and girls with a bleeding disorder, carriers and siblings

Ages: 7–14

Ages: 15–20 Junior and Asst. Counselors

Location: Camp Oakhurst; Coarsegold, CA

7. HFNC Family Camp

Date: Oct. 15, 2022

Open to: HFNC families, including newly diagnosed, affected by a bleeding disorder

Location: Camp Arroyo; Livermore, CA

Contact: Ashley Gregory, 510-658-3324
ashley.gregory@hemofoundation.org

Host: Hemophilia Foundation of Northern California, www.hemofoundation.org



8. The Female Factor Retreat

Date: April 8-10, 2022
Open to: Local, national and international women, teens, identifying, affected and connected to the bleeding disorders community
Ages: 12 and up
Location: St. Clare's Retreat; Soquel, CA
Contact: Ashley Gregory, 510-658-3324 ashley.gregory@hemofoundation.org
Host: Hemophilia Foundation of Northern California, hemofoundation.org



Female Factor

9. Teen Camp Dragonfly

Date: July 9-13, 2022
Open to: Teen boys and girls with a bleeding disorder; siblings and carriers (space permitting)
Ages: 14-17 **Ages:** 21+ General Staff
Location: South Fork of the American River Lotus, CA
Contact: Nooshin Kosar, 619-325-3570 info@hasdc.org
Host: Hemophilia Association of San Diego County, www.hasdc.org



Dragonfly



Firefly

10. Camp Firefly

Date: Aug. 7-12, 2022
Open to: Boys and girls with a bleeding disorder, siblings and carriers (space permitting)
Ages: 7-14
Ages: 16-17 Jr. Counselors
Ages: 18+ Counselors and General Staff
Location: YMCA Camp Oakes Big Bear, CA
Contact: Nooshin Kosar, 619-325-3570 info@hasdc.org
Host: Hemophilia Association of San Diego County, www.hasdc.org



Firefly

11. Camp Blood Brothers & Sisters

Date: July 19-23, 2022
Open to: Boys and girls with a bleeding disorder
Ages: 7-16
Ages: 17-18 Leader-in-Training
Ages: 19+ Volunteers
Blood Brothers and Sisters Sibling Camp

Date: Aug. 12-16, 2022
Open to: Siblings of children with a bleeding disorder
Ages: 7-16
Location: The Painted Turtle Camp Lake Hughes, CA
Contact: Cynthia Chavez, 626-765-6656 cynthia@hemosocal.org
Host: Hemophilia Foundation of Southern California www.hemosocal.org



Blood Brothers & Sisters



Blood Brothers & Sisters

12 HFSC Family Retreat

Date: June 3-5, 2022
Open to: Anyone with a bleeding disorder and their immediate family
Location: Pali Mountain Retreat Running Springs, CA
Contact: Cynthia Chavez, 626-765-6656 cynthia@hemosocal.org
Host: Hemophilia Foundation of Southern California, www.hemosocal.org

COLORADO

13. Colorado Chapter Family Camp

Date: May 20-22, 2022

Open to: Adults with bleeding disorders and their families, families with a child with a bleeding disorder too young for camp, and young adults

Location: Rocky Mountain Village; Empire, CO

Contact: Hanna Beary, 646-499-0684

hbeary@hemophilia.org

Host: Colorado Chapter NHF, 720-545-0755
www.cohemo.org



In Conjunction with Montana | Wyoming Mile High Camp

Date: July 17-21, 2022

Ages: 7-14

Open to: Boys and girls with a bleeding disorder and siblings

Teen Leadership Weekend

Date: July 15-17, 2022

Open to: Teens with a bleeding disorder

Ages: 15-17

Location: Rocky Mountain Village Empire, CO

Contact: Hanna Beary, 646-499-0684

hbeary@hemophilia.org

Host: Colorado Chapter NHF, 720-545-0755

www.cohemo.org and Rocky Mountain Hemophilia Bleeding Disorder Association
www.rmhbda.org



FLORIDA

14. Camp Spirit

Date: July 14-18, 2022

Open to: Boys and girls with a bleeding disorder

Ages: 7-16

Family Camp Spirit Getaway

Date: October 7-9, 2022

Open to: Families affected by a bleeding disorder

Location: Camp Boggy Creek; Eustis, FL

Contact: Fran Haynes, 407-629-0000

franhaynes@hemophiliaflorida.org

info@hemophiliaflorida.org

Host: Hemophilia Foundation of Greater Florida, www.hemophiliaflorida.org



Spirit

GEORGIA

15. Camp Wannaklot

Date: July 17-22, 2022

Open to: Boys and girls with a bleeding disorder

Ages: 7-12 Junior Camp

Ages: 13-17 Teen Camp

Location: Camp Twin Lakes; Rutledge, GA

Contact: Kristi Fulford, 770-518-8272

kffulford@hog.org

Host: Hemophilia of Georgia

www.hog.org/camp/



HAWAII

16. Koko Ohana Family Camp

Date: June 24-26, 2022

Open to: Families and individuals affected by a bleeding disorder

Location: Camp Molukeyia; Waiialua, HI

Contact: Kyra Calbero, 808-284-7417

kcalbero@hemophilia.org

Host: Hawaii Chapter-NHF

www.hawaiiinhf.org



Koko Ohana

IDAHO

17. Red Sunshine Family Camp

Date: June 23-25, 2022

Open to: Families affected by a bleeding disorder

Location: Sawtooth Methodist Camp Fairfield, ID

Contact: Marlyn Walker, 208-344-4476

208-631-9729, mwalker@hemophilia.org

Host: Idaho Chapter of NHF

www.idahoblood.org



Red Sunshine Family

ILLINOIS

18. Camp Warren Jyrch

In-Person Date: July 31-Aug. 6, 2022

Virtual Date: Aug. 26-27, 2022

Open to: Boys and girls with a bleeding disorder and diagnosed carriers, siblings accepted on a case-by-case basis

Ages: 7-17

Location: YMCA Camp Benson Mt. Carroll, IL

Contact: Noelle Simpson, 206-724-9390

nsimpson@bdai.org

Host: Bleeding Disorders Alliance Illinois

www.bdai.org/campwarrenjyrch



Warren Jyrch

INDIANA

19. Camp Brave Eagle

Date: June 12-17, 2022

Open to: Boys and girls with a bleeding disorder and carriers

Ages: 7-17

Location: Camp Crosley YMCA North Webster, IN

Contact: Angel DiRuzza, 317-570-0039 x102

adiruzza@hoii.org

or Scott Ehnes, sehnes@hoii.org

Host: Hemophilia of Indiana, Inc.

www.hoii.org, www.campbraveeagle.org



20. Riley Camp Independence

Date: June 26-July 1, 2022

Open to: Boys and girls with hematological disorders

Ages: 8-18

Location: Bradford Woods Martinsville, IN

Contact: Nick Hunter, 765-349-5121

nyhunter@indiana.edu

Host: Riley Hospital for Children at Indiana University, <https://bradfordwoods.iu.edu/>



IOWA

21. Hemophilia Bleeding Disorders Camp

Date: June 19-24, 2022

Open to: Boys and girls with a bleeding disorder and one camper guest per family, space permitting

Ages: 6-17

Location: Camp Tanager; Mount Vernon, IA

Contact: Michelle Krantz, 319-356-2890

michelle-krantz@uiowa.edu

or Karla Watkinson, 319-356-4271

karla-watkinson@uiowa.edu

Host: Hemophilia of Iowa, Inc.

www.hemophiliaofiowa.org with Iowa Hemophilia and Thrombosis Center



Iowa Bleeding Disorders Camp

KANSAS | MISSOURI

22. Camp Wilderness

Date: Aug. 1-5, 2022

Open to: Boys and girls with a bleeding disorder and carriers

Ages: 7-17

Location: Lake Doniphan

Retreat Center

Excelsior Springs, MO

Contact: Luke Saulsberry

816-315-7308

campdirector@midwesthemophilia.org

Host: Midwest Hemophilia Association

www.midwesthemophilia.org



Wilderness

KENTUCKY

23. Camp Discovery

Date: July 24–28, 2022
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 7–15

Ages: 16–17 Jr. Counselors-in-Training
Location: Cedar Ridge Camp; Louisville, KY
Contact: Ursela Kamala, 502-456-3233
ursela@kyhemo.org, info@kyhemo.org
Host: Kentucky Hemophilia Foundation
www.kyhemo.org



Discovery

24. Center for Courageous Kids Camp Family Camp

Date: June 28–July 2, 2022
Open to: Families with bleeding disorders (hemophilia, vWD, ITP, SCA)
Location: CCK: Scottsville, KY
Contact: Hannah Reckart
270-618-2900 x287
hreckart@courageouskids.org
Host: Center for Courageous Kids
www.courageouskids.org



Courageous Kids

LOUISIANA

25. Camp Bayou Bruisers

Date: July 24–30, 2022
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 7–17

Location: Dry Creek Camp; Dry Creek, LA
Contact: Ashley Castello, 225-291-1675
director@lahemo.org or Danielle Rowley
outreach@lahemo.org
Host: Louisiana Hemophilia Foundation
www.lahemo.org



Bayou Bruisers



Bayou Bruisers

MICHIGAN

26. Camp Bold Eagle

Date: June 26–July 2, 2022 **Ages:** 13–17
Date: July 10–15, 2022 **Ages:** 6–9
Date: July 17–23, 2022 **Ages:** 10–12
Open to: Boys and girls with a bleeding disorder
Location: Pioneer Trails; Holton, MI

Camp Old Beagle

Date: September 9–11, 2022
Open to: All former staff and campers of Bold Eagle, Eagle Outpost, Eagle Expedition and Eagle Quest
Ages: 18+
Immediate family members (spouse/significant other) are included. Children under 18 are included if their parent is attending
Location: Pioneer Trails; Holton, MI

Camp Eagle Outpost

Date: July 24–30, 2022
Open to: Boys and girls with a bleeding disorder
Ages: 14–16
Location: Throughout Michigan



Camp Eagle Quest

Date: June 11–17, 2022
Open to: Adults with a bleeding disorder
Ages: 18+
Location: Backpacking excursion on North Manitou Island in Lake Michigan
Contact: Tim Wicks, 734-961-3507
twicks@hfmich.org
or Anthony Stevens, 734-961-3510
astevens@hfmich.org
Host: Hemophilia Foundation of Michigan
<https://hfmich.org/camp/>

MINNESOTA | DAKOTAS

27. HFMD Summer Camp

Date: June 19–24, 2022
Open to: Boys and girls with a bleeding disorder
Ages: 8–17
Location: YMCA Camp Iduhapi; Loretto, MN
Contact: Melissa Andrisani
melissaa@hfmich.org or James Paist
651-406-8655, jamesp@hfmich.org
Host: Hemophilia Foundation of Minnesota/Dakotas, www.hfmd.org

NEHA Camper Testimonial

“Getting my Big Stick felt very exciting! It seemed kind of normal because I also stuck myself during Virtual Camp the year before. I knew I was ready. My favorite thing about it was when my counselor, Banana Mike, gave me his ice cream coupon as a congratulations gift. I felt proud to stand up in front of the whole camp and get my picture taken. Most importantly, I really wanted to see if I would be able to do any ninja moves with my big stick but it’s a bit too heavy.”

— Alex, with help from mom, Diane B.

MISSOURI

28. Camp Notaclotamongus

Date: June 6–8, 2022
Open to: Boys and girls with a bleeding disorder
Ages: 7–10

Date: June 8–10, 2022
Open to: Teen boys and girls with a bleeding disorder
Ages: 11–17
Location: Camp Wyman; Eureka, MO

29. GHF Adult Retreat

Date: April 29–May 1, 2022
Open to: GHF’s adult members with a bleeding disorder and their significant other
Ages: 20+
Location: Margaritaville; Lake Ozark, MO
Contact: Bridget Tyrey, 314-482-5973
info@gatewayhemophilia.org
Host: Gateway Hemophilia Foundation
www.gatewayhemophilia.org



Notaclotamongus



Notaclotamongus

MONTANA | WYOMING

30. RMHBDA Teen Retreat

Date: Aug. 11–12, 2022
Open to: Teens from Montana and Wyoming with a bleeding disorder
Ages: 13–21

RMHBDA Family Camp

Date: Aug. 12–14, 2022
Open to: Families or caregivers affected by a bleeding disorder
Location: Flathead Methodist Camp; Rollins, MT
Contact: Brad Benne, 406-586-4050
brad@rmhbda.org
Host: Rocky Mountain Hemophilia Bleeding Disorders Association, www.rmhbda.org

In Conjunction with Colorado 13. Mile High Camp

Date: July 17–21, 2022
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 7–14

Teen Leadership Weekend

Date: July 15–17, 2022
Open to: Teens with a bleeding disorder
Ages: 15–17

Location: Rocky Mountain Village; Empire, CO
Contact: Hanna Beary, 646-499-0684
hbeary@hemophilia.org
Host: Colorado Chapter NHF, 720-545-0755
www.cohemo.org and Rocky Mountain Hemophilia Bleeding Disorder Association
www.rmhbda.org



NEBRASKA

31. CoHoLo Children's Cancer Camps

Date: July 17-20, 2022

Open to: Boys and girls impacted by cancer or blood disorders

Ages: 6-11



CoHoLo Teen Camp

Date: July 20-24, 2022

Open to: Teens impacted by cancer or a blood disorder

Ages: 12-17

CoHoLo Sibling Camp

Date: TBD

Open to: Siblings of boys and girls impacted by cancer or a blood disorder

Ages: 6-13

Location: Eastern NE 4H Center; Gretna, NE

Contact: Berta Ackerson, 402-707-2154
director@campcoholo.com

Host: Camp CoHoLo, www.campcoholo.com

NEW HAMPSHIRE | NEW ENGLAND

32. New England Hemophilia Assoc.

Family Ohana Camp

Date: June 22-25, 2022

Open to: New England families affected by a bleeding disorder

Location: Geneva Point Center
Moultonborough, NH

Contact: Diane Bruno, 781-326-7645
dbruno0405@gmail.com

Host: New England Hemophilia Association
www.nehemophilia.org



Family Ohana

NEHA Camp Testimonial

"It's important for counselors to be present at the infusion classes as I feel it allows campers to show their counselors that they're taking their own first steps to becoming role models themselves. Counselors bring a level of comfort that can't come from a parent or a healthcare provider. Being a part of that milestone is really important to me because I love seeing the looks on the campers' faces when they get that stick and when they have blood return. Their first stick becomes a core memory for many of these campers and they won't ever forget that feeling. I'm honored to have the opportunity to be able to help them achieve that feeling."

— Kenny Thatch, former camper and long-time camp counselor

NEW MEXICO

33. Camp Sangre Valiente

Date: June 5-10, 2022

Open to: Boys and girls with a bleeding disorder and siblings

Ages: 7-17

Location: Camp Oro Quay; Sandia, NM

Contact: Alfonso Jaramillo, 505-341-9321
alfonso.jaramillo@sangredeoro.org

Host: Sangre de Oro, Inc. Bleeding Disorders Foundation of NM, www.sangredeoro.org



Sangre Valiente

NEW YORK

34. Camp Little Oak

Date: July 24-30, 2022

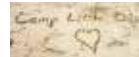
Open to: Girls with a bleeding disorder, carriers and sisters of boys with a bleeding disorder

Ages: 7-17

Location: Camp Aldersgate; Greig, NY

Contact: Hannah Russell, 425-770-1801
hannah.m.russell.p@gmail.com

Host: Camp Little Oak; camplittleoak.org



Camp High Hopes

Date: July 24-30, 2022

Open to: Boys with a bleeding disorder, male siblings and male family members of women with a bleeding disorder

Ages: 7-17

Location: Camp Aldersgate; Greig, NY

Contact: Joe Brennan, 607-226-5474
jbrennan@camphighhopes.org

or Hope Woodcock-Ross, 607-222-8412
hope@camphighhopes.org

Host: Camp High Hopes, Inc.
www.camphighhopes.org



BDAN Family Camp

Date: Oct. 8-10, 2022

Open to: Families and adult individuals affected by a bleeding disorder

Location: Camp Aldersgate; Greig, NY

Contact: Bob Graham
315-396-2944
bdaninc@gmail.com

Host: Bleeding Disorder Advocacy Network
www.bdaninc.org



BDAN



BDAN Family

35. Double H Ranch

Dates: #1 June 23-27, #2 June 30-July 4, #3 July 7-11, #4 July 15-19, #5 July 22-26, #6 July 29-Aug. 2, 2022

Alumni Session Aug. 5-9, 2022

Open to: Boys and girls with a bleeding disorder

Ages: 6-16

Location: Lake Luzerne, NY

Contact: Tara Bogucki, 518-696-5676 x222
tbogucki@doublehbranch.org

Host: Double H Ranch

www.doublehbranch.org



36. Camp SAIL Teen Retreat

Date: April 8-10, 2022

Open to: Boys and girls with a bleeding disorder, carriers and siblings in New York State

Ages: 13-18 One parent must accompany each attendee under 18

*Must provide proof of vaccination

Location: Camp Quinipet
Shelter Island Heights, NY
Contact: Tyshawn Constantine
212-682-5510
tconstantine@hemophiliany.com

Host: Hemophilia Association of New York
www.hemophiliany.com



SAIL

NORTH CAROLINA

37. Camp Carefree

Date: July 24-29, 2022

Open to: Boys and girls with a bleeding disorder

Ages: 6-16

Carefree Sibling Camp

Date: June 19-24, 2022

Open to: Siblings of children with a bleeding disorder

Ages: 6-16

Carefree Well Children Camp

Date: July 17-22, 2022

Open to: Well children with a chronically ill parent

Ages: 6-16

Location: Stokesdale, NC

Contact: Rhonda Rodenbough
336-427-0966, directors@campcarefree.org

Host: Camp Carefree

www.campcarefree.org



NEW MEXICO'S HYBRID CAMP

BY FELIX L. GARCIA, CAMP COUNSELOR

That's right – summer camp can be hybrid! In my home state of New Mexico, our bleeding disorders camp committee thought this would be the way to engage as many campers as possible, as safely as possible, given the potential hazards of COVID-19. Hybrid was different, to say the least, and by no means can it be compared to an in-person awesome week at the campground together but given the circumstances, it proved to be a great option. I'm a camp counselor and this is my take on hybrid camp for children with bleeding disorders.

As an adult with hemophilia in my late 40's, I went to bleeding disorders camp as a kid and eventually returned to serve as a counselor, program director and even camp director at various camps for kids affected by bleeding disorders. I'm currently a counselor and help create programming for Sangre de Oro Bleeding Disorder Foundation of New Mexico's Camp Sangre Valiente. Last year, in an attempt to include as many campers as possible, the idea of a hybrid version of camp was encouraged.

Hybrid Camp means a camp that is both virtual via a Zoom platform and in-person. Our camp committee led by Camp Director Alfonso Jaramillo had to first decide what a hybrid camp was going to look like. We opted for an "on-the-road" style camp. This meant taking our camp program to a couple of sites in the state, while still hosting a virtual camp on other days. This was a lot to ask of the chapter staff and volunteers, but of course, the dedicated team decided it was worth the effort to provide the very best programming for our youth.

For ease of scheduling, we decided to have 3 consecutive days of virtual programming, followed by two days of in-person programming. Camp was held June 9-13, 2021. During our virtual programming June 9-11, we made meals from all over the world and included a bit of education on what it's like to live with hemophilia in that region. Before camp, the registered families were sent the recipes, a grocery list and a gift card to purchase the ingredients so they could cook along... and cook along they did! I was able to represent Italy and led a program called Pizza Dude. My campers made their own pizza and learned a few key tips on how to order a pizza as well as how to order their factor and supply products from their specialty pharmacy.

On another day we made garlic noodles and chicken nuggets as we learned about bleeding disorders in Asia. Campers also made desserts with their other counselors, which was sweet! Virtual camp was attended by around 40 campers and family members who jumped in on the fun. It was a delicious and educational time!



The in-person part of our hybrid camp took place June 12-13. We sponsored travel and overnight accommodations for anyone 2 or more hours away from either of the two camp locations, Ruidoso and Albuquerque. What made the in-person camp experience extra special is that to have as many campers attend as possible, we opened the activities to the entire household. At each location, attendance was limited due to restrictions and precautions, but with more than 50 participants, we were still able to make awesome memories!



The chapter led a special arts & crafts project where we decorated shoes, which were later donated to the Ronald McDonald House in Albuquerque. After hearing from our guest speaker, Christopher Ingram, a professional bowler with severe hemophilia, families had an opportunity to enjoy a few games of bowling at nearby alleys. Christopher is a great role model and his story was an awesome inspiration to us all.

And then there was the Gaga Pit. Any camper who has played Gaga knows it is a camp highlight! The pit was constructed with corral panels and everyone, especially the dads, had a riot!

This year, we are all hopeful in-person camp returns full force. As an adult, there is nothing like hanging with a bunch of kids to bring out the kid in you. If it turns out that we can't gather in person, the New Mexico chapter and camp planners are ready to go hybrid again! Good luck to all the campers out there, and remember, even if camp is virtual, you don't want to miss it!

New Mexico Camp Sangre Valiente

Date: June 5-10, 2022

Open to: Boys and girls with a bleeding disorder and siblings
Ages: 7-17

Location: Camp Oro Quay; Sandia, NM

Contact: Alfonso Jaramillo, 505-341-9321

alfonso.jaramillo@sangredeoro.org

Host: Sangre de Oro, Inc. Bleeding Disorders Foundation of New Mexico, www.sangredeoro.org

38. Victory Junction

Date: July 30–Aug. 3, 2022
Open to: Boys and girls with bleeding disorders or other serious illnesses
Ages: 6–16



Victory Junction Family Weekends

Dates: March 18–20, June 10–12, June 17–19, June 24–26, and July 1–3, 2022
Open to: Families of boys and girls ages 6–16 with a bleeding disorder

Location: Victory Junction; Randleman, NC
Contact: Camper Admissions Team 336-498-9055
camperadmissions@victoryjunction.org
Host: Victory Junction
www.victoryjunction.org



39. Camp Rainbow

Date: June 12–18, 2022
Open to: Boys and girls with a bleeding disorder treated by East Carolina University Brody School of Medicine
Ages: 6–18

Location: Don Lee Camp and Retreat Center Arapahoe, NC

Contact: Jacquelyn Sauls 252-744-3304
saulsj@ecu.edu or Tamika Mackey 252-744-1170

Host: East Carolina University HTC



Rainbow

OHIO

40. Camp Njoyitall

Date: July 24–29, 2022
Ages: 7–12
Date: July 17–22, 2022
Ages: 12–17

Open to: Current patients of Cincinnati Children's Hospital Medical Center/Cancer and Blood Diseases Institute

Location: Camp Joy; Clarksville, OH
Contact: Abbie Caplinger, 513-636-9736
cbdi.camp@cchmc.org

Host: Cincinnati Children's Hospital Medical Center, www.cincinnatichildrens.org/service/c/cancer-blood/patients/camp



Njoyitall



Flying Horse Farms

41. Flying Horse Farms Family Camp

Dates: April 22–24, 2022 and May 6–8, 2022
Open to: Children ages 7–15 with a serious medical illness and their immediate family members

Flying Horse Farms Hematology/Oncology Camp

Date: June 20–25, 2022
Open to: Boys and girls with a serious medical illness **Ages:** 8–15

Flying Horse Farms Siblings Camp

Date: August 2–7, 2022
Open to: Siblings of campers with a serious medical illness **Ages:** 8–15

Flying Horse Farms Ranger Summer Programs

Date: June 20–25, 2022
Open to: Teenagers who have aged out of above camps. Campers accepted into the program will engage in camp service projects that support activities and maintain camp facilities. Rangers will engage in intentional service learning and reflection activities that inspire leadership and personal growth.
Ages: 16–17

Location: Mt. Gilead, OH
Contact: Abby Rieger, 419-751-7077
abbyrieger@flyinghorsefarms.org
Host: Flying Horse Farm Camps
www.flyinghorsefarms.org



Flying Horse Farms

OKLAHOMA

42. Camp Independence

Date: July 25–29, 2022
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 6–18

Location: Camp Bond; Tishomingo, OK
Contact: Co-Chairs: Nathan Holloway 918-804-8184, nathan@okhemophilia.org
Nate Anders, 405-833-1730
nateanders2@gmail.com, or Lindsey Russell 479-306-8115, russell@okhemophilia.org
Host: Oklahoma Hemophilia Foundation
www.okhemophilia.org



OREGON | PACIFIC NORTHWEST

43. Camp Tapawingo

Date: August 1–6, 2022
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 8–17
Location: Camp Tapawingo; Falls City, OR



44. PNWBD Family Camp

Date: June 16–19, 2022
Open to: Oregon and SW Washington families affected by a bleeding disorder
Location: Camp Myrtlewood Myrtle Point, OR

Contact: Madonna McGuire Smith 541-753-0730
m.mcguiresmith@pnwbd.org
Host: Pacific Northwest Bleeding Disorders 541-753-0730, www.pnwbd.org



Tapawingo

PENNSYLVANIA

45. Camp Dragonfly Forest

Date: July 31–Aug. 5, 2022
Open to: Boys and girls with a bleeding disorder, sickle cell or asthma
Ages: 7–15

Location: Camp Speers YMCA

Dingmans Ferry, PA
Contact: Dani Robbins 570-828-2329
campers@philaymca.org
Host: Camp Speers YMCA
www.dragonflyforest.org



Dragonfly Forest

46. Eastern Pennsylvania Hemophilia Foundation Family Camp

Date: September 23–25, 2022
Open to: Eastern PA families of children affected by a bleeding disorder, max 6 per family
Location: Camp Kweebec Schwenksville, PA
Contact: Sarah Pilacik, 484-445-4282
sarahp@hemophiliasupport.org
Host: Eastern PA Hemophilia Foundation, www.hemophiliasupport.org

SOUTH CAROLINA

47. Camp Burnt Gin

Virtual Date: July TBD
Open to: Boys and girls with hemophilia, sickle cell and other blood disorders
Ages: 7–15
Location: Online
Contact: Marie Aimone 803-898-0784
campburntgin@dhec.sc.gov
Host: SC Dept of Health
<https://scdhec.gov/welcome-camp-burnt-gin>



TENNESSEE

48. Camp Freedom

Date: July 9–15, 2022

Open to: Boys and girls with a bleeding disorder and carriers

Ages: 7–15

Ages: 16–17 Leaders-in-Training

Location: Brandon Spring Group Center
Dover, TN

Contact: Teresa Nothan, teresa@thbdf.org
or Robby Bond, 615-900-1486

robb.bond@thbdf.org

Host: TN Hemophilia and Bleeding Disorders Foundation, www.thbdf.org



Freedom

TEXAS

49. Camp Ailihpomeh

Date: July 17–22, 2022

Open to: Boys with hemophilia A or B with less than 20% severity or Type 3 VWD who are currently seen at a partnering Texas HTC

Ages: 7–14

Ages: 15–17 Leadership program

Location: Camp John Marc; Meridian, TX

Contact: Grant Spikes, 281-732-0483 or Dallas Hayes, info@camp-ailihpomeh.org

Host: Texas Bleeding Disorders Camp Foundation, www.camp-ailihpomeh.org

www.campjohnmarc.org



Ailihpomeh

50. Camp United Hands

Virtual Date: July 10–15, 2022

Open to: Boys and girls affected by a bleeding disorder and siblings

Ages: 7–17

Location: Online

Contact: Jesus Escobedo, 915-540-4569
915-621-8285; jescobedo1.hoep@gmail.com

Host: Hemophilia Outreach El Paso
<http://www.hemoelpaso.org>

UTAH

51. Camp Valor

Date: Aug. 1–4, 2022

Open to: Children with a bleeding disorder and carriers

Ages: 8–13

Valor Sibling Camp

Open to: Siblings of children with a bleeding disorder and children of affected parents

Ages: 10–11

Location: Camp Wapiti; Tooele, UT

Contact: Jan Western, 801-484-0325
western@hemophiliautah.org

Host: Utah Hemophilia Foundation
www.hemophiliautah.org



VIRGINIA

52. VHF | HACA Family Camp

Date: July 15–17, 2022

Open to: VA and Capital area families with children impacted with a bleeding disorder

Ages: Families with children between the ages of 5–17

Location: Camp Holiday Trails
Charlottesville, VA

Contact: Virginia Hemophilia Foundation
804-740-8643 or Hemophilia Association of the Capital Area, 703-352-7641

Host: VHF, vahemophilia.org and

HACA, www.hacacares.org

Camp Holiday Trails Pop-Up Camp

Open to: Boys and girls, new and previous campers with bleeding disorders and other medical needs.

Ages: 5–17 and families

Location: Taking CHT on the road! A van will bring camp activities and counselors to several medical organizations, clinics, and community partners throughout the Mid-Atlantic region to hold programs in outdoor spaces.

Contact: Tina LaRoche, 434-305-0929

tina@campholidaytrails.org or Katrina

campisgood@campholidaytrails.org

Host: Camp Holiday Trails

<https://campholidaytrails.org/campers>



Camp Holiday Trails
MULTI-DIAGNOSIS POP-UP

WEST VIRGINIA

53. Camp HemoVon

Date: June 6–10, 2022

Ages: 7–17

Open to: Boys and girls affected by a bleeding disorder or oncology diagnosis

Location: Camp Twin Creeks, Marlinton, WV

Contact: Anita Graham, 304-293-1205,
agraham@hsc.wvu.edu

Host: West Virginia University HTC West



West Virginia Chapter Family Camp

Date: June 10–12, 2022

Open to: West Virginia families affected by a bleeding disorder

Location: Camp

Twin Creeks
Marlinton, WV

Contact: Chelsea Hilty, 304-212-2616
chilty@hemophilia.org

Host: West Virginia Chapter of NHF

www.wvnhf.org



WVC Family

54. Camp BleedSTEM

Date: June 12–16, 2022

Open to: Teens affected by a bleeding disorder in WV and surrounding areas

Ages: Incoming high school freshman to seniors

Location: Morgantown, WV

Contact: Chelsea Hilty, 304-212-2616
chilty@hemophilia.org

Host: WVNHF, www.wvnhf.org and WVU College of Engineering and Mineral Resources

WISCONSIN

55. Camp Klotty Pine

Date: August 8–13, 2022

Open to: Boys and girls with a bleeding disorder and carriers

Ages: 7–15 (age exceptions made on a case-by-case basis)

Ages: 15–18 Leaders-In-Training Program for former campers from Wisconsin, Minnesota, Michigan or Illinois

Location: Campbellsport, WI

Contact: Karin Koppen, 414-937-6782
kkoppen@glhf.org

Host: Great Lakes Hemophilia Foundation
414-257-0200, www.glhf.org



Klotty Pine

NATIONAL INHIBITOR CAMP

56. After the Shock

Date: June 24–27, 2022

Open to: Families with a child (ages 0–18)

managing a currently active or previously active inhibitor within

3 years regardless of what bypassing agents and/or factor products they use.

Those who have tolerized greater than 3 years will be accepted space permitting.

Location: Camp Zeke
Lakewood, PA

Contact: CHES, 781-878-8561
info@ches.education

Host: nSpiration Foundation
<https://nspiration.foundation/after-the-shock>

Location: Camp Zeke
Lakewood, PA

Contact: CHES, 781-878-8561
info@ches.education

Host: nSpiration Foundation
<https://nspiration.foundation/after-the-shock>



After the Shock



After the Shock

SUMMER CAMPS ARE A *Wonderful* THING!

BY SARAH HENDERSON

When a child has a medical challenge, we are often reluctant to send them to camp. Scary possibilities creep into the mind and fear begins to take root. Let's explore what happens when our children with a bleeding disorder attend camp. Summer will be here soon, and deadlines to apply for camp are approaching. The bleeding disorders community has many camps designed specifically for children with hemophilia, VWD and other bleeding disorders. The skills, friends, and experiences your child will gain at camp are priceless.



Kentucky:
Center for
Courageous
Kids Camp

As parents of children with a bleeding disorder, we have spent the first many years of their life protecting them from the world. The thought of sending your child off for the first time without you can

be gut-wrenching. Just knowing you won't be able to see and assess them and monitor bleeding prevention and treatment for a week is a hard pill to swallow. Adding to the stress is knowing these kids are going to participate in a lot of unfamiliar activities that we may have not considered acceptable due to the risk involved. A very important thing to remember is that the people you would call if a bleeding episode happened are the very people who will be diligently watching your children at camp!

The medical staff stands by, interacting and teaching your child how to participate safely! Campers may find a new sport or hobby they never knew they would love. While at camp they will also spend time learning about their bleeding disorder. As parents, we sometimes forget our children will need to fully understand and be prepared to handle their disorder on their own. At camp, they can

take responsibility and learn to become accountable for their bleeding disorder care. Kids need to learn and practice being independent so they can be ready to manage their own health as they grow to adulthood.



Pennsylvania:
Camp Dragonfly
Forest

Summer camps provide safe opportunities for children as they learn how to cope with life away from home, problem-solve, engage in critical thinking, and feel like they belong.



Arkansas: Camp Nopokamee

Many adults have fond memories of summer camp. Our children with bleeding disorders shouldn't be excluded from these childhood adventures and friendships. At camp, kids find others who have similar life challenges and can make truly valuable, lifelong friendships.

There are many helpful things you can do to prepare your child for attending camp the first time. If your child knows you are feeling apprehensive about sending them, they will likely pick up on it and begin to feel anxiety as well. Talk about the experiences they will have from a positive perspective and be excited for them! Be available to answer any questions they may have about camp. Ask chapter staff, HTC staff, or other parents for details about the specific camp so you are ready and able to answer the your child's questions. If possible, look at pictures of the camp from previous years as posted on the camp website, in newsletters or on social media to show your child all the fun activities and the smiling faces of the campers.

A packing list will be provided upon camp registration. When packing, remember – camp is about kids having fun, making friends, and learning about themselves! Camp is NOT about what brand of clothes or shoes they are wearing or who has the best material possessions. Don't put unnecessary pressure on your child by sending expensive or irreplaceable items. Let them have fun playing and getting dirty by packing old clothes and shoes that can get lost or ruined. Belongings will be stained, torn, shoved in corners or under bunks, packed up with wet clothes, or possibly used in the pranking of another cabin!

When packing, keep in mind not every item will make it back home. If your child is lacking old, worn-out clothes to pack, a trip to a resale shop could save a lot of money in the event their clothes don't make



California:
Camp Firefly

Kanasa-Missouri: Camp Wilderness



it home. That's also a great place to buy a duffel bag or backpack that may be ruined at camp.

There are various places to find camps that are good for our kids with bleeding disorders. First, right here in this newsletter is a list of camps around the country! Other parents are a great resource and are usually happy to share where their kids went to camp and about their experiences. Many adults with bleeding disorders may have fond memories to share about where they attended camp as a youth, or even now as a counselor. Your HTC and local chapter will be able to point you in the direction of local camps as well.

Summer camps provide your child with the opportunity to learn, engage, try new things and play the same as a child without a bleeding disorder. The programs are specifically geared toward children with a bleeding disorder and are designed and implemented in a way that is safe and enjoyable. Your child will gain knowledge and experience around their specific bleeding disorder, learn independence, gain confidence, make lifelong friends, and enjoy a sense of belonging. Find your local camp and register today to ensure your child doesn't miss out on this life-changing experience!



Assisting Educating Advocating For The Bleeding Disorders Community.



Time for Fun!

Puzzles on Page 27

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

1. Emblem is missing
2. Lanyard/badge are gone
3. Tree trunk is gone
4. Boy now has a bandana
5. Shirt says WE instead of YOU
6. Shirt is missing pictures
7. Boy now has taller socks
8. Girl's ankle bandana is gone
9. Bag is now orange
10. Boy's hat is now red
11. Lanyard is now dark blue
12. Shorts are now maroon
13. Lanyard is shorter
14. Sleeve are now long



BIOMATRIX] ON THE MOVE!

We are happy to report we are beginning to transition back to in-person events! We are making this switch slowly and very carefully with everyone's best interest at the forefront. This past quarter has seen more in-person than virtual events; however, at a moment's notice, our Education Team can quickly set up virtual programs as the need arises. Read on to see what we've been up to! If your group (large or small) is interested in scheduling an education session with our team or for a current list of programs available, please contact your Regional Care Coordinator or message us at education@biomatrixsprx.com.

VIRGINIA - VIRTUAL

Terry Stone

Oh the joys of growing up – so much to learn, right? Parents, when it comes to teaching the art of advocacy to your children, you are not alone! The Hemophilia Association of the Capital Area and The Virginia Hemophilia Foundation joined forces and gathered teens January 29th for a **Virtual Teen Advocacy Program**. This session engaged everyone in a highly interactive discussion about advocacy relating to their lives, encounters with friends, family, and their Hemophilia Treatment Center team.

It's a parent's job to teach their child how to manage basic life skills as they grow, from holding a fork to keeping track of their bank balance and everything in between. With a bleeding disorder or other chronic condition, the art of advocating for your health needs finds its way to the top of the list of important things to master.

Guided by BioMatrix's Shelby Smoak, Ph.D., teens talked through several mock scenarios they could potentially encounter and shared how they would manage such a situation. They listened and learned from each other. The thought-provoking session provided a way to learn in a safe, yet "real-time" moment.

The takeaway for participants was that advocacy is a uniquely personal matter. Learning and identifying what you need and being comfortable enough to stand up for it and express it to others is powerful and important.

Advocacy = Living your best life!

OHIO

Shelia Biljes

WhirlyBall – one of the few things you can only find in Cleveland! A combination of bumper cars, lacrosse and basketball, and more exciting than words can describe! It's a favorite when it comes to chapter events, and it certainly did not disappoint February 9th as Northern Ohio Hemophilia Foundation (NOHF) members gathered for **Family Chapter Awareness** at WhirlyBall in Bedford to learn about the 2022 NOHF programs and join in the fun!



Tanya Ricchi is ready to roll

Decorated in a Llama theme, the BioMatrix booth was in full swing! Kids entered into a *No Drama Llama* coloring contest, a llama maze activity page and crafted llama Valentine's Day cards. "Save the Drama for your Llama (No-Hassle Shipping)" was the message of our booth and the adorable llamas brought curious visitors over to see what we were up to! After visiting sponsor booths, dinner was served and then the action began! For those not quite brave enough or tall enough to play WhirlyBall, bowling lanes and laser tag were also available. Many thanks to NOHF for such an enjoyable evening!



Future WhirlyBallers, Reagan and Lucius



Keep your eyes ahead, Aaron!



Tyler and Tanya get competitive



Carmelo and Jacob check the score

OHIO

Shelia Biljes

It makes me chuckle when I hear Valentine's Day referred to as *Single Awareness Day*. As much as I love a day to celebrate love, I also love to celebrate the friendship of my lady friends. So on February 10th we celebrated a **GALentine's Lunch for Ladies** with a group of hemophilia moms in northern Ohio. Octapharma sponsored lunch at Bonefish Grill in Westlake and Patient Experience Manager Bri Vieke spoke about the company and developments within the bleeding disorder community.

Before the waiter had a chance to clear the tables, we began to get rowdy! Playing games is probably the favorite part of our monthly meetings.



Enjoying time with special friends! Starr, Brooklynn, Amber and Charlene, June and Jen



Happy GALentine's Day! (back) Bri, Brooklynn, Starr, Amber, Connie, Kristen, Charlene, Jen, Cheryl, (front) Shelia, June, Ben and Stephanie

We are so competitive! *What's in Your Phone* brought much laughter as secrets were revealed. Word scramble and a speedy word search had the ladies competing for prizes. We then held a brainstorming session to gather ideas for a gift basket to be auctioned at a chapter fundraiser. A group photo and lots of hugs wrapped up the luncheon. Thank you, Bri and Octapharma, for sponsoring our fabulous gathering!

VIRGINIA – VIRTUAL

Terry Stone

Sometimes, just sometimes, don't you just want to turn off the TV, grab the family, and CRAFT! We knew it! And so did the crew at the Virginia Hemophilia Foundation (VHF).

Without much ado on a normally quiet Thursday evening, February 10th, VHF friends along with sponsors BioMatrix, Genentech, CSL Behring, Pfizer and Takeda gathered for a **Virtual Education & Community Craft Night**. Warmed by the glow of computer screens, we crafted! Wait... is that it? Of course not! The BioMatrix dynamic duo of Art Educator Michelle Stielper and Shelby Smoak, our resident Ph.D. and DeeJay Master Mixer, teamed up to add fun and friendly competition to the night by engaging everyone in 1980s love songs music trivia. Michelle led the group through making a no-sew pillow while Shelby spun some rocking love songs for all to guess the artist. All good fun just before Valentine's Day. Everyone had a ball and now have a pillow too. They are also ready to slay the next Jeopardy game if the category is 80s love songs!



Simone made a puppy pillow



Andrew and Jackson show off their handiwork

WEST COAST – VIRTUAL

Jeff Johnson

Chef Mike again partnered with BioMatrix to present a truly super, **Live Cooking Demonstration** for Super Bowl weekend February 12th. This event was a fun and unique spin on Chef Mike's usual cooking demos as he pitted local favorites from each Super Bowl city against each other



Chef Mike!

in a head-to-head cook-off! Representing the city of Los Angeles, Mike prepared a plate of delicious carne asada street tacos on warm, fresh tortillas, showing everyone how to properly grill and portion the steak exactly right for taco making.



Representing the city of Cincinnati, Mike prepared their legendary local dish, Cincinnati Chili! He showed the group in attendance what exactly it is and isn't, and prepared the unique dish "Five Ways" as a local would! Both dishes were spectacular, and we couldn't decide which to crown the Chef Mike Super Bowl Champion – our "big cookoff" resulted in a delicious and too-close-to-call tie game!

OHIO

Shelia Biljes

Presidents Day is a favorite among school children across America but especially up North! It usually follows several weeks of rough winter weather and school snow days, so now it was a perfect time for something new! What better way to spend the afternoon than an **Anime Drawing** class? Anime drawings are very popular and, with instruction, easier to create than one would think.

Allowing the kids to sleep in and enjoy lunch, BioMatrix planned an afternoon of fun and art! The class began with Shelby Smoak presenting the advantages of art: increasing memory, reducing pain, elevating oxygen and blood flow to the brain, improving brain health, and creating positivity and a better quality of life. Research shows art is a way of expressing thoughts and ideas that cannot be captured through language; art is refuge from those intense emotions that a chronic illness can generate. Michelle then led everyone through easy-to-follow instructions on how to draw facial features and hair, contrasting male and female anime features.

Since stick figures are a challenge for me, I was impressed with my own personal drawing! Kids and adults were equally drawn in (no pun intended) to Michelle's calm voice and easy techniques. Thank you to everyone who shared their afternoon with us!



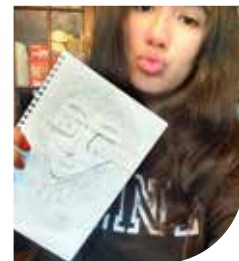
Madelyn and Madison



Collin



Calissa



Madison



Upcoming Events

Though more in-person events are being planned, be sure to verify the status as the date approaches!

APRIL 8, 2022 DELAWARE

Co-Pay Accumulator Program

Brandywine Valley Hemophilia Found.
www.brandywinehemophilia.org
Columbus Inn; Wilmington

APRIL 14, 2022 OHIO

Family Dinner and Egg Hunt

BioMatrix with Bayer
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Brew Garden Restaurant; Strongsville

NATIONAL EVENT!

APRIL 20-23, 2022 TEXAS and VIRTUAL

Symposium 2022

Hemophilia Federation of America,
202-675-6984, www.hfasymposium.org
San Antonio Marriott Rivercenter

APRIL 30, 2022 DELAWARE

5K Brandywine Red Run

Brandywine Valley Hemophilia Found.
www.brandywinehemophilia.org
Bellevue State Park; Wilmington

MAY 4, 2022 FLORIDA

Camera On: Healing and the Art of Photography

BioMatrix with Bayer
Contact: Marcy Foertsch, 941-518-7063
marcy.foertsch@biomatrixsprx.com
Maggiano's Little Italy; Tampa

MAY 5, 2022 OHIO

Cinco De Mayo "Loteria" Family Event

BioMatrix with HEMA Biologics
Contact: Shelia Biljes, 440-813-1626,
shelia.biljes@biomatrixsprx.com
Brew Garden; Middleburgh Heights

MAY 6-8, 2022 DELAWARE

Men's Retreat (age 21+)

BioMatrix with Medexus, Octapharma and Country Boy Fishing
Contact: Rich Vogel, 732-991-7373
richard.vogel@biomatrixsprx.com
For application:
<http://countryboymfishing.org/cbmfmensretreat>
Rehoboth Beach

MAY 6, 2022 OHIO

Ladies Lunch

BioMatrix with Octapharma
Contact: Shelia Biljes, 440-813-1626,
shelia.biljes@biomatrixsprx.com
B A Sweetie Ice Cream Parlor;
Cleveland

MAY 12-15, 2022 ILLINOIS

Annual Statewide Meeting

Bleeding Disorders Alliance Illinois
312-427-1495, bdai.org
William Tell Holiday Inn; Countryside

MAY 19, 2022 OHIO

Adult Dinner and Workshop "Let's Talk Finance"

BioMatrix with Novo Nordisk
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Aviation Restaurant; Cleveland

NATIONAL EVENT!

MAY 19-22, 2022 FLORIDA and VIRTUAL

Annual Symposium

The Coalition for Hemophilia B
212-520-8272, www.hemob.org
Renaissance Orlando at SeaWorld

AUGUST 11, 2022 NEW YORK

Eternal Spirit Award Gala

The Coalition for Hemophilia B
212-520-8272, www.hemob.org
The Mansion at Oyster Bay; Woodbury

NATIONAL EVENT!

AUGUST 25-27, 2022, TEXAS and VIRTUAL

Annual Conference

National Hemophilia Foundation
212-328-3700 Ext 728
<https://events.hemophilia.org>
Marriott Marquis & Hilton Americas;
Houston



THE COALITION FOR HEMOPHILIA B SYMPOSIUM 2022 ORLANDO, FL MAY 19-22

APPLICATIONS FOR TRAVEL AND
HOTEL GRANTS AVAILABLE:
HEMOB.ORG/ANNUAL-SYMPOSIUM

Hi Kids!

Time for Fun!

Can you spot the 14 differences in these photos? Good luck! Answers on page 26.



New England Hemophilia Association Camp Ohana



New England Hemophilia Association Camp Ohana

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

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



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

BIOMATRIX

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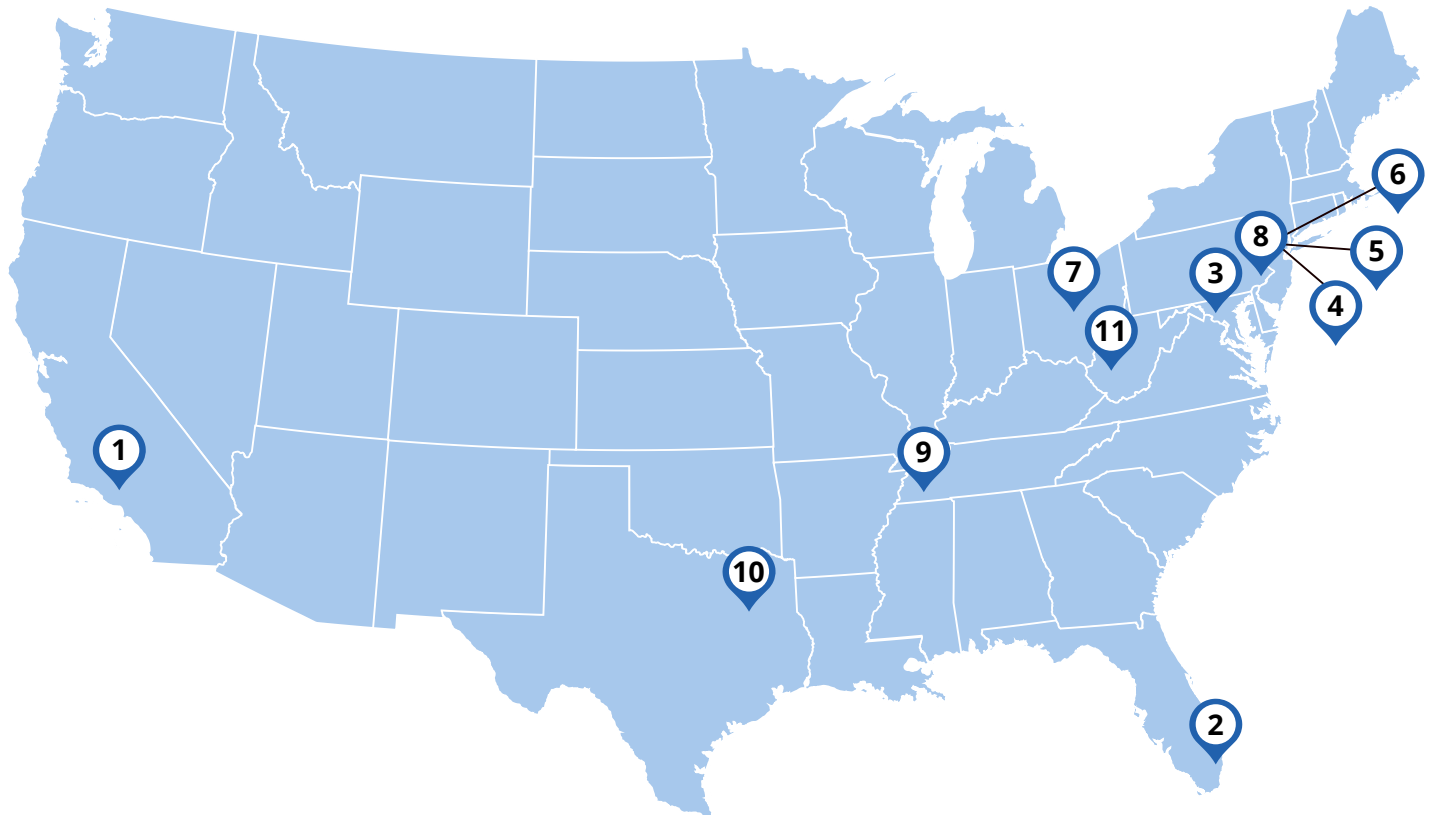
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Specialty Pharmacies



1. Canoga Park, California
2. Plantation, Florida
3. Columbia, Maryland
4. Totowa, New Jersey

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

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

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2019, 2020 & 2021