BIOMATRIX Specialty Infusion Pharmacy News

Spring 2024
Volume 18 | Issue 2

Dedicated to Making a Difference

> **Enjoy the little things, for one day you may look back and realize they were the big things.**
>
> **— Robert Brault**

VOLUME 19 | ISSUE 2
Spring 2024

About BIOMATRIX

As an independent specialty infusion pharmacy, we provide injected and infused medications not typically found at your neighborhood pharmacy. These medications are costly, involve unique shipping and handling, and require patients to receive training or home nursing support to safely take the medication at home.

Because of the high level of care required to handle these complex infused or injected medications and the conditions they treat, we support our patients at every step. From prescription intake and insurance clearance, through medication delivery, training, and beyond, we are committed to our patients' success.

Our Promise

Every day, in every interaction, we are a specialty infusion pharmacy dedicated to making a difference.

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.

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BIOMATRIX
Specialty Infusion Pharmacy

Insurance Issues? We can help!

Securing access to prescribed therapy, resolving insurance issues, and dealing with medically related challenges faced by members of the bleeding disorders community.

Our Bleeding Disorders Patient Navigation program is here to help.

For more information, visit:
bit.ly/bd-patientnavigation

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A Note from the Editor

Check out our new website!
https://www.biomatrixsprx.com

Dear Readers:

A fresh season and a fresh cover and colors for our quarterly publication! We at BioMatrix have jumped into spring full force! As tradition would have it, our spring issue highlights a list of the many bleeding disorder camps across the country! If help is needed in finding a camp near you, please contact us and we'll be sure to assist!

I share this personal story whenever the subject of camp comes up. Fifty years ago, the executive director of our local chapter managed to convince my parents to let my little brother, Danny, attend camp. Considering my parents are immigrants from Italy and spoke very little English, sending him away with "strangers" was a huge deal. Except for hospital stays, it was the first time he was away from home. Although there were four other kids, our house felt quiet and empty.

A week later, we climbed into our station wagon and drove to pick him up. I remember being excited to see where he had been. I also very much remember riding home with the windows down. The boy stunk. He smelled of sweat and dirt and happiness.

Danny Santucci
1974, Camp Warren Jyrch

We lost our brother seven years ago on Valentine's Day. However, in my heart, the scruffy boy in this camp photo will live forever. Parents, please encourage your kids to go to a bleeding disorders camp. Your child will forever carry the memories of adventure, friendship and freedom.

We hope you enjoy this issue of BioMatrix News!

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

Our cookbook brings together recipes from our family to yours!

Our Territory Account Managers have provided their very best recipes—from appetizers to entrees and desserts. To get your free cookbook, contact your Territory Account Manager or request online:
https://mailchi.mp/biomatrixsprx/cookbook

Being Heard:
THE IMPORTANCE OF EFFECTIVE COMMUNICATION

BY SHELBY SMOAK, Ph.D.

For almost fifteen years of my career, I taught communications classes, ten of which were at the University of North Carolina at Greensboro. The goal was always to get students to learn the tools they would need to communicate effectively in their lives and especially in their jobs. However, the failures were always the same and can usually be summed up as this: Too much talking!

As a member of the bleeding disorder community, I know our community, and I know that many of you reading this right now have likely been given the gift of gab. We talk, we talk, and we talk. Talking, however, is not communicating.

"The great enemy of communication," says journalist and sociologist William H. Whyte, "is the illusion of it." We may think because we are talking we are being heard and are communicating effectively, but that isn't always true.

Effective communication is about being understood. It is also about listening. When it comes to having a chronic illness like a bleeding disorder, communicating effectively can increase positive outcomes in health and work. Remaining quiet can undermine a positive outcome; filling your mouth with words without making a point confuses a situation and delays a solution.

Being an effective communicator about your bleeding disorder is not an easy task. Health is personal. Sharing with others is often difficult, but crafting good strategies for talking about your condition with your physician and employer only benefits you.

Let's look at some strategies to help you become more effective at communicating about your bleeding disorder in the physician's office and at work.

COMMUNICATING WITH YOUR PHYSICIAN:

- Start by recognizing that your care or your child's care is a team effort between you and the physician. They have the expertise; you have the experience of the condition. When at an HTC for a visit, I treat it as a coffee meeting (but without the coffee), and we are not here to talk about my latest favorite book but about my favorite subject: ME! Treating your visits like a conversation, which does include a lot of listening, goes a long way to having a successful visit.
- Don't save the most significant question for the end. You may feel working up to the "important" issue is best, but time may run out before you get there. Starting with your main issue also lets the doctor know it's a priority.
- Write down the things you want to talk about. Stick to 3 or 4 main points you want to discuss. Some of you may have a plethora of things to discuss, but you need to prioritize those issues ahead of time and whittle them down for your visit. The night before a clinic appointment, I usually ask myself, "Should we discuss my ankle bleed, that knee bleed three months ago, the joint pain in my elbow, the crackling in my right ankle, the heel lifts I need, the increase in blown veins, etc." I must decide what is most important and relay that to my physician.
- Provide good records, especially regarding infusions. An infusion log like the MicroHealth system helps capture infusion information (the MicroHealth app is available for iPhone, iPad and Android: https://microhealth.org/pages/learn-more.html)
- Provide a list of all your medications and doses.
- Revisit the past year and consider ongoing issues before your appointment.
- Be clear about what you need. What do you want to walk away with? A new script? A new therapy? A new treatment plan? An orthopedic appointment? No changes?

- Listen attentively and respect the physician's knowledge. This is where you must stop talking and must not interrupt unless asked a question.
- Be positive and thank the physician for their time. With a chronic illness, it can often be hard to remain optimistic, but this may be more important to healing than you think. A recent study in the Journal of American Geriatrics Society found that optimism and positive thinking increased a person's life by fifteen percent![i]
- Leave the appointment with a clear understanding of what you need to do, fill a prescription, call another physician, or keep doing what you've been doing!

It may happen sometimes, however, that your physician fails to address your concerns satisfactorily. Lack of time, often due to increased patient loads and limited clinic hours, is usually the culprit. A study published in the Journal of General Internal Medicine found that in 67% of patient/physician office visits studied, patients had an average of 11 seconds to speak before being interrupted.[ii]

If you feel you are not being heard by your doctor, here are some things you can do.[iii]

- Stay calm. Getting angry at a situation rarely has a positive outcome.
- Be sure to speak up and vocalize your concerns. It's easier for your doctor to brush past a concern if the importance of it or the description is not fully expressed. For example, be clear with explaining the level of pain you're experiencing using specific words such as "sharp," or "dull but consistent." Describe your pain on a 1-10 scale and be ready to when the pain is at its worst, what makes it better, etc.
- Ask specific questions that require a full answer. For example, is the problem serious? What may have led

to the problem? Will it go away on its own, or does it need follow-up care? Ask for more detail or for a simpler explanation.

- Bring someone with you to your appointment. If you find yourself becoming frustrated or confused, your person can take notes and step in to ask questions or ask for clarification.
- If you find you are still not making headway, consider making statements like, "This issue is significant and it's important to me to know that you understand this," or "I know you are very busy, but I'm not confident that I understand the resolution."
- Perhaps the best course of action would be to email your dissatisfaction and concerns afterwards. Writing gives you a chance to express your unhappiness with being heard, and it also gives the physician an opportunity to respond when they may have more time.
- If you still feel you are not being heard, it's perfectly reasonable to consider another physician for your care.

COMMUNICATING WITH AN EMPLOYER:

Should you tell your employer about your hemophilia? This is a tough question and one I have wrestled with a few times. In most cases, I did share because it is hard for me to conceal my limp or in the South, where short-sleeved shirts frequently abound, to hide the blue needle marks on my arms. I guess I am a drug user, but not "that kind," and so I wanted to dispel any rumors that could arrive and negatively impact my employment. Yet, I did not typically do this during the interview. Often, I waited for a month or so after being hired when I felt more secure in my job and felt I had a boss I could trust.

Either way, there is no right or wrong answer when sharing your health information with an employer. How and when to talk with your employer about your condition can be tricky. Here are some things to know:

- You are *not required* to reveal your medical condition to your employer. This is always a personal choice you make based on a host of personal reasons.
- Confiding in your work friends can often be a safe place to get support. Many a co-worker covered for me when I ran late due to an unexpected morning infusion.
- The HR department is there to support you and can serve as a go-between.
- If you talk to your employer, frame the conversation about how the condition will or will not impact your day-to-day work.
- Your condition may be invisible, though hiding it may not always be best. Honesty about your bleeding disorder can benefit you. Disclosing your condition will also establish expectations between you and the employer.

- Disclosing protects you. If you divulge your health condition and are later terminated for performance reasons, a case to the Equal Employment Opportunity Commission (EEOC) may be submitted. If you are fired but did not disclose, there is no case.
- While disclosure via email can work, it may be better as an in-person conversation. When it comes to my bleeding disorder, I have found that talking about it to an employer goes much further than writing to them about it. Conversation opens the door for them to ask questions and work with you on solutions for job situations that could arise.
- Don't give into a fear of being stigmatized.

In closing, I'll lean into a poet I much admire, Robert Frost, who said: "Half the world is composed of people who have something to say and can't, and the other half who have nothing to say and keep on saying it."

If you can't talk about your bleeding disorder, learn how to. And if you are talking about your bleeding disorder, be sure you are understood!

If you would like to learn more about Effective Communication, please request the BioMatrix Education Team pamphlet, "*The Keys to Effective Communication About Your Chronic Illness*," which includes content on schools and more tips on messaging and body language. We also offer a community education program on the same topic. Email us at education@biomatrixsprx.com.

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13 Ways
To Get a Doctor to Take You (Very, Very) Seriously When You're in Pain

BY: ASH FISHER, WRITER AND COMEDIAN

How we see the world shapes who we choose to be — and sharing compelling experiences can frame the way we treat each other, for the better. This is a powerful perspective.

Let's say you've been suffering from pain for a while, perhaps years. Thinking, ever so naively, that being in constant pain for months on end isn't normal, you go to your doctor. He orders blood work and maybe an X-ray or a sonogram. All results come back normal, so your doctor dismisses your concerns. Maybe he accuses you of being a drug seeker, since the only people with "real" pain are either dying or lying. I get it.

It took me 32 years to get a doctor to take my pain seriously — and to get a diagnosis with a connective tissue disease I was born with that no doctor ever noticed my obvious symptoms of, whoops. I don't want you to wait decades for answers, though. So here are some expertly curated tips and tricks to get your doctor to listen to you, take your pain seriously, and — gee-whiz-gosh-golly! — maybe even help.

1. Say "I am in pain." Be ignored or dismissed, because it can't be that bad. Leave with your tail between your legs, you wascally wabbit.
2. Say "I am in severe pain." This time your doctor will respond! With an eye roll. Followed by a reminder that all your blood work is negative and you don't "look sick." Leave the doctor's office, you dramatic exaggerator, you!
3. Wear a button that says, "Friendly reminder: I Am in Pain." Pin it to your shirt that says, "REAL BAD PAIN, DOC." Make sure he looks at your throat so when you stick your tongue out and say "ah," he'll see your new tongue tattoo that says: "YOU TOOK AN OATH."
4. Bring a polygraph machine to your next appointment. Make sure you're hooked up to it when you remind your doc that you're in severe, daily pain. He'll acknowledge that while the machine claims you aren't lying, your insurance doesn't cover polygraph tests, and thus, he can't take the results into account when determining your treatment plan, which is yoga.
5. When your doctor suggests yoga, solemnly inform him that your pain is so bad you can't even do yoga. So, if he could just help with this widespread joint and muscle pain that is slowly, steadily debilitating you

more and more each week — whether that be physical therapy or pain meds or a specialist or just, you know, something — you promise to take a yoga class.

6. Write a guide called "A 30 Second Primer on Basic Human Decency" and anonymously mail it to your doctor the week before your appointment. He won't read it — that is the catch-22 of the decency primer.

7. Get your hands on a traffic light costume. Cut out two red felt circles and sew them over the yellow and green lights. When it's time for your next appointment, don you now your pain apparel. The doctor will take in your costume of three red lights and begin to ask "Why?" This is when you chime in with, "Why are they all stop lights? Glad you asked! So you'll STOP ignoring my pain."

8. Bring your corgi for sympathy because that wily pup with those big brown eyes can get any human to do anything for her, up to and including persuading medical professionals to take her mother's pain seriously. If you don't have a corgi, you can borrow mine.

9. Dress like a clown. Cry, cry your big, sad clown tears. "Doc," you'll plead, "they say clowns only cry in secret. But look at me go!" Your doctor will diagnose you with "Crocodile Tear-Itis" and likely give you a psych referral before officially dropping you from his practice. That night you'll ruminate in your rocking chair, still clad in your clown costume, muttering to yourself as you try to figure out where it all went wrong, "But... everybody loves a clown.

10. Bribery is a solution that never backfires! Your doctor may be rich in money, but you're rich in pain! Bake him a cake of pain. Or get one of those novelty buzzers your elementary school teachers hated and shock him when he shakes your hand. When he hollers, explain, "Now you know how I feel! Let's talk pain management solutions."

11. Get your partner or a friend to come with you wearing an altered "I'm With Stupid" shirt so it says, "I'm with My Loved One Who Is Suffering and I Want You to Listen to Her and Stop Making Her Life Harder." Make sure they position themselves so that the arrow points to you.

12. Go to medical school and become a doctor, figure out the source of your pain, cure it with an outrageous, newfangled, revolutionary, Nobel Prize–winning new treatment. You're now pain-free, but don't lose focus! Make sure you rub it in your doctor's face and never forget that you didn't do all this to cure your pain, but to spite him.

13. Die in front of your doctor, with fingers crossed (to increase the chances of resuscitating you). If you don't die, he will probably say you were exaggerating. If you die, congratulations! Your pain was real, you were very sick, and everyone who doubted you is very sorry. We wish you lots of success in the afterlife.

ABOUT ASH FISHER

Ash Fisher is a writer and comedian living with hypermobile Ehlers-Danlos syndrome. When she's not having a wobbly-baby-deer-day, she's hiking with her corgi, Vincent. She lives in Portland, Oregon. Learn more about her at ashfisherhaha.com.

Fisher, Ash. "13 Ways to Get a Doctor to Take Your Pain (Very, Very) Seriously." Healthline, Healthline Media, 30 July 2019, https://www.healthline.com/health/get-pain-taken-seriously#1.

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ADVOCATING FOR MYSELF AND FOR *All* WOMEN

BY PAMELA LAUER

Advocating for myself became the biggest life lesson of my adult years and I have learned how to advocate in many ways. To continually learn more about my condition, I attend educational workshops in-person and online and seek out books and autobiographies of others with hemophilia. I speak candidly with my healthcare team - my primary care doctor, the hemophilia treatment center (HTC), acupuncturist, specialty pharmacy representative, and pharmacist.

Every bleed I experience is detailed in writing - what happened, the specific symptoms and my level of pain. My notebook comes with me to each doctor's appointment so I can refer to particular experiences and not be vague about the symptoms or extent of pain. For some reason, I feel a need to prove myself to show I am not making things up or exaggerating.

A big part of self-advocacy has been accepting I may need help in an emergency. It is still quite humbling and difficult for me to share my disorder with employers, co-workers, friends and family members. My speech is practically memorized. "I have hemophilia A. If I experience a bleed, I need the clotting factor that is kept in the fridge. If I get hurt or hit my head and can't speak for myself, the factor needs to come to the hospital with me. The EMTs should be told I have hemophilia and that I have standing orders at our local emergency department. Sharing this openly is something I'm still working on. I don't want to be a burden or the focus of attention, but I know how much it matters. All the hard work I have gone through to understand my condition is in vain if I am injured and no one knows how to help me.

Details about my bleeding episodes are shared with one of my close friends or a trusted family member. I tell them the symptoms and associated difficulties and ask them to attend my HTC visit with me. This way, I have someone to help support my history and remember what I need to mention if I get flustered and forget something important. Plus, they may hear something from the doctor that I didn't or later forget.

However, the biggest part of advocating that needs work is learning to trust myself. I am a 43-year-old daughter of a man with moderate hemophilia A. My father passed in 2001 from hepatitis complications. He was a hard worker and a hard bleeder. My dad tried his best to hide his bleeds from my mom, waiting until things got really bad before seeking treatment. When he finally did treat, his sister, a nurse with two affected sons of her own, would come to help him. Later, the Red Cross would visit our home to treat my dad. He never learned how to self-infuse and never let me stay in the room while he was being infused, seemingly ashamed of his bleeds.

My dad knew I was a carrier but as far as he understood, girls couldn't have hemophilia. While in middle school, my teacher called him voicing concern over my constant bruises. He brushed his worries aside and told him to keep his nose out of other people's health problems. Back then I was upset my father had been rude to my teacher, but now I understand the stigma many men with hemophilia faced at the time.

When I was 34, I had a hysterectomy and rested in bed as advised. However, a full month later I began hemorrhaging severely and went to the emergency room where I was labeled a "symptomatic carrier." Four years later my son

and I were celebrating the end of the school year by playing on a trampoline. We were jumping, laughing, and singing Alice Cooper's "School's Out" when I attempted to land on one leg like a ballerina. Trust me, I was nothing like a ballerina – it was not graceful or pretty as I managed to completely tear my ACL.

After spending the whole night in an emergency room and not being seen promptly, I learned what was going on. A nurse who was leaving her shift quietly pulled me aside as I was waiting for a taxi and confided that the reason it took so long for me to be seen is because I had written "Hemophilia - symptomatic carrier" on the intake form, and the staff was very hesitant to treat me for fear of not knowing how.

"Maybe don't tell people you have a bleeding disorder next time?" was her advice. She couldn't have been more wrong! I do just the opposite. I practically scream it from the rafters when I enter an ER. I make sure they know immediately and tell them what I need because often, they don't know.

A few weeks later, finally armed at 38 years old with a proper diagnosis of mild to moderate hemophilia A, my first dose of clotting factor was administered for the ACL surgery. During the next two weeks at home, I self-infused via a PICC line. My mom helped me get through the surgery. Unbeknown to me at the time, she carried some internal guilt. She later told me how sorry she was that she didn't do anything to treat my bleeds growing up. She blamed herself for my current problems. Of course, I told her it wasn't her fault. How could it be when even doctors didn't acknowledge that women could have hemophilia?

Unfortunately, within three years, two more surgeries were required for a meniscus debridement and then an ACL replacement. I now take factor prophylactically three times a week. My ankles are my newest problems – painful swelling from minor activities such as doing housework or walking short distances on the beach. I spend a lot of time with ice packs on my elevated knees and ankles.

After ignoring and discounting bleeding episodes for most of my life, it has been a difficult journey to understand what one actually feels like. Part of my path toward healing has been watching videos of hemophiliacs explaining what a bleed feels like. Yes - I was, in fact, experiencing bleeds for years. Although I still have inner battles with denial, I am learning to comprehend when something isn't right and know that I need to trust myself.

When a doctor asks about my pain level, I respond, "Well, that is a trick question! What may be a 7 for some people may only be a 3 to me. I am in pain all the time." It's not specifically my doctor's fault that I am in chronic pain, but it's hard to ignore the medical world's dismissal of a woman's bleeding. Until very recent history, doctors were not trained to believe that women can have a bleeding disorder. Without a proper diagnosis, many women labeled as symptomatic carriers have not received appropriate treatment, subsequently living their lives in chronic pain.

I must be vocal and definitively lay out how I feel to ensure I am being heard. Just saying, "It still hurts" is ineffective. They will tell me to take more painkillers. I have learned to say, "It hurts all the time, and I do not want to live on painkillers my whole life. However, the level of pain is debilitating." It's repeatedly reminding doctors that I now know what a bleed feels like. Most of my concerns aren't listened to the first or even second time they are mentioned to my physician, but the more often I bring it up, the more likely I may be taken seriously. It shouldn't be this hard to be heard. It shouldn't be so easy to be ignored.

> **I don't want to be a burden or the focus of attention, but I know how much it matters.**

Pamela with son, Kopely, at Washington Days

Advocacy is so much more than just sharing my bleeding episodes and injuries with my HTC. It is speaking up and speaking out. It's reminding treaters that symptomatic carriers are women with a bleeding disorder. It's reminding myself that I deserve to maintain mobility and joint health and be able to infuse factor when I know I am bleeding. Advocating at offices that don't often see hemophilia patients is as important as speaking up at my HTC. My dentist, acupuncturist, chiropractor, yoga instructor, tattoo artist, and even my friends and family sometimes need to be reminded of my bleeding disorder. Okay, I'll admit, I even need to remind myself sometimes!

Another form of advocacy is one that many people do not consider - mental advocacy. It's difficult to find a therapist who understands what it is like to live with hemophilia. Instead, I have reached out to the bleeding disorders community and have found it vitally important to my mental health to remember I am not alone. Attending female retreats, online meetings and workshops on infusing, pain management and mental health support groups truly helps. Speaking candidly with others who are affected has brought me some peace of mind. My family sees what I go through, but other bleeders know what I go through. The time I have spent communicating with the bleeding disorders community is monumental to my mental state. When I leave these gatherings, I know I can do this. I can go on as others have before me and others still will.

For me and many other women, advocacy needs to stop being a battle to be believed. The recent recognition that

women can have inadequate levels of clotting factors and experience bleeding episodes is a huge step forward for future generations, but it's just the beginning. Advocating for myself is advocating for other women just like me. We are in this together!

What's your favorite recipe?

We're putting together a new edition of our famous community cookbook!

Join us in celebrating the joy of culinary creativity by sharing your favorite recipe with the community!

Submit your recipe at:
https://bit.ly/bmx-recipes-2024

[BIOMATRIX]

2024 BLEEDING DISORDER CAMPS *Across the Country!*

Every year, many of our bleeding disorders community members look forward with excitement to spending time at camp. It's an enchanting 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 as they learn to manage their bleeding disorder.

Check our list for the camp nearest you. If a camp isn't listed, it may be because we did not receive the information by print time. Please check with your chapter's program director or or contact your BioMatrix Territory Account Executive "TAE" (formerly Regional Care Coordinator) for help locating one near you.

Campers, counselors, volunteers, medical personnel... We wish you all a magical time!

Clot Not

ALABAMA

1. Camp Clot Not

Date: June 15–20, 2024
Open to: Boys and girls with a bleeding disorder and carriers
Ages: 6–18

1. Camp Harvest

Date: Oct 16–20, 2024
Open to: Active HBDA families with a parent or child with a bleeding disorder

Location: Children's Harbor on Lake Martin Alexander City, AL
Contact: Amanda Jennings, 334-577-0125
hbdaevents@gmail.com
Host: Hemophilia and Bleeding Disorders of Alabama, Inc., www.hbda.us

Clot Not

ALASKA

2. Camp Frozen Chosen

Date: June 3–7, 2024
Open to: Boys and girls with a bleeding disorder and siblings
Ages: Completed 1st grade through–age 17
Location: King's Lake Camp; Wasilla, AK
Contact: Michelle Palmatier, 907-229-6017
alaskahemo@gmail.com
Host: Alaska Hemophilia Association and Bleeding Disorder Center, 907-917-9235
www.alaskableedingdisorders.org

ARIZONA

3. Camp HONOR

Date: June 4–9, 2024
Open to: Boys and girls with a bleeding disorder, siblings and children of an affected parent
Ages: 8–17
Location: Chauncey Ranch Camp; Mayer, AZ
Contact: Vickie Parra, 602-955-3947
vickie@arizonahemophilia.org
Host: Arizona Bleeding Disorders
www.arizonahemophilia.org

3. HUG Family Camp

Date: Oct 25–27, 2024
Open to: AZ families with a parent or child affected by a bleeding disorder
Location: Camp Friendly Pines; Prescott, AZ
Contact: Vickie Parra, 602-955-3947
vickie@arizonahemophilia.org
Host: Arizona Bleeding Disorders
www.arizonahemophilia.org

ARKANSAS

4. Camp Aldersgate

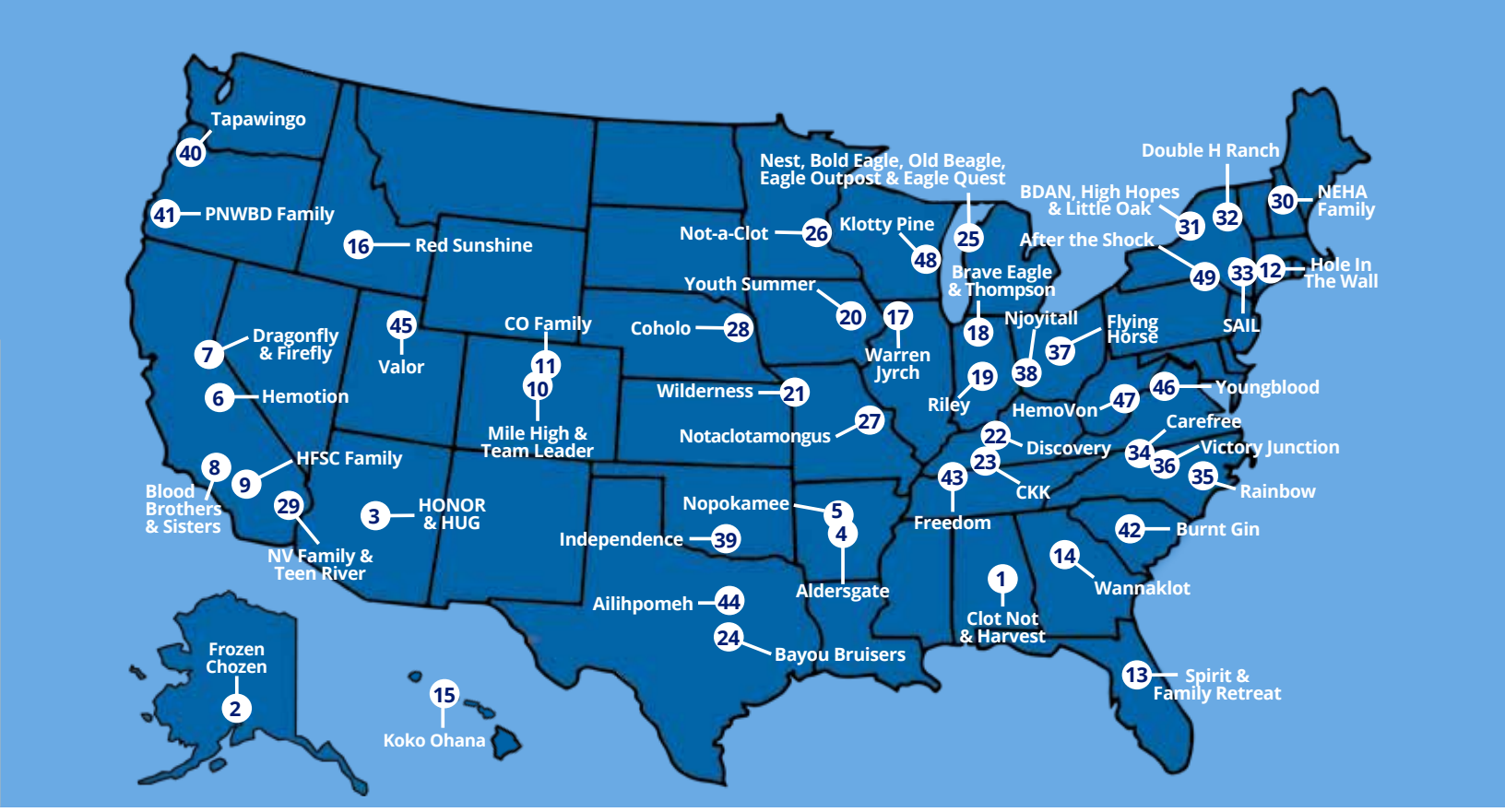
Date: July 14–19, 2024
Open to: Boys and girls with a bleeding disorder
Ages: 6–18
Location: Camp Aldersgate; Little Rock, AR
Contact: Ashley Zeiler, 501-225-1444
azeiler@campaldersgate.net
Host: Camp Aldersgate
www.campaldersgate.net

5. Camp Nopokamee

Date: July 14–18, 2024
Open to: Boys and girls with a bleeding disorder, carriers and siblings
Ages: 8–18
Location: 4H Club; Ferndale, AR
Contact: Angela Hodgdon, 501-428-5754
secretary@arkhemofoundation.org
Host: Hemophilia Foundation of Arkansas
http://arkhemofoundation.org

Nopokamee

Hemotion



CALIFORNIA

6. California Camp Hemotion

Date: June 23–June 29, 2024
Open to: Boys and girls with a bleeding disorder, carriers, siblings and cousins
Ages: 7–14
Ages: 15–17 Junior Counselors
Ages: 18–20 Assistant Counselors
Ages: 21+ Adult Counselors
Location: Camp Oakhurst; Coarsegold, CA
Contact: Andrea Orozco, 510-658-3324
andrea.orozco@hemofoundation.org
Host: Hemophilia Foundation of Northern California, www.hemofoundation.org

7. Teen Camp Dragonfly

Date: July 8–12, 2024
Open to: Teen boys and girls with a bleeding disorder, carriers and siblings; must be able to self-infuse
Ages: 14–18
Ages: 21+ General Staff

Location: ETC River Camp, 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

7. Camp Firefly

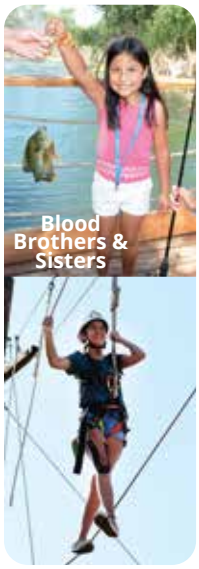
Date: July 28–12, 2024
Open to: Boys and girls with a bleeding disorder, carriers and siblings (space permitting)
Ages: 7–14
Ages: 16–18 Jr. Counselors
Ages: 19+ Counselors and General Staff
Location: ETC River Camp; Lotus, CA
Contact: Nooshin Kosar, 619-325-3570
info@hasdc.org
Host: Hemophilia Association of San Diego County
www.hasdc.org

Camp Hemotion!

By Scarlett P.

Coming back to Camp Hemotion after three years of lockdown was such an amazing experience full of new and reminiscent memories! My friends and I got to choose activities which we couldn't overcome when we were younger like the rock wall, and even try new things like learning to play chess. It makes me happy to know that this year I will have the opportunity to help young girls overcome the fears I had when I was their age like performing in the talent show.

Getting to see the faces of those who I know I can always relate to and talk about my experiences again was so wonderful. Sometimes it can be hard to let yourself feel free in a world where you are always in fear of yourself or a loved one having a bleed. Camp Hemotion creates a space where you don't have to feel this way because of the amazing people there to support you.



8. Camp Blood Brothers & Sisters

Date: July 16–21, 2024
Open to: Boys and girls with a bleeding disorder
Ages: 7–16
Ages: 17–18 Leader-in-Training
Ages: 19+ Volunteers
Location:
The Painted Turtle Camp
Lake Hughes, CA
Contact: Rigo Garcia
626-765-6656
rigo@hemosocal.org
Host: Hemophilia Foundation of Southern California
www.hemosocal.org

9. HFSC Family Retreat
Date: June 1–2, 2024
Open to: Anyone with a bleeding disorder and their immediate family
Location: Pali Mountain Retreat Running Springs, CA
Contact: Rigo Garcia, 626-765-6656 rigo@hemosocal.org
Host: Hemophilia Foundation of Southern California, www.hemosocal.org

COLORADO
10. Mile High Camp
Date: July 14–18, 2024
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 7–17

10. Teen Leadership Weekend
Date: July 12–14, 2024
Open to: Teen boys and girls with a bleeding disorder and siblings
Ages: 14–17

Location: Rocky Mountain Village; Empire, CO
Contact: Perry Jowsey, 720-626-1263 pjowsey@hemophilia.org
Host: Colorado Chapter NHF, 720-545-0755 www.cohemo.org

11. Colorado Chapter Family Camp
Date: June 7–9, 2024
Open to: All families/ households with a bleeding disorder member
Location: Highlands Presbyterian Camp and Retreat Center; Allenspark, CO
Contact: Perry Jowsey, 720-626-1263 pjowsey@hemophilia.org
Host: Colorado Chapter NHF, 720-545-0755 www.cohemo.org

CONNECTICUT
12. The Hole in the Wall Gang Camp
Dates: June 24–30, July 3–9, July 22–26, and Aug 7–13, 2024
Open to: Boys and girls with bleeding disorders and other serious illnesses
Ages: 7–15

12. The Hole in the Wall Gang Camp Sibling Session
Date: Aug 17–23, 2024
Open to: Siblings of campers attending the summer program or Hero's Journey
Ages: 7–15

12. The Hole in the Wall Gang Hero's Journey
Adventure–based wilderness search and rescue program in the woods of Connecticut
Dates: June 24–30, July 3–9, July 12–18, 2024
Open to: Adolescents with a bleeding disorder or other serious illness, and siblings
Ages: 16–17

12. The Hole in the Wall Gang Champion's Journey
Dates: July 29–Aug 4 and Aug 7–13, 2024
Open to: Adolescents with a bleeding disorder or other serious illness and siblings
Ages: 16–17

12. The Hole in the Wall Gang Camp Family Sessions
Date:
May 30– June 2, 2024
Open to: Families with bleeding disorders and other serious illnesses
Ages: All ages

Location: Ashford, CT
Contact: 860-429-3444 admissions@holeinthewallgang.org
Host: The Hole in the Wall Gang www.holeinthewallgang.org

FLORIDA
13. Camp Spirit
Date: June 19–23, 2024
Open to: Boys and girls with a bleeding disorder
Ages: 7–16

13. Camp Spirit Family Retreat Weekend
Date: October 18–20, 2024
Open to: Families affected by a bleeding disorder

Location: Camp Boggy Creek; Eustis, FL
Contact: Fran Haynes or Samantha 407-629-0000, events@bleedingdisorders.org franhaynes@hemophiliaflorida.org info@hemophiliaflorida.org
Host: Bleeding Disorders Foundation of Florida, www.hemophiliaflorida.org

GEORGIA
14. Camp Wannaklot
Date: July 7–12, 2024
Open to: Boys and girls with a bleeding disorder
Ages: 7–12 Junior Camp
Ages: 13–17 Teen Camp
Location: Camp Twin Lakes Will-A-Way Winder, GA
Contact: Kristi Fulford, 770-518-8272 kffulford@hog.org
Host: Hemophilia of Georgia, www.hog.org

HAWAII
15. Family Camp Koko Ohana
Date: June 21–23, 2024
Open to: Families and individuals affected by a bleeding disorder
Location: Camp Moluke'ia; Waialua, HI
Contact: Kyra Calbero, 808-284-7417 kcalbero@bleeding.org
Host: Hawaii Chapter, NBDF www.hawaiinhf.org

IDAHO
16. Red Sunrise Family Camp
Date: June 26–29, 2024
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, NBDF www.idahoblood.org

ILLINOIS
17. Camp Warren Jyrch
Date: July 21–27, 2024
Open to: Children with inherited bleeding disorders
Ages: 7–17
Location: YMCA Camp Benson; Mt. Carroll, IL
Contact: 312-427-1495, info@bdai.org
Host: Bleeding Disorders Alliance Illinois www.bdai.org

INDIANA

18. Camp Brave Eagle

Date: June 16–21, 2024
Open to: Boys and girls with a bleeding disorder and carriers
Ages: 7–16
Location: Camp Crosley YMCA
North Webster, IN

18. Doug Thompson Teen Leadership Program

Date: July 8–12, 2024
Open to: Teen "leaders" with a bleeding disorder and carriers
Ages: 14–17
Location: TBD
Contact: Angel DiRuzza, 317-570-0039 x102
adiruzza@hoii.org
Host: Hemophilia of Indiana, Inc.
www.hoii.org

19. Riley Camp Independence

Date: June 23–28, 2024
Open to: Boys and girls with hematological disorders
Ages: 8–18
Location: Bradford Woods Martinsville, IN
Contact: Nich Hunter, 765-349-5121
nyhunter@indiana.edu
Host: Riley Hospital for Children at Indiana University
https://bradfordwoods.iu.edu/index.html

IOWA

20. Youth Summer Hemophilia Camp

Date: June 16–21, 2024
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:
Brooke Loving
319-721-1664
bdh_director@bdheartland.org
Host: Bleeding Disorders of the Heartland
319-721-1664, https://bdheartland.org

KANSAS|MISSOURI

21. Camp Wilderness

Date: July 29–Aug 2, 2024
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

KENTUCKY

22. Camp Discovery

Date: July 21–25, 2024
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 7–15
Ages: 16–18 Counselors-in-Training

22. Family Camp at Camp Discovery

Date: September 27–29, 2024
Open to: Families and individuals affected by a bleeding disorder

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

23. Center for Courageous Kids Camp

Date: June 4–8, 2024
Open to: Children with bleeding disorders (hemophilia, VWD, ITP)
Ages: 7–16
Location: CCK; Scottsville, KY
Contact: Hannah Reckart, 270-618-2912
hreckart@courageouskids.org
Host: Center for Courageous Kids
www.courageouskids.org

LOUISIANA

24. Camp Bayou Bruisers

Date: June 30–July 5, 2024
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 7–17
Location: Camp for All; Burton, TX
Contact: Ashley Castello, 225-291-1675
director@lahemo.org or
Danielle Rowley, outreach@lahemo.org
Host: Louisiana Hemophilia Foundation
www.lahemo.org

MICHIGAN

25. Eagles Nest Family Camp

Date: June 26–29, 2024
Open to: Young children with a bleeding disorder and their families for an introduction to the Camp Bold Eagle experience
Ages: 5–9

25. Counselor-in-Training

Date: July 8–27, 2024
Open to: Former campers exhibiting strong leadership skills
Ages: 16–17

25. Camp Bold Eagle

Date: July 14–18, 2024
Ages: 6–9

Date: July 20–26, 2024
Ages: 10–12

Date: June 30–July 6, 2024
Ages: 13–17

Open to: Youth with a bleeding disorder

25. Camp Old Beagle

Date: September 13–15, 2024
Open to: All former staff and campers of Bold Eagle, Outpost, Expedition and Quest
Ages: 18+ Immediate family members (spouse/significant other) are included; under 18 must have a parent attend

Location: Pioneer Trails; Holton, MI
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

25.Camp Eagle Outpost

Date: August 4–10, 2024
Open to: Youth with a bleeding disorder
Ages: 14–15
Location: Throughout Michigan

25. Camp Eagle Quest

Date: June 8–14, 2024
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

MINNESOTA|DAKOTAS

26. Camp Not-a-Clot

Date: July 14–19, 2024
Open to: Boys and girls with a bleeding disorder
Ages: 7–17
Location: YMCA Camp Iduhapi
Loretto, MN
Contact: James Paist, 651-406-8655
jamesp@hfmd.org or
Tammy Ward, 651-406-8655
tammyw@hgmd.org
Host: Hemophilia Foundation of Minnesota/Dakotas, www.hfmd.org

MISSOURI

27. Camp Notaclotamongus

Date: June 1–4, 2024
Open to: Boys and girls with a bleeding disorder
Ages: 7–17
Location: Camp Wyman; Eureka, MO
Contact: Bridget Tyrey, 314-482-5973
info@gatewayhemophilia.org
Host: Gateway Hemophilia Association
www.gatewayhemophilia.org

Notaclotamongus

NEBRASKA

28. CoHoLo Children's Cancer Camps (In-Person and Virtual)

Date: July 14–17, 2024
Open to: Boys and girls impacted by cancer or a blood disorder
Ages: 6–11

28. CoHoLo Teen Camp (In-Person and Virtual)

Date: July 17–21, 2024
Open to: Teens impacted by cancer or a blood disorder
Ages: 12–17

Location: Camp Fontinelle; Nickerson, NE
Contact: Berta Ackerson, 402-707-2154
director@campcoholo.com
Host: Camp CoHoLo
https://camp-coholo.com/camp-life

NEVADA

29. Nevada Chapter Family Camp

Date: June 18–21, 2024
Open to: Families of the Nevada Chapter, NBDF
Location: Camp de Benneville Pines Angelus Oaks, CA

NV Family Camp

29. Teen River Camp

Date: July 8–12, 2024
Open to: Nevada Chapter campers (diagnosed patients) and their siblings
Ages: 13–18
Location: South Fork of the American River with San Diego County's Camp Dragonfly

Contact: Danielle Bell, 702-306-5513
dbell@hemophilia.org
Host: Nevada Chapter, NBDF, www.hfnv.org

NEW YORK

31. BDAN Family Camp

Date: Oct 12–14, 2024
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 Family

NEW HAMPSHIRE | NEW ENGLAND

30. NEHA Annual Family Camp

Date: June 26–29, 2024
Open to: New England families affected by a bleeding disorder
Location: Geneva Point Center
Moultonborough, NH
Contact: Diane Bruno, 781-326-7645
dbruno@nehemophilia.org
Host: New England Hemophilia Association www.nehemophilia.org

Family Camp

Alex was one of 19 NEHA campers who earned a Big Stick in 2023 for successfully self-infusing! Congratulations to Alex and all Big Stick achievers!

"Getting my Big Stick felt very exciting. It seemed kind of normal because I also stuck myself during Virtual Camp. 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. 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."

A few facts about NEHA Camp as shared by Brandon Greene:

- 2023 was our 31st Year of Family Camp. We even hosted virtual camp during COVID to ensure that patients and families didn't miss out on the beloved tradition of camp. We're happy to be back in-person again!
- In 2023, we had 44 families and 280+ individuals present.
- We're proud to subsidize 95% of the cost of Family Camp to help make it affordable for everyone to attend.

31. Camp High Hopes

Date: July 21–27, 2024
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
Host: Camp High Hopes, Inc.

31. Camp Little Oak

Date: July 21–27, 2024
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: Hope Woodcock-Ross
607-222-8412, hope-mw@hotmailcom
Host: Camp Little Oak

32. Double H Ranch

Dates: June 20–25, June 28–July 3, July 6–11, July 15–20, July 23–28 and July 31–August 5, 2024
Alumni Session: August 8–12, 2024
Open to: Boys and girls with a bleeding disorder or other chronic disorder
Ages: 6–16
Location: Double H Ranch; Lake Luzerne, NY
Contact: 518-696-5676, ext 222
www.doublehranch.org/contact/
Host: Double H Ranch
www.doublehranch.org

Double H Ranch

33. Camp SAIL Teen Retreat

Date: April 26–28, 2024
Open to: Teen boys and girls with a bleeding disorder or a sibling in the same household, and one accompanying adult.
Ages: 13–18
Location: YMCA Camp Bernie
Port Murray, NJ
Contact: Elizabeth Cedeno
212-682-5510
elizabethc@hemophiliany.com
ltapia@hemophiliany.com
Host: Hemophilia Association of New York
www.hemophiliany.com

SAIL

NORTH CAROLINA

34. Camp Carefree

Date: July 21–26, 2024
Open to: Boys and girls with a bleeding disorder
Ages: 6–16

34. Carefree Sibling Camp

Date: June 16–21, 2024
Open to: Siblings of a child with a bleeding disorder
Ages: 6–16

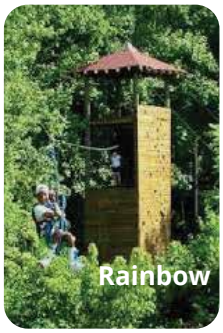
34. Carefree Well Children Camp

Date: July 14–19, 2024
Open to: Well children with a chronically ill parent
Ages: 6–16

Location: Camp Carefree; Stokesdale, NC
Contact: 336-427-0966
directors@campcarefree.org
Host: Camp Carefree, www.campcarefree.org

35. Camp Rainbow

Date: July 16-21, 2024
Open to: Boys and girls with a bleeding disorder treated by East Carolina University Brody School of Medicine
Ages: 6–18
Location: The Refuge
Ayden, NC
Contact: Jacquelyn Sauls 252-744-3304
saulsj@ecu.edu
Host: East Carolina University HTC


Rainbow

36. Victory Junction

Date: June 9–13, 2024
Open to: Boys and girls with bleeding disorders or other serious illnesses
Ages: 6–16
Location: Victory Junction
Randleman, NC
Contact: Admissions Team, 336-498-9055
camperadmissions@victoryjunction.org
Host: Victory Junction, www.victoryjunction.org

Victory Junction

OHIO

37. Flying Horse Farms Family Camp

Dates: Oct 11–13, Oct 25–27, and November 1–3, 2024
Open to: Children ages 7–15 with a serious medical illness and their immediate family members

37. Flying Horse Farms Hematology/Oncology Camp

Date: June 25–30, 2024
Open to: Boys and girls with a bleeding disorder or oncology patients
Ages: 8–15

37. Flying Horse Farms Siblings Camp

Date: July 29–August 3, 2024
Open to: Siblings of campers with a serious medical illness
Ages: 8–15

37. Flying Horse Farms Ranger Summer Program

Date: June 25–30, 2024
Open to: Teens with a bleeding disorder or hematology patients who have aged out of summer camps; must be a returning camper; rangers will engage in intentional service learning and reflection activities that inspire leadership and personal growth
Ages: 16–17

37. Flying Horse Farms Trailblazer Adolescent Young Adult Camp

Date: August 9–11, 2024
Open to: Teens with a serious medical illness who have aged out of summer camps and do not qualify for or wish to participate in the Ranger program; session will focus on camp activities, life skills and transitioning into adulthood
Ages: 16–21

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

Flying Horse Farms

38. Camp Njoyitall

Date: July 21–26, 2024
Ages: 7–12
Date: July 14–19, 2024
Ages: 12–17
Open to: Current patients of Cincinnati Children's Hospital Medical Center/Cancer and Blood Diseases Institute (By invitation)
Location: Camp Joy; Clarksville, OH
Contact: Abbie Caplinger, 513-636-9736
cbdi.camp@cchmc.org
Host: Cincinnati Children's Hospital Medical Central, www.cincinnatichildrens.org/service/c/cancer-blood/patients/camp

Camp Njoyitall Quotes!

"I'm thankful to know that I'm not the only one here that's different."

"I can't wait to go to camp again. It gives me something to look forward to on the hard days."

"It's something that makes you feel like you are a part of family since you matter to everyone."

NJoy It All

OKLAHOMA

39. Camp Independence

Date: July 22–26, 2024
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 6–18
Location: Camp Bond; Tishomingo, OK
Contact: Kerri Crabtree
918-605-2579
director@okbleedingdisorders.org
Host: Oklahoma Hemophilia Foundation
918-605-2579, www.okhemophilia.org

OREGON|PACIFIC NORTHWEST

40. Camp Tapawingo

Date: August 5–11, 2024
Open to: Boys and girls with a bleeding disorder and siblings
Ages: 8–17
Location: Camp Tapawingo; Falls City, OR

Tapawingo

41. PNWBD Family Camp

Date: June 20–23, 2024
Open to: Oregon and SW Washington families affected by a bleeding disorder
Location: Camp Myrtlewood; Myrtle Point, OR

Contact: 541-753-0730, info@pnwbd.org
Host: Pacific Northwest Bleeding Disorders 541-753-0730, https://pnwbd.org/ and the Hemophilia Center at OHSU

SOUTH CAROLINA

42. Camp Burnt Gin

Date: July 8–13, 2024
Open to: Boys and girls with hemophilia, sickle cell and other blood disorders, residents of South Carolina
Ages: 7–15
Location: Camp Burnt Gin Sumter County, SC
Contact: 803-898-0784
campburntgin@dhec.sc.gov
Host: South Carolina Dept of Health https://scdhec.gov/welcome-camp-burnt-gin and PRISMA Health Partnership

TENNESSEE

43. Camp Freedom

Date: July 7–13, 2024
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: Amanda Wilson, 615-900-1486
amanda.wilson@thbdf.org
Host: TN Hemophilia and Bleeding Disorders Foundation, www.thbdf.org

Freedom

TEXAS

44. Camp Ailihpomeh

Date: July 14–19, 2024
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: Amanda Wolgamott, 713-686-6100
info@camp-ailihpomeh.org
Host: Texas Bleeding Disorders Camp Foundation, www.camp-ailihpomeh.org
www.campjohnmarc.org

Ailihpomeh

53. Camp United Hands

Date: July 8–12, 2024
Open to: Boys and girls affected by a bleeding disorder and siblings
Ages: 7–17
Location: Black River Learning Center Carlsbad, NM
Contact: Jesus Escobedo, 915-621-8285
jescobedo1.hoep@gmail.com
Host: Hemophilia Outreach El Paso
http://www.hemoelpaso.org

UTAH

45. Camp Valor

Date: Aug 5–8, 2024
Open to: Children with hemophilia, von Willebrand disease, and carriers. Siblings and children of affected parents, ages 10-14
Ages: 8–14
Location: Camp Wapiti; Tooele, UT
Contact: Jan Western, 801-484-0325
western@hemophiliautah.org
Host: Utah Hemophilia Foundation
www.hemophiliautah.org

VIRGINIA

46. Camp Youngblood

Date: July 14–19, 2024
Open to: Boys and girls with a bleeding disorder, siblings and children of members of bleeding disorder community residing within the VHF or HACA coverage area
Ages: 7–17
Location: Camp Holiday Trails Charlottesville, VA
Contact: Hemophilia Association of the Capital Area, 703-712-2266
admin@hacacares.org or
Virginia Hemophilia Foundation
804-740-8643, info@vahemophilia.org
Host: HACA, https://hacacares.org and VHF, https://vahemophilia.org
Camp Holiday Trails, campholidaytrails.org/

WEST VIRGINIA

47. Camp Winaca HemoVon

Date: June 10–14, 2024
Ages: 7–17
Open to: Boys and girls affected by a bleeding disorder or oncology diagnosis
Location: Camp Twin Creeks Marlinton, WV
Contact: Chelsea Hilty, 304-641-2622
chilty@hemophilia.org
Host: West Virginia Chapter NBDF
304-212-2616, www.wvnhf.org

WISCONSIN

48. Camp Klotty Pine

Date: August 4–9, 2024
Open to: Children living with a bleeding disorder in Wisconsin, or attending a Wisconsin HTC
Ages: 7–15
Ages: 15–18 Leaders-In-Training Program for former campers from WI, MN, MI or IL
Location: Campbellsport, WI
Contact: Karin Koppen, 414-937-6782
kkoppen@glhf.org
Host: Great Lakes Hemophilia Foundation
414-257-0200, www.glhf.org

NATIONAL INHIBITOR CAMP

49. After the Shock

Date: June 21–24, 2024
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
Location: Camp Zeke; Lakewood, PA
Contact: CHES, 781-878-8561
info@ches.education
Host: CHES Foundation
https://ches.education/after-the-shock

BIOMATRIX ON THE *Move*

The BioMatrix Education Team and Territory Account Executives (formerly Regional Care Coordinators) have been busy hosting educational events and attending community gatherings. Our team offers a wide and expanding menu of educational topics and fun activities to choose from, including on-line sessions. Interested in scheduling a session for your group of any size either in-person or virtually? Please contact your Territory Account Executive or message the Education Team at: education@biomatrixsprx.com.

TENNESSEE

LeAnn Wilson and David Tignor

BioMatrix partnered with CSL Behring and the Tennessee Hemophilia and Bleeding Disorder Foundation (THBDF) December 9th to bring something new and exciting to the mid-south! Guests attended a ***Holiday Event*** at the Memphis Redbirds AutoZone Park. Everyone was enchanted with the 190 light structures that bedazzled Deck the Diamond as the festive lights surrounded a giant 60-foot Christmas tree! A spectacular fireworks show was a bonus to the already awesome event. Many thanks to THBDF and CSL for this fun holiday evening!

Bright as the holiday lights! Madison, Shannon, Miracle, and Sydney

Visiting Santa - Clay, Hannah and Charity, Thaddeus and Isaac

TENNESSEE

Cyndy Coors and David Tignor

With Bayer's Beth Owens as our sponsoring host, we gathered December 14th at Calhoun's in Knoxville for ***Dinner and Game Night***. After enjoying a fabulous meal, BioMatrix's David Tignor emceed a game of BioMatrix *JeoParody*, testing the knowledge of our guests on a wide range of topics from bleeding disorders to TV dramas, and more! Such a fun evening! Thank you to Bayer for partnering with us!

Linnea – SO excited!

Zoe and Anthony

TENNESSEE

December 16th, guests boarded a Chattanooga ***Christmas Train*** on the Tennessee Valley Railroad taking guests on an imaginary journey to the North Pole! Stories were told while everyone marveled over the lighted displays along the way, enjoying hot chocolate and cookies. Much to everyone's delight, Santa boarded the train to visit with the boys and girls! Many thanks to CSL Behring for joining BioMatrix in hosting this magical holiday event!

Zoe and Brooks

DELAWARE

Tina McMullen

A delightful afternoon of education, great food, cookie decorating, and socializing was had by the Brandywine Valley Hemophilia Foundation's (BVHF) community December 17th at Timothy's Riverfront Grill in Wilmington for this year's ***Education and Cookie Decorating Event***.

Cookie Tester Walter

Before a lovely buffet lunch was provided, Novo Nordisk Representative Dan Bull presented a program on *Money and Finances*. Each family was then provided with everything needed to make amazing cookie creations. Children and adults displayed their fantastic imaginations as they crafted incredible artwork on their cookies!

Thank you to Novo Nordisk and BVHF president Gail Novak for this merry event!

Tina, Becky and Jerry

Happy Holidays from BVHF! Dave and Gail

NEVADA

John Martinez

BioMatrix had the special privilege of sponsoring a booth at the ***2nd Annual Women's Empowerment*** event with the Nevada Chapter of NDBF January 13th at the West Las Vegas Library.

Amber Federizo, DNP Clinical Nurse Educator with Octapharma provided an in-depth look into the changing environment about recognizing women's bleeding issues.

Presented by Clark County Genealogical Society, the next session covered an overview of genealogy and the importance in learning about your ancestry. On behalf of BioMatrix, I then gave a short presentation on our resources and the unique qualities our services offer. To wrap up the event, the chapter presented each attendee with a terrarium and instructions on building and caring for the live plants.

With important topics discussed, this event proved to be a great way to start the year building relationships and resources to address the challenges faced by women in the bleeding disorders community.

FLORIDA

Hector Heer

Energy and enthusiasm describe the atmosphere January 20-21 at the ***2nd Annual Latino Conference*** of the Bleeding Disorders Foundation of Florida held at Renaissance SeaWorld in Orlando! Following a warm welcome from Chapter Executive Director, Fran Hayes, BioMatrix got the crowd going with a lively version of bleeding disorders *JeoParody*.

Participants of all ages engaged in categories including education in bleeding disorders, music, television, and cinema. The friendly competition became increasingly enthusiastic as the teams competed for the much-coveted *JeoParody* champion crown of the Latino Conference 2024.

John Martinez emcees JeoParody

After lunch, a panel of physicians provided valuable insights into treatment protocols. The attendees then separated into his-and-her breakout sessions where more topics were discussed in-depth, and testimonies shared. With the variety of industry booths available in the exhibit area, participants were able to learn about new products and connect with the companies that provide their treatments. At the BioMatrix booth, there was much discussion about our unique Patient Navigation program and other services we provide.

Sunday's breakfast gathering provided another opportunity for families to connect and network. Brief presentations from each sponsor were made, including from BioMatrix Territory Account Executive Hector Heer who shared his strong connection with the local foundation and community and his enthusiasm for the future in Florida. We are all very appreciative of the efforts of the Bleeding Disorders Foundation of Florida staff and the many dedicated volunteers necessary to bring to life such a vibrant program!

Hector Heer shares his connection to the community

OHIO

Rania Salem and Shelia Biljes

Love was in the air for ***Couples Night Out*** in Ohio! It wasn't too early to start celebrating Valentine's Day as partners gathered February 8th in the "heart" of Columbus at Cooper's Hawk and Winery and at Strongsville's Bucci's J Bella Restaurant February 9th. Octapharma and BioMatrix joined with the Northern and Central Ohio Hemophilia Foundation to host the events.

The two evenings were filled with fun and romance as BioMatrix's Director of Education Shelby Smoak, Ph.D., led the groups in games of *Who Knows Best?*, a parody of *The Newlywed Game*, bringing many secrets to light with so much laughter! In Strongsville, three brave men volunteered to play a game for a chance to win their date a box of chocolates. Unknown to them, the game entailed jumping and twerking with a tissue box filled with ping pong balls tied around their waist. The object was to be the first to bounce the balls out of the box. The brazen men twisted, jumped and shook their booties to the music of Taylor Swift's *Shake It Off* as the room roared with hilarity.

Many thanks to the NOHF chapter and Octapharma for allowing us to co-host these delightfully unique and loving events!

Chris and Stephanie

Chad and Jennifer

Tony and Starr

Charlene and Bob

Joey and Kitty

Judy and Ray

Ben and June

Paul and Abby

Aaron and Ashley

Kristin and Noel

FLORIDA

Marcy Foertsch and Peggy Klingmann

BioMatrix and Takeda partnered February 13th to present an ***Educational Dinner*** program to bleeding disorders community members at Maggiano's Little Italy in Tampa. The evening began with Jan Martin, RN, a former HTC nurse, presenting on Takeda's current factor VIII therapy and patient assistance program. After Jan was Takeda's guest speaker Tony Allen who followed with a chronicle of his hemophilia journey as a middle-aged man and the changes he has experienced in his treatment over the years.

After a delicious meal, we rounded out the evening with a BioMatrix presentation of *Patient Navigation* which led to an interactive and informative question-and-answer session. Many thanks to Takeda, speakers and community members who made this event a success!

NEW MEXICO

Felix Jacquez Garcia

Keeping with Albuquerque tradition, the bleeding disorder community came together for their February ***Love and Friendship Event*** on the 22nd. HEMA Biologics, Medexus and BioMatrix came together to host this event at Albuquerque's Flix Brewhouse and Theater.

Felix Jacquez Garcia presents on advocating for the care and providers you deserve.

Bernadette Ortiz discusses her experience with *Any Willing Provider* law in her state

Following brief presentations by the sponsors who spoke about their products and services, community member Bernadette Ortiz spoke to the group about working with insurance companies to be able to use your pharmacy of choice. Having received a denial to use BioMatrix, Bernadette decided not to take no for an answer. After researching the *Any Willing Provider* law in her state, Bernadette went into protective grandmother mode and pushed back against her insurance company demanding she be allowed her provider preference.

This powerful program was followed by an even more powerful movie, *Ordinary Angels*. In this film, the same "I don't take no" for an answer mentality saved the life of a young girl who needs more than could be asked for. What a wonderful way to celebrate love and friendship than coming together to make a difference while sharing advocating efforts for someone in a medical situation.

Thank you to HEMA Biologics and Medexus, and everyone who chose to spend their evening with us!

MISSOURI

Eva Kraemer

Gateway Hemophilia Association hosted their annual ***Membership Meeting*** on March 3rd at the Chicken and Pickle in St Charles. The unseasonably warm weather drew a large crowd of community members to a meet-and-greet with fun in the sun on the pickleball court!

BioMatrix booth visitors! Mike, Kristina with sons Quentin and Jackson

The HTC staff from Washington University were there to introduce themselves and touch on everything included in a comprehensive visit from hematology to physical therapy and social work. It was a wonderful opportunity for facetime with healthcare providers outside the clinical setting.

Even though it was only the beginning of March, the weather felt like early June so enjoying a game of pickleball outside was just what the doctor ordered to make the afternoon complete. It was a pleasure for BioMatrix to be a part of this valuable day!

OHIO

Shelia Biljes

Spring is still a couple of weeks away but the mild weather in Ohio has everyone ready to celebrate. In partnership with Sanofi, BioMatrix hosted a ***Family Dinner*** with the Easter Bunny for Northern Ohio community members. With the group gathering at Tony K's Restaurant in Berea March 6th, Sanofi's speaker and nurse coordinator at Ohio State University Hemophilia Treatment Center, CJ Hanson presented *The Role of Factor Activity in Hemophilia Patients*. Laithe Elkurd, Community Relations and Education Manager at Sanofi assisted with the presentation, which included trivia questions and an interactive demonstration of how a clot is formed.

As families enjoyed their meal and listened to the overview of Sanofi's product, ALTUVIIIO®, children worked on their coloring contest pictures. The excited young guests took photos with the Easter Bunny who arrived after dinner, and each took home a bag of eggs earned from answering questions about infusion supplies. It was such a fun evening for those of us suffering from Spring fever. Thank you, Sanofi for sponsoring this fabulous event with us!

Matthew

Lila and Kaiden

Arwynn

Forrest

TENNESSEE

David Tignor and Cyndy Coors

The Tennessee Hemophilia Bleeding Disorders (THBD) chapter and Octapharma partnered with BioMatrix March 9th to host ***Sleeping with the Sharks*** at Ripley's Aquarium of the Smokies in beautiful Gatlinburg. While this location can be difficult for many community members to get to given its remote location in the Great Smoky Mountains, we knew it had the potential to be an amazing educational event, especially for the children. And indeed, we had a great turnout of families and kids for this overnight experience.

The staff took the group on a behind-the-scenes tour where we learned how the aquarium makes coral and sand for all their tanks. Participants also learned how to up their photography game with a session on *Camera On: Healing and the Art of Photography* by our own Shelby Smoak, Ph.D.. This highly interactive session discusses the impact of art and photography on one's health, and Shelby showed the group how to take more captivating cell phone pictures to get amazing shots of the marine life. We did close ups, cam shots, and used the tank's colored lighting to get some really fantastic pictures!

In addition to taking awesome photos, families were able to pet stingrays. Did you know they can weigh up to 70 pounds?! We also watched a brave diver swim with and feed the sharks and other marine life. Families then explored the aquarium which offered valuable one-on-one time with the sea creatures like anemones, starfish, trigger fish, and lionfish. After snacks, a scavenger hunt and more picture taking, the time had come to unroll the sleeping bags, snuggle up and sleep. It is an astounding experience to doze off in the shark tunnels with the sharks swimming all around you.

Tucker meets up with a stingray face-to-face!

Following a quick breakfast in the morning, the group was off to see the penguins. Everyone enjoyed the incredible experience and pledged to return for a penguin pajama party next year! Many thanks to THDB and Octapharma for making this event happen!

Silas, Mom and brother Jackson find this all amazing!

Frank and Margo head to the Penguin Parade

Ashley, Sawyer and Silas pose with the shark diver

Group Shot!

NEW JERSEY

Richard Vogel and Carolina Luna

Members of the New Jersey bleeding disorder community made their way to the America Dream Mall in East Rutherford March 10th for Hemophilia Association of New Jersey's (HANJ) ***Community Connections*** event, a day of education, comradery and a lot of fun. Old friends hugged and reconnected, and new friends were welcomed into the fold.

During breakfast attendees had time to visit and gather information about products and services from industry sponsors. After opening remarks by Executive Director Stephanie Lapidow, a branded educational session followed on *Switching Up Treatments and Perspectives*. In this session, a caregiver and son shared their journey switching to Sanofi's product, ALTUVIIIO®.

Kathiria, Delvis and Yamuel visit with BioMatrix reps Rich Vogel (left) and Carolina Luna (right)

The next session was an introduction into investigational gene therapy clinical trials for hemophilia, their purpose, and how they are conducted. Participants felt informed and empowered after this discussion.

The final presentation focused on *Expecting the Unexpected: Preparing for Anything*. As many of us are aware, emergency room staff, including physicians, may have little experience in the management of patients with a bleeding disorder. Helping to avoid but also prepare for a possible trip to the ER even when traveling or during a natural disaster was a perfect topic for the upcoming travel season.

After lunch, attendees were treated to an afternoon at the Nickelodeon Universe Theme Park. A great way for the community to connect and have fun! Many thanks to HANJ for hosting this informative and enjoyable event!

Celebrating Bleeding Disorders Month!

NEW HAMPSHIRE

Richard Vogel

The 2024 New England Hemophilia Association (NEHA) ***Consumer Medical Symposium*** kicked off March 16th at the Sheraton Nashua with a welcome reception to celebrate Bleeding Disorders Awareness Month and a presentation by Dr. Shveta Gupta on Sanofi's new replacement therapy for hemophilia A, ALTUVIIIO®.

NEHA's Executive Director Rich Pezzillo and his team consistently think "outside the box" for new and innovative topics for the community. One such example is a presentation by Keynote speaker Roderick Russell, CHt, CPH, CMH who spoke on the *Benefits of Hypnosis*. Roderick taught us how hypnosis can be applied to our unique situation explaining some of the tools and techniques to practice self-hypnosis to manage the many challenges bleeding disorders may present.

Dr. Larissa Bornikova spoke on *Expanding Horizons: Advancements in Treatment of Bleeding Disorders*, giving a broad overview of recently approved products, treatments coming down the pipeline, as well as medical practice updates.

Deciding which breakout session to attend was difficult. Some options were *Mucosal Challenges and Bleeding Disorders* and *Adapting and Understanding the Changes in Bleeding Disorder Care*. The afternoon offered rap sessions such as *Young Adult Challenges*, *Insurance*, and *Aging/Comorbidities*. We even had a visit from therapy dogs and learned how helpful they can be in treating stress and anxiety. The final presentation of the day was on *Community Voices in Research*, a community-based registry using real life experience to further research efforts.

Hypnotist Comedy Show

After dinner, a *Hypnotist Comedy Show* entertained us all and was followed by *Family Game Night and Music*. Arcade games, board games, and cards were available for families to play the night away.

The next morning everyone was up bright and early for more learning opportunities. *A Conversation about Mental Health and Bleeding Disorders* covered topics like needle phobia, guilt, isolation, and body image. We had an open and heartfelt discussion on the challenges we face in the bleeding disorders community.

As a person with severe hemophilia A, I was honored to be on the panel of *Bleeding Disorders: Community Perspective*. My fellow panelists and I shared our history including treatments, challenges, and outlook for the future. I was taken by the fact that while we were all different, our stories and journey were much the same.

Thank you, NEHA, for another great educational weekend with lots of interesting topics to choose from!

VIRGINIA

Terry Stone and Michelle Stielper

As the luck of the Irish would have it, the Hemophilia Association of the Capital Area brought everyone together under the rainbow for HACA'S ***Chapter Education Day*** at the Richard J. Ernst Community Cultural Center at Northern VA Community College in Annandale on St Patty's Day weekend, March 16th. With gold prices what they are, the traditional pot of gold was upgraded to many nuggets of knowledge and learning for all, even for the little leprechauns on this lucky day of learning and networking.

Michelle Stielper offers Callie a copy of her children's book, *This Is My Something* translated in Spanish

The first speaker was Miriam Goldstein, Esq, who has personal and professional experience in the bleeding disorder community. She presented on accumulator adjustors and co-pay maximizers; what they are, and the negative effects they have on our family's financial security.

Next was Dr. Michael Guerrera, HTC Director at Children's National Medical Center, to discuss sports activities for children with bleeding disorders. Also on hand was Dr. Gary Kupfer, of Medstar Georgetown University Hospital,

for an *Ask the Doctor Session*. Christi Humphrey, LCSW presented *Mental Health: A Deep Dive*. It focused on mental health concerns seen in the bleeding disorder community and offered skills and resources to address these growing concerns.

The White House Nannies were on hand to play with and care for the wee ones, while Camp Holiday Trails staff slide in on their magical camp rainbow in their "keep camp weird" mobile and set up a fun and fabulous pop–up camp experience. Spanish speaking HACA members were able to experience the entire day of learning thanks to an onsite interpretation team that translated the sessions real time. BioMatrix also had our children's book entitled, *This is My Something"* available in Spanish which tells the story of a boy with hemophilia. It helps children understand and accept their bleeding disorder as a unique and special part of who they are. (If you would like to obtain a copy of our children's book in English or Spanish, please contact us at info@biomatrixsprx.com).

Thank you HACA for hosting this very special gathering!

OHIO

Shelia Biljes

It's a hard-knock life for sure! All the more reason to gather with our bleeding disorders families March 24th at Cleveland's Crown Plaza Hotel. The Northern Ohio Hemophilia Foundation (NOHF) in partnership with several industry sponsors provided an ***Educational Program*** for its members.

Roy and Brooklyn at the glamorous theater

Over a delicious brunch, Jasmine Pauldurai, Education Specialist with NBDF, presented *Being Different, Belonging Together* – an interactive presentation addressing the issue of bullying and learning to understand what the person next to you may be feeling.

It was a short walk to Playhouse Square – a performing arts center in downtown Cleveland where historic theaters were renovated rather than being demolished in the 1970s. At the Connor Palace Theater, we were treated to the Broadway play *Annie*. Many of the guests had never been to this theater before and were impressed by the gorgeous architecture and the talented performers. Thank you NOHF for this entertaining event!

Tony and Starr under the massive and iconic Playhouse Square Chandelier boasting 4200 crystals, 20 feet tall, suspended by a 44 foot structure. Then they are off to see *Annie*!

ILLINOIS

Eva Kraemer

It's always beneficial and empowering to collaborate, which is what happened at the ***Educational Dinner*** March 27th at Beatrix in Oak Brook. BioMatrix teamed up with Sanofi who provided a lively discussion about ALTUVIIIO®. BioMatrix Director of Education Shelby Smoak, Ph.D., then elaborated on using photography as a form of therapy in *Camera On: Healing and the Art of Photography* and invited us to use our phone cameras, exploring different perspectives, colors and textures from around the room. The unanimous consensus was that the activity allowed everyone to see things differently while allowing a wave of creativity to wash over us. BioMatrix is committed to the Illinois bleeding disorders community to provide various opportunities to network and share. Many thanks to Sanofi for partnering with us and to our guests for taking time in their busy week to spend the evening with us. It was great to see you all!

Camera On
Great takes!

The gangs all here! Shelby Smoak, Alvaro, Octavio, John, Genny, Johnny, John, Cory, Shari, Cortez, Mural, Sridevi, Jim, Christine and Alex

Time for Fun!

Games on page 27

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

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

1. away
2. bleeding
3. climbing
4. lake
5. roasting
6. campfire
7. try
8. factor
9. nurse
10. infuse
11. needle
12. myself
13. smile
14. camp

Upcoming Events

APRIL 30, 2024 OHIO
Ladies Educational Lunch
Hosts: Novo Nordisk and BioMatrix
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
SantoSuossos'; Medina

MAY 1, 2024 NEVADA
Educational Dinner
Hosts: Octapharma and BioMatrix
Contact: John Martinez, 559-593-2306
john.martinez@biomatrixsprx.com
Dave and Busters; Las Vegas

MAY 3, 2024 DELAWARE
Blue Rocks Baseball
Brandywine Valley Hemophilia Found.
Contact: Gail Novak, 302-598-4632
gvannicola@verizon.net
www.brandywinehemophilia.org
Daniel S. Frawley Stadium; Wilmington

MAY 3–5, 2024 VERMONT
Men's Retreat
New England Hemophilia Association
www.newenglandhemophilia.org
Contact: Richard Vogel, 732-991-7373
richard.vogel@biomatrixsprx.com
Stratton Mountain Resort; Stratton

MAY 3–5, 2024 PUERTO RICO
Moin Conference
Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado
787-647-7985, https://hemofiliapr.org/
Embassy Suites; San Juan

MAY 10, 2024 KANSAS
Community Outreach Program
Hosts: Takeda and BioMatrix
Contact: Jeanette Jones, 405-229-0855
jeanette.jones@biomatrixsprx.com
Season 52; Kansas City

MAY 15, 2024 FLORIDA
Educational Dinner
Hosts: Bayer and BioMatrix
Contact: Marcy Foertsch, 941-518-7063
marcy.foertsch@biomatrixsprx.com
Whiskey Cake; Tampa

MAY 18, 2024 TENNESSEE
A Day in the Wild!
Hosts: TN Hemophilia & Bleeding Disorders Found., Bayer and BioMatrix
Contact: Teresa Nothan, ED
615-900-1486, https://www.thbdf.org/
Tennessee Safari Park; Alamo

MAY 22, 2024 PENNSYLVANIA
Family Education Dinner
Hosts: Western PA Bleeding Disorders Found., HEMA Biologics and BioMatrix
Contact: Kara Dornish, ED
724-741-6160, https://wpbdf.org/
Luciano's Brick Oven; Cranberry

MAY 23, 2024 NEW MEXICO
Educational Dinner
Hosts: Sanofi and BioMatrix
Contact: Felix Jacquez Garcia
505-322-0479
felix.garcia@biomatrixsprx.com
Pappadeaux; Albuquerque

MAY 23, 2024 TENNESSEE
Nashville Sounds Baseball Game
Hosts: Tennessee Hemophilia & Bleeding Disorders Foundation, CSL Behring and BioMatrix
Contact: Teresa Nothan, 615-900-1486
https://www.thbdf.org/
First Horizon Park; Nashville

MAY 25, 2024, OKLAHOMA
Mother's Celebration Tea
Hosts: Novo Nordisk and BioMatrix
Contact: Jeanette Jones, 405-229-0855
jeanette.jones@biomatrixsprx.com
La Madeleine French Bakery; Norman

MAY 29, 2024 NORTH CAROLINA
Educational Dinner
Hosts: Octapharma and BioMatrix
Contact: Austin Caldwell, 980-255-0528
austin.caldwell@biomatrixsprx.com
Circa 1922; Wilmington

MAY 31 – JUNE 2, 2024 DELAWARE
Men's Retreat
Hosts: Country Boy Fishing, Medexus, Octapharma; HEMA Biologics and BioMatrix
Contact: Richard Vogel, 732-991-7373
richard.vogel@biomatrixsprx.com
Atlantic Sands Resort; Rohoboth Beach

MAY 31 – JUNE 1, 2024 TENNESSEE
54th THBDF Annual Meeting
Tennessee Hemophilia & Bleeding Disorders Foundation
Contact: Teresa Nothan, 615-900-1486
https://www.thbdf.org/
Westin; Chattanooga

JUNE 12, 2024 PENNSYLVANIA
Annual Meeting
Eastern PA Bleeding Disorder Found.
Contact: Sarah Ross Pilacik, ED
610-770-5215, sarah@epbdf.org
www.hemophiliasupport.org
Sheraton Valley Forge; King of Prussia

JUNE 21–23, 2024 TEXAS
Bleeding Disorders Conference
Lone Star Bleeding Disorders Foundation, 713-686-6100
www.lonestarbleedingdisorders.org
and Texas Central Hemophilia Foundation, 972-386-3865
https://texcen.org/
Renaissance Austin Hotel; Austin

JUNE 28, 2024 NEW MEXICO
Educational Dinner
Hosts: Novo Nordisk and BioMatrix
Contact: Felix Jacquez Garcia
505-322-0479
felix.garcia@biomatrixsprx.com
Fogo de Chao Steakhouse
Albuquerque

AUGUST 11, 2024 MARYLAND
HACA Chapter Picnic
Hemophilia Association of the Capital Area, 703-352-7641
https://hacacares.org/
Watkins Regional Park; Upper Marlboro

NATIONAL EVENT!
SEPT 12–14, 2024 GEORGIA
76th Annual Bleeding Disorders Conference
National Bleeding Disorders Foundation
212-328-3700 Ext.728,
https://na.eventscloud.com/website/64934/home/
Georgia World Congress Center; Atlanta

SEPT 20-22, 2024 VIRGINIA
Women's Retreat
Hemophilia Assocociation of the Capital Area, 703-352-7641
https://hacacares.org/
Meadowkirk at Delta Farms
Middleburg

SEPT 28, 2024 VIRGINIA
Medical Symposium
Virginia Hemophilia Foundation
804-740-8643
https://vahemophilia.org/
Great Wolf Lodge; Williamsburg

Hi Kids! Time for Fun!

Johnny isn't sure he wants to go to camp. Can you use words from the Word Box to help him learn more about camp? Good luck and have fun! Answers are on page 25.

"Dad, I'm not sure I want to go to bleeding disorders camp. I'll be _ _ _ _ from home for a whole week!"

"Oh, but it will be such a great adventure!" Johnny's dad replied, "You will have so much fun and will make new friends who have a _ _ _ _ _ _ _ _ disorder just like you. And don't get me started about all the fun camp activities!"

WORD BOX

infuse	camp
myself	roasting
away	campfire
needle	factor
bleeding	try
lake	climbing
smile	nurse

"What kind of activities?" asked Johnny.

"The camp has rock _ _ _ _ _ _ _ _, arts and crafts, swimming in a pool, canoeing and fishing out on a _ _ _ _, hiking and archery. And there's _ _ _ _ _ _ _ _ marshmallows and singing around the _ _ _ _ _ _ _ _."

"What else?" asked Johnny.

Johnny's dad answered, "Well, there is a very important activity you can _ _ _ at camp if you think you are ready. When it's time for your _ _ _ _ _ _ treatment, a _ _ _ _ _ will be there who can teach you how to self– _ _ _ _ _ _."

Johnny thought about it for a minute and asked, "Dad, do you really think I can do that? Like with a butterfly _ _ _ _ _ _ and everything? All by _ _ _ _ _ _?"

"Johnny, I KNOW you can do it!" his dad said with a big _ _ _ _ _.

"Well then, bleeding disorders _ _ _ _, get ready because here I come!" laughed Johnny.

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

Sudoku!

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

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

[BIOMATRIX]
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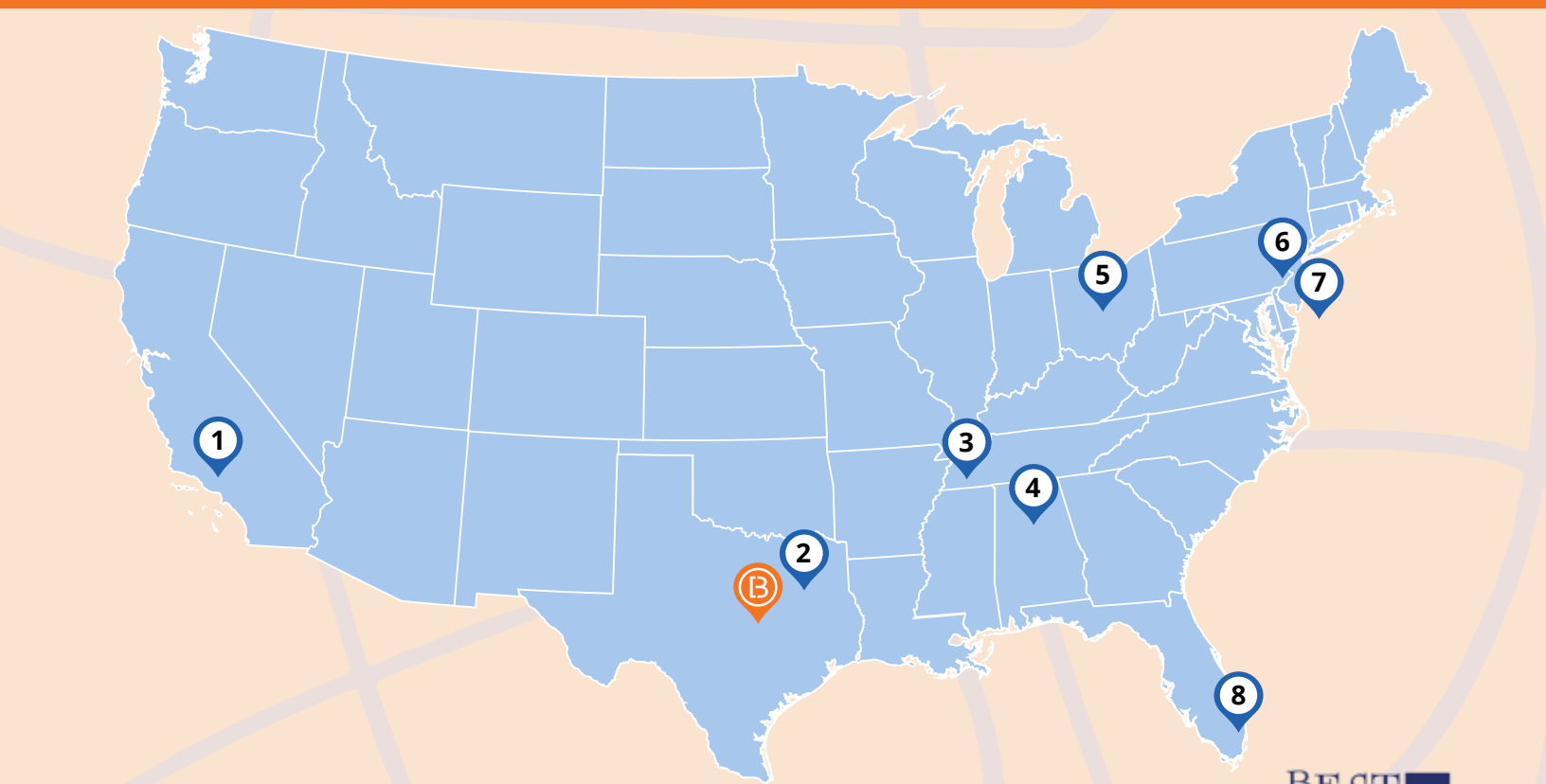
fb.com/BioMatrixBleedingDisorders
x.com/biomatrixsprx
linkedin.com/company/biomatrixsprx

Dedicated to Making a Difference

BioMatrix values your privacy. We are committed to keeping your information secure and confidential. We take your privacy very seriously by complying fully with HIPAA regulations and employing a team of IT experts whose job is to keep our data safe and secure. Our mailing list is private and will never be sold or shared with a third party. If you have any questions or would like to review our Privacy Policy, please contact our corporate office at 877-337-3002.



Specialty Infusion Pharmacy Locations

1. Van Nuys, California
2. Tyler, Texas
3. Bartlett, Tennessee
4. Birmingham, Alabama
5. Dublin, Ohio
6. Garnet Valley, Pennsylvania
7. Totowa, New Jersey
8. Plantation, Florida

Infusion Suite

Waco, Texas

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