

BIOMATRIX

NEWS



Special Camp Issue!



**DEDICATED
TO MAKING
A DIFFERENCE**

**SPRING 2023
VOLUME 18 | ISSUE 2**



“ A bad day doesn't cancel out a good life. Keep going. ”

— Richie Norton

ABOUT BIOMATRIX

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

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

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

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

MISSION + VISION

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

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

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

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

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

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

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

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

FINE PRINT

Editor-in-Chief: Maria Santucci Vetter

Editors: Susan Moore and Justin Lindhorst

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

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

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A NOTE FROM THE EDITOR

Welcome to our Spring issue of BioMatrix News! As we shrug off the cold of winter, we begin looking forward to outdoor activities and warm sunshine. Like many of you, I love to be out in the sunshine digging in the dirt while planting my garden. There's nothing like fresh, hand-picked tomatoes in a recipe!

Especially for the younger members of our community, warm weather means time for camp. Bleeding disorders camp has become a tradition – it is a sought after, eagerly anticipated, break from life that so many - kids and adults alike - look forward to every year. Meeting up with old and new friends, participating in games, sports, skits, arts and crafts, and learning new skills that may include managing a

bleeding disorder and self-infusing are some of the many activities camp offers. Keeping with tradition, this issue of our newsletter highlights the camps across our country.

This issue also highlights the stories of two community member families. We all benefit when others share their journeys and the trials and triumphs they face. Often, we can see our own challenges and victories reflected in their words; it helps to know we are not on this path alone.

Enjoy this issue, and know that all of us at BioMatrix wish you a happy and healthy spring!

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

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>





Now Accepting Applications for the 2023 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 accepted through August 1, 2023.

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

UNDERSTANDING REDETERMINATION FOR MEDICAID AND CHIP BENEFICIARIES



BY SHELBY SMOAK, PH.D.

ALL MEDICAID BENEFICIARIES WILL UNDERGO AN ELIGIBILITY REVIEW IN THE COMING MONTHS

If your health insurance benefits are provided by Medicaid and/or CHIP (Children's Health Insurance Program), it is important to understand how redetermination could impact your health benefits in the coming months. This article explains redetermination, outlines why states are undergoing the redetermination process, provides information on how to prepare for redetermination and includes resources for maintaining access to insurance coverage if no longer eligible for Medicaid or CHIP because of the redetermination process.

What is Redetermination?

Redetermination is a term used to describe the process of re-verifying eligibility for government health benefits such as Medicaid. All persons currently receiving Medicaid and/or CHIP benefits will undergo redetermination in the coming months. States must start the redetermination process by April 1, 2023, with many states starting as early as February 1st. States will have 12 months to complete the redetermination process once they begin. Medicaid beneficiaries who fail to complete the redetermination process will lose their Medicaid benefits. To aid the process, the Federal Communications Commission (FCC) is allowing states and managed care plans to text beneficiaries.

Why are Medicaid and CHIP going through this redetermination period?

During the pandemic, the federal COVID-19 public health emergency mandate did not allow states to disenroll any of its Medicaid recipients. This significantly increased the number of Medicaid beneficiaries. Over the past two years, almost 1 in 4 Americans became Medicaid recipients.¹ During the pandemic, the government floated federal money - Public Health Emergency (PHE) funds - to cover the growing Medicaid population. Those PHE funds are scheduled to expire May 11th of this year.

What can I do to prepare for the redetermination process?

1. Make sure your address, email, phone number, and other information are up to date.

Make sure you receive your Medicaid redetermination letter and/or text by assuring they have your most current contact information.

2. **Check your mail and email and check it frequently.**
Your state will eventually contact you, so be ready to respond. There is no "maybe" in this redetermination - this is certain. If your state requires you to complete a renewal form, do so promptly and return it to the listed address on the form. Doing so will help avoid a gap in your coverage.
3. **Have your proof of income ready to share.**
Medicaid is a federal assistance program based on an individual's income and the federal poverty level. Proof of income will likely become a vital part of redetermination.

Where can I go to learn more about my state's redetermination process?

Visit your state's Medicaid website to learn more. The Hemophilia Federation of America (HFA) has created a resource page that includes links, phone numbers and information about each state's Medicaid plans: <https://www.hemophiliafed.org/resource/state-medicaid-websites/>.

What if I am disenrolled from a Medicaid or CHIP plan as a result of the redetermination?

If you are disenrolled but believe you are still eligible, you may go through the appeals process. Read about the appeals process by visiting HFA's resource page: <https://www.hemophiliafed.org/resource/state-medicaid-websites/> or reach out to the *BioMatrix Patient Navigation Program* at bdpatientnav@biomatrixsprx.com. However, if you are disenrolled because you no longer qualify for Medicaid or CHIP, you may be able to buy a plan through the Health Insurance Marketplace at [Healthcare.gov](https://www.healthcare.gov). Plans are comprehensive and can cost as little as \$10 a month.

The primary thing to remember is that if you meet your state's Medicaid requirements and complete all the requested redetermination forms in the timeframe requested, your Medicaid will stay in place. If you no longer qualify for Medicaid coverage, you will qualify for a "special enrollment period" during which you can secure coverage through the healthcare exchange.

REFERENCE

- i. Pradhan, Rachana. "Why Millions on Medicaid are at Risk of Losing Coverage in the Months Ahead." KHN. 14 Feb. 2022. <https://khn.org/news/article/why-millions-on-medicaid-are-at-risk-of-losing-coverage-in-the-months-ahead/>.

OUR FIRST YEAR OF LIVING WITH HEMOPHILIA: *A Reflection*

BY JEREMY SOBOTKA WITH RAGINA AUCH

Ragina and I are the parents of two adorable children – Jade, age 14 and Tristan, 9. We were introduced to the world of bleeding disorders when our son was diagnosed with severe hemophilia B. We’ve learned a lot in the past few years and would like to share the experiences of our first year.

After Tristan was born, his heel was pricked for routine newborn lab work. Throughout the day, the tiny puncture bled through the bandage and booties and onto the blanket. His nurse did a complete bandage, bed and clothing change. The next day, another nurse came in and changed the bandage, put clean clothes on, and brought in fresh blankets. On the third day another nurse arrived to change everything again, and this time I asked, “Why is he still bleeding?” I mentioned that the other nurses had changed everything each day prior because of the bleeding. Apparently, the nurses had not communicated that with each other and the doctor was unaware. When the doctor was notified, a blood draw was ordered to test his platelet count and check for other bleeding disorders. Later that afternoon he came in and gave us the shocking news that Tristan had hemophilia.



Our initial reaction to learning our son has severe hemophilia B was one of fear, grief, confusion and hopelessness. Though Ragina had heard of hemophilia, she didn't know much about it. Never having heard of it myself, I didn't even know how to spell it! I hoped Tristan would just be given some kind of medicine, and everything would be fine. When I understood it was a lifelong medical condition, I instantly felt sick to my stomach, angry, scared and helpless.

It wasn't until the 3rd or 4th visit to the hemophilia treatment center when the doctor suggested inserting a port so Tristan could be placed on a weekly prophylactic schedule that I began to realize the lifelong impact. There really isn't anything that can or would prepare a parent for that kind of news. Everything sounded even worse when our pediatrician said he had never had a patient with hemophilia in his 30+ years of being a doctor.

As Tristan started learning how to get around, bruises began appearing all over. As the bruising increased with his activity level, we became more interested in having a port placed so he could start prophylactic treatments. However, we had to wait until after Tristan's first birthday to proceed. He was already walking, and we knew things could get worse.

At first Ragina and I had split opinions on the decision to have a port inserted. After all, who wants to have their child go through any surgery, especially at a year old?

After weeks of debating, we decided it would be best for him to have a port. After going through all the difficult blood draws and injections, we have been happy with our decision. For us, it's been a night and day difference - now that we can give him his treatments and have labs drawn without a single tear! Learning to infuse him via the port was nerve racking at first, but it became our weekly evening family ritual that we did together. Jade's job was to keep Tristan entertained as I held him while Ragina did the infusion.

He didn't experience many bleeds before the port was placed, so we have not learned how to access a vein. At nine-years-old, Tristan's port is still fully functioning, but we are now exploring how best to learn to infuse our son through venous access.

Since those early days, we have accepted that Tristan will have hemophilia forever, or at least until a cure is found. We have realized the best thing we can do is learn as much as possible about his bleeding disorder so we can be better prepared to teach him as he grows up. We've been doing our best to treat Tristan as normally as possible. At the same time, overprotectiveness kicks in and sometimes I just want to put him in a bubble. On occasion, we have to get on our daughter because she tends to play rough with him, but he is usually the one instigating the horseplay! As he's gotten older, he's proven to be a typical boy who loves to climb and get into things... go figure!

With my son's first year of life, I have learned that when it comes to bad news about my family, I tend to blow it way out of proportion. I am supposed to be the rock for them to lean on and I admit I am the least qualified for the job. I envy Ragina for being able to keep her cool and be strong enough to handle everything better than I do.

Presently, even though we are not together as a couple, we continue to work together for the benefit of Tristan's health. We have worked well together in both routine and emergent care. Jade, even years later, still enjoys roughhousing with her younger brother!



Tristan is doing very well these days and enjoys video games, playing with his friends and family, driving an ATV, and has just signed up for 4-H. He hasn't had many emergencies, a few stitches, but the biggest issue he continues to experience are bleeds in his ankles. We are in the process of having his dosage adjusted and getting orthopedic inserts for his shoes to hopefully help with that. You would never know by looking at him that he has hemophilia, he is just a normal 9-year-old boy living life to the fullest.

Hemophilia has been an experience for all of us. It has taught us a whole new level of patience. Tristan didn't understand in that first year that anything was wrong with him. Even now, his hemophilia has been so well controlled that in his eyes, the problem he has is with the port and treatment rather than bleeding episodes. I don't want him to know any different! Kids with hemophilia are the same as any child and shouldn't be treated differently - they still play and fight with siblings. Just remember to be a bit more cautious and alert and know they will have a few extra bruises now and again no matter how careful they are. Take each day one at a time and have faith everything will work out fine!



IN SEARCH OF *Support*

BY FEL ECHANDE

My family is a mix of Costa Rican and Mexican descent and we have lived in the USA for 24 years now. I am a commercial driver, and my wife, Laura, is a photographer. We have two sons, Fiach, 22 years-old, and Yanni, who is 17.

Our first-born son was diagnosed with severe hemophilia B at 10-months old. After consistently showing up to the pediatrician's office with unexplained bruising, our physician suspected abuse. However, after running a battery of blood tests, it became evident that Fiach has hemophilia.



With no family history of a bleeding disorder, we knew very little about hemophilia. We had a lot to learn. We knew the diagnosis was going to be a struggle, but thanks in part to amazing support from the bleeding disorder community, our family is thriving.

Twenty-plus years ago, the internet was in its infancy. In those early days, the lack of information was challenging us. There was very little information available in Spanish.

My wife came across a book authored by Laurie Kelley, which had been translated to Spanish (no longer available in Spanish). The book proved to be a huge help for us as we struggled to find more information.

Outside of the clinical support provided by our medical team, we began to realize the importance of connecting with others in the bleeding disorders community. Becoming involved with local and national chapters was instrumental in broadening our education, comfort, and ability to deal with hemophilia.

Laura and I began meeting so many wonderful people in the community. Each friendship brought a fresh perspective and helped us see that our son could live a largely normal life. We learned so much from the

individuals and families having already walked in our shoes.

Making friends with other children with hemophilia helped our son understand that he is not alone in the world. The friendships taught him to embrace life with a bleeding disorder. When things were stressful for us as parents or for Fiach as an affected child, we knew we could lean into community-based support provided by our local chapter and organizations like The Coalition for Hemophilia B. Through our involvement we learned to be strong advocates for ourselves, for our son, and for others in the bleeding disorders community.

As the years went by,



we became more knowledgeable and confident, and were compelled to get involved and give back to the community that had helped us so much.

We are now very involved in volunteering. I am currently on the board of directors for the Hemophilia Association of San Diego County. My wife and I have been part of National Hemophilia Foundation's *Guías Culturales* (Cultural Guides helping NHF with workshops for the Hispanic families). My wife was involved with the Hemophilia Chapter of Northern California's *The Female Factor Retreat*. We are both very involved nationally with



The Coalition for Hemophilia B and we also lead community support groups to help our local families.

We encourage all bleeding disorder families to get involved, get educated, and take advantage of the support provided by the organizations serving this community locally and nationally. Attend events, connect with families, and learn through our shared experiences. For those who are dealing with a new diagnosis know that it does get better. Our community is a family - don't ever be hesitant to reach out.

Spanish Language Resources

The Coalition For Hemophilia B
Newsletters in English and Spanish
www.hemob.org/newsletter
www.hemob.org

National Hemophilia Foundation
Guías Culturales (Cultural Guides)
<https://www.hemophilia.org/educational-programs/outreach/guias-culturales>
HemAware en español, <https://hemaware.org/es>

Hemophilia Federation of America
Sangre Latina
<https://www.hemophiliafed.org/join-sangre-latina/>

Let's get together to talk about IXINITY®



My own diagnosis keeps me very attached to this community as a family. I love seeing someone with a bleeding disorder accomplish something they thought they couldn't, and I live for helping them to get there.

Myles Ganley,
Community Experience Manager



▶ Scan me
or visit
IXINITY.com
today!

▶ Contact Myles at 208-602-0780 or myles.ganley@medexus.com

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coagulation factor IX
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2023 BLEEDING DISORDER CAMPS

Across the Country!

Every year, a slew of bleeding disorders community members excitedly look forward 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.

The end of the pandemic status of COVID-19 may be in sight with the availability of vaccines, better management of symptoms, and the US ending its emergency declaration in May 2023. Although we must remain vigilant, most camps have moved forward and are resuming camp activities as usual. Check our list for the camp nearest you or contact your BioMatrix Regional Care Coordinator for help locating one near you.

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

ALABAMA

1. Camp Clot Not

Date: June 17-22, 2023

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

Ages: 6-18



1. Camp Harvest Family

Date: Oct. 20-22, 2023

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



Location:

Children's Harbor on Lake Martin Alexander and siblings City, AL



Contact: Amanda Jennings, 334-577-0125 amandajennings525@gmail.com

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

ALASKA

2. Camp Frozen Chosen

Date: July 9-14, 2023

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

Ages: Completed 1st grade through high school senior



Location: Birchwood Camp; Chugiak, AK

Contact: Michelle Palmatier, 907-229-6017 michelle.alaskahemo@gmail.com alaskahemo@gmail.com

Host: Alaska Hemophilia Association and Bleeding Disorder Center, 907-917-9235 www.alaskableedingdisorders.org

ARIZONA

3. Camp HONOR

(Hemophiliacs Overcoming New Obstacles Resourcefully)

Date: June 6-10, 2023

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

Ages: 8-17

Location: Camp Wamatochick Prescott, AZ

Contact: Vickie Parra 602-955-3947, vickie@arizonahemophilia.org

Host: Arizona Bleeding Disorders www.arizonahemophilia.org



3. HUG Family Camp

(Hemophilia Uniting Generations)

Date: Oct. 20-22, 2023

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 16-21, 2023

Open to: Boys and girls with a bleeding disorder

Ages: 6-18

Location: Camp Aldersgate; Little Rock, AR

Contact: Luke Nipper, 501-225-1444

Lnipper@campaldersgate.net

Host: Camp Aldersgate

www.campaldersgate.net



5. Camp Nopokamee

Date: July 16-20, 2023

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

Ages: 8-18

Location: 4H Club; Ferndale, AR

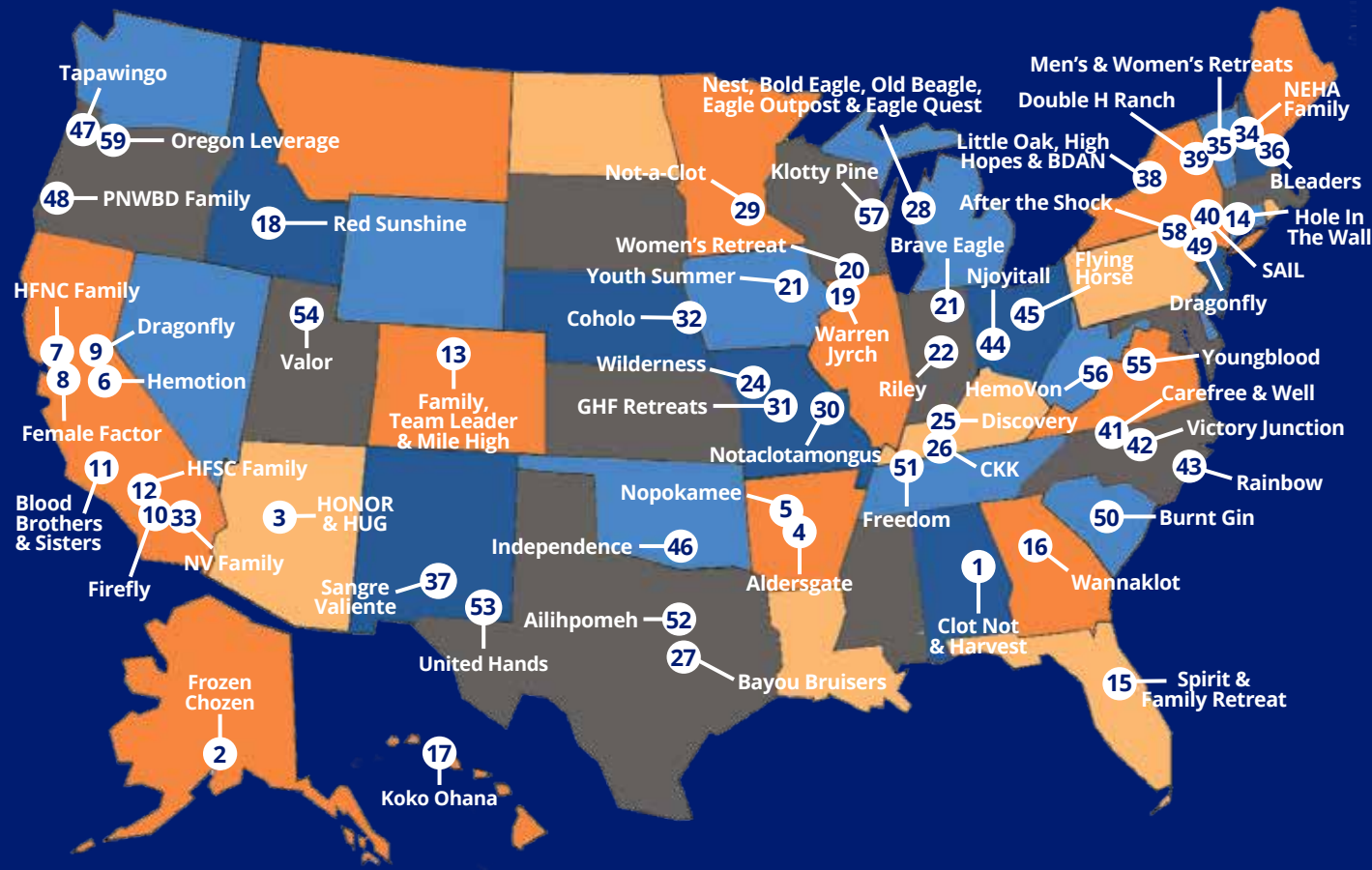
Contact: Angela Hodgdon, 501-428-5754

secretary@arkhemofoundation.org

Host: Hemophilia Foundation of Arkansas

<http://arkhemofoundation.org>





CALIFORNIA

6. California Camp Hemotion

Date: June 25–July 1, 2023

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

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



7. HFNC Family Camp

Date: March 10–12, 2023

Open to: HFNC families 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: Feb 17–19, 2023

Open to: Women and those identified female at birth in the bleeding disorders community

Ages: 12 and up

Location: Walker Creek Ranch
Petaluma, CA

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

Host: Hemophilia Foundation of Northern California, hemofoundation.org



9. Teen Camp Dragonfly

Date: July 10–14, 2023

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

Ages: 14–17

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



10. Camp Firefly

Date: July 24–28, 2023

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: 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



11. Camp Blood Brothers & Sisters

Date: July 16–21, 2023

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



Be Part of the Magic

BY ISSAIAH WILLIAMS

I am an adult man with hemophilia A. Hemophilia is a part of me but will never define who I am. However, one benefit of having hemophilia was the unique experiences I gained from it. I have been able to be a part of the hemophilia community and had the chance to know people I wouldn't have otherwise. Having hemophilia has allowed me to get involved with the Hemophilia Association of NJ and attend Double H Ranch Camp and Hole in the Wall Gang Camp.



how campers go from total strangers to best friends in just a few days.

Being able to go to camp as a kid was a life-changing experience. At camp, I was no longer bound by the constraints of my hemophilia and there were basically no limits to the

activities in which I could participate. My experiences as a camper led to a desire to become a camp counselor as an adult. I wanted to give back to the camps that gave me some of my best childhood memories. In 2015, I returned to camp for the first time as a volunteer and have since volunteered in some way as much as possible.

As a counselor, I get the opportunity to return to camp and share the magic that I felt as a camper. Over the years, I have been fortunate enough to get to know many of the campers and staff. Camp has become a special place for me where its positive energy gets me pumped simply by being there. As a former camper, I can relate to some of the campers' experiences while sharing stories. I draw on my camp experiences to make connections with the people in my cabin.

I believe my greatest contribution as a counselor is being able to connect with the campers. Creating a strong bond with the campers helps them open up to others and enhances the friendships they make. When they return in following years, I am able to see that my efforts have positively impacted their lives. This influence inspires me to keep working hard so I can continue to be a positive force in the lives of others. I am proud to be a part of camp's magical joy and am eager to share that magic!

These camps give kids and teens with chronic illnesses (like hemophilia) a chance to have fun and enjoy themselves. Campers are able to enjoy a wide range of fun adventures that can be tailored to meet their individual needs.

There's also a full medical staff, so campers (and their parents) don't have to worry about their medicine or treatments. Being a camper gave me the chance to try activities I never thought I would be able to do. I was able to participate in archery, wood-burning, and climbing a high-ropes course for the first time.

To me and many others, camp is a paradise full of smiles, fun and happiness. Camp is a place where you can be as unique and silly as you want – even the counselors! In addition to countless fun things to do, the people and the friendships are what make camp so special.

During the ride to camp, new campers are usually nervous and afraid to talk, but camp is able to create a tight bond between the kids. By the time we leave camp, those same campers can spend the whole ride home talking to each other about their week. It's amazing

12. HFSC Family Retreat

Date: June 2–4, 2023

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

13. Colorado Chapter Family Camp

Date: June 10–11, 2023

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: Highlands Presbyterian Camp & Retreat Center; Allenspark, CO

Contact: Hanna Beary, 646-499-0684
hbeary@hemophilia.org

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



13. Teen Leadership Weekend

Date: July 21–23, 2023

Open to: Teen boys and girls with a bleeding disorder

Ages: 14–18

13. Mile High Camp

Date: July 23–27, 2023

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

Ages: 6 and up

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



CONNECTICUT

14. The Hole in the Wall Gang Camp

Dates: June 17–23, June 26–July 2, July 15–21, July 24–30 and August 12–18, 2023

Open to: Boys and girls with bleeding disorders and other serious illnesses

Ages: 7–15

14. The Hole in the Wall Gang Camp Sibling Session

Date: August 21–27, 2023

Open to: Siblings of campers attending the summer program or Hero's Journey

Ages: 7–15



The Hole in the Wall Gang

14. The Hole in the Wall Gang Hero's Journey

Adventure-based wilderness search and rescue program in the woods of Connecticut

Dates: June 17-23, June 26-July 2, July 6-12, July 15-21, and July 24-30, 2023

Open to: Adolescents with a bleeding disorder or other serious illness, and siblings

Ages: 16-18

Location: Ashford, CT



14. The Hole in the Wall Gang Champion's Journey

Dates: July 24-30, August 2-8, August 12-18 and August 21-27, 2023

Open to: Adolescents with a bleeding disorder or other serious illness and siblings

Ages: 16-18

Location: Ashford, CT

Contact: Paige Breton, 860-429-3444 x121
paige.breton@holeinthewallgang.org
admissions@holeinthewallgang.org
Host: The Hole in the Wall Gang
www.holeinthewallgang.org

14. The Hole in the Wall Gang Camp Family Sessions

Date: March 31-April 2, April 14-16, April 28-30, May 5-7 and May 12-14, 2023

Open to: Families with bleeding disorders and other serious illnesses

Ages: All ages

Location: Ashford, CT

Contact: Beth Starkin, 203-745-2720
beth.starkin@holeinthewallgang.org
Host: The Hole in the Wall Gang
www.holeinthewallgang.org



FUN FACT: In 2024, The Hole in the Wall Gang Camp is opening a new camp on the Eastern Shore of Maryland!

FLORIDA

15. Camp Spirit

Date: June 12-16, 2023

Open to: Boys and girls with a bleeding disorder

Ages: 7-16

Family Retreat Weekend

Date: Oct. 13-15, 2023

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



15. Camp Spirit Youth Retreat

Date: July 29, 2023

Open to: Young adult boys and girls with a bleeding disorder

Ages: 13-20

Location: TBA, FL

Contact: Fran Haynes, 407-629-0000
franhaynes@hemophiliaflorida.org
info@hemophiliaflorida.org

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



GEORGIA

16. Camp Wannaklot

Date: July 1-7, 2023

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



HAWAII

17. Family Camp Koko Ohana

Date: June 23-25, 2023

Open to: Families and individuals affected by a bleeding disorder

Location: Camp Molute'ia; Waialua, HI

Contact: Kyra Calbero, 808-284-7417
kcalbero@hemophilia.org

Host: Hawaii Chapter-NHF
www.hawaiiinhf.org



IDAHO

18. Red Sunrise Family Camp

Date: June 22-24, 2023

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



A POSITIVE EXPERIENCE

BY MICHAEL DAGUE

In 1983, when I was just 7 years old, I attended a hemophilia summer camp on the Kentucky/Tennessee line. It was the first time I had been away from my family for an entire week. Initially, I'm sure I was homesick, but the feeling must have gone away quickly because I don't remember it.

Camp had an encouraging and positive effect on my outlook as I grew older. I met friends from the surrounding states, kids who had joint bleeds and pain issues and had to learn to infuse clotting factor, just like I did. It was at camp that I realized I was not alone with what I have.

As I look back to those days, I remember what a fantastic experience camp was. The best things about camp are the immeasurable skills I gained and the friends I made. To this day, my blood brothers are still in my life. Having their friendship and support continues to be a major part of my adult life!



Mike as a young camper

CAMP WARREN JYRCH CELEBRATES *50 Years!*

BY JOHN THORSON - LONGTIME CAMP VOLUNTEER

Bleeding Disorders Alliance Illinois Camp Warren Jyrch (CWJ) is celebrating a golden anniversary! Fifty years of summer camp began in 1973 when at the time, the Illinois chapter went by the name of Hemophilia Foundation of Illinois. The camp was named to honor Warren C. Jyrch (1921-1971) of Chicago, the first person with hemophilia to undergo and survive open-heart surgery to replace a valve. The surgery was extremely risky with 2400 pints of blood used during the operation.



Camp Warren Jyrch 1973

Through the years, there have been a lot of changes, but many things have remained constant. One area that has seen changes in the past 50 years is the variety of treatment options. Back then, patients spent a significant time in hospitals recovering from bleeding episodes and orthopedic issues. They missed a lot of school and opportunities to bond with other kids. For some young patients, their primary friendships were with hospital staff.

Today's medical advancements and treatment options allow kids with a bleeding disorder to rarely miss school.



Most often, they can participate in all sorts of physical activities like rock climbing, cycling, running, and sports such as baseball, basketball and volleyball, to name a few.

Fifty years ago, communication with affected families was through a tethered phone line or a stamped letter. It wasn't always easy to make announcements about camp or request information from families. Even getting to camp involved maps and directions rather than an address easily plugged into a GPS. Today our ability to communicate is instant and helps to offer a more positive outlook on managing a bleeding disorder.

In those times, only boys were thought to have hemophilia. Girls were not invited to camp. Siblings weren't invited either. Today we have a better understanding of how girls are affected by bleeding disorders, especially as more than carriers, and are now included. We also better understand how a bleeding disorder diagnosis affects the whole family, so siblings are also invited to share the camp experience.

Despite the challenges of those days, it was deemed important enough to gather this group of young patients for a week every summer with the purpose of socializing, bonding and feeling less isolated with their medical conditions. And so CWJ was started. Over the years, we have learned to overcome obstacles and have adapted to many changes. We continue to look toward the future and move forward.



Camp was founded to give boys with hemophilia an opportunity to be with others just like them, to talk, laugh, try new things, support each other, bond, and just be! At its inception, the mission was to encompass a safe and fun environment, encourage peer relationships, and increase self-confidence and independence.

Although many changes have been implemented along the way, the mission of camp remains the same - to encompass a safe and fun environment, encourage peer relationships, and increase self-confidence and independence. Plenty of education has been added. Kids learn more about managing their disorder and camp is where many first learn to self-infuse.

The first time I volunteered at camp was in 2009. I wanted to bring energy and inspiration, and be a mentor. I also wanted to gain an understanding of what kids with a bleeding disorder deal with and why camp is magical to them. By offering a safe environment and gentle suggestions, camp helps kids think differently, allowing them to go outside their comfort zones to try new activities, and learn and share with one another without judgment.

I want to leave a legacy of having done the best I could to help kids develop and reach whatever goals they set for themselves. The good stuff is when a camp activity applies to life at home, and a camper declares, "I never thought I could, but I can, and I did!" Watching a child grow to adulthood and graduate from being a camper to a counselor is especially rewarding.

On their 50th anniversary, we thank the CWJ pioneers who paved the way with such bravery for future generations of camp goers! We celebrate every attendee, family, caregiver, medical staff and volunteer who has been associated with the success of Camp Warren Jyrch!

With gratitude and appreciation, I am glad to have been a part of it!



MILD MATTERS

Disparities in the diagnosis and care of people with mild bleeding disorders are evident in both males and females.

We're working to change that.
hemophiliafed.org

hemophiliafed.org/mild-matters/



Time for Fun!

Puzzles are on Page 31



1. Girl #1 lettering is missing from hat
2. Girl #1 large circle is gone instead of blue
3. Girl #3 flag is now red and white
4. Girl #3 "VALOR" is now on hat
5. Girl #4 lanyard is gone
6. Girl #5 shirt stripes are black
7. Girl #6 now has long sleeves from the shirt logo
8. Girl #7 hat is now blue
9. Building in the back is missing

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

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

ILLINOIS

19. Camp Warren Jyrch

Date: July 30–August 5, 2023

Open to: Children with inherited bleeding disorders

Ages: 7–17

Location: YMCA Camp Benson; Mt. Carroll, IL

20. Women's and Girl's Retreat

Date: July 21–22, 2023

Open to: Women and girls with a bleeding disorder

Location: The Abbey Resort in Cape Geneva Geneva Lake, WI

Contact: 312-427-1495, info@BDAL.org

Host: Bleeding Disorders Alliance Illinois www.bdai.org



INDIANA

21. Camp Brave Eagle

Date: June 11–16, 2023

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

Ages: 7–16

Location: Camp Crosley YMCA North Webster, IN

Contact: Angel DiRuzza, 317-570-0039 x102 adiruzza@hoii.org

Host: Hemophilia of Indiana, Inc.

www.hoii.org, www.ihtc.org/campbraveeagle



22. Riley Camp Independence

Date: June 18–23, 2023

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/Programs/rectherapy/campriley/applications/index.html>



IOWA

23. Youth Summer Hemophilia Camp

Date: June 18–23, 2023

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: Missy Aitchison

michelle-aitchison@uiowa.edu or Karla

Watkinson, 319-356-4271

karla-watkinson@uiowa.edu

Host: Hemophilia of Iowa, Inc.

www.hemophilaofiowa.org with Iowa Hemophilia and Thrombosis Center



Youth Summer Bleeding Disorders Camp

KANSAS | MISSOURI

24. Camp Wilderness

Date: July 24–28, 2023

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

25. Camp Discovery

Date: July 23–27, 2023

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

Ages: 7–15



Discovery

25. Family Camp at Camp Discovery

Date: May 19–21, 2023

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

26. Center for Courageous Kids Camp

Date: July 11–15, 2023

Open to: Families with bleeding disorders (hemophilia, VWD, ITP)

Location: CCK; Scottsville, KY

Contact: Hannah Reckart

270-618-2912

hreckart@courageouskids.org

Host: Center for Courageous Kids, www.courageouskids.org



CCK

LOUISIANA

27. Camp Bayou Bruisers

Date: May 28–June 2, 2023

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



Bayou Bruisers

MICHIGAN

28. Camp Nest Family Camp

Date: June 28–July 1, 2023

Open to: Young children with a bleeding disorder and their families for an introduction to the Camp Bold Eagle experience

Ages: 5–9

28. Counselor-in-Training

Date: July 3–22, 2023

Open to: Former campers exhibiting strong leadership skills

Ages: 16–17

28. Camp Bold Eagle

Date: July 9–13, 2023 **Ages:** 6–9

Date: July 15–21, 2023 **Ages:** 10–12

Date: July 23–29, 2023 **Ages:** 13–17

Open to: Youth with a bleeding disorder

28. Camp Old Beagle

Date: Sept. 8–10, 2023

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>

28. Camp Eagle Outpost

Date: August 6–12, 2023

Open to: Youth with a bleeding disorder

Ages: 14–15

Location: Throughout Michigan

28. Camp Eagle Quest

Date: June 10–16, 2023

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

29. Camp Not-a-Clot

Date: July 16–21, 2023

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@hfmnd.org or Tammy

Ward, 651-406-8655, tammyw@hgmnd.org

Host: Hemophilia Foundation of Minnesota/Dakotas, www.hfmnd.org



Not-a-Clot

MISSOURI

30. Camp Notaclotamongus

Date: June 7-9, 2023

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

31. GHA Men's Retreat

Date: March 24-26, 2023

Open to: Men with a bleeding disorder, the spouse of someone with a bleeding disorder or a parent or legal guardian of someone with a bleeding disorder residing in the GHA service area.

Ages: 21 and older

31. GHA Adult Retreat

Date: April 28-30, 2023

Open to: GHA's adult members with a bleeding disorder and their significant other, or parents of a child with a bleeding disorder

Ages: 21 and older

31. GHA Women's Retreat

Date: Oct. 13-15, 2023

Open to: GHA's adult women with a bleeding disorder, carrier, spouse of someone with a bleeding disorder, or parent of a child with a bleeding disorder

Ages: 21 and older

Location: Margaritaville; Lake Ozark, MO

Contact: Bridget Tyrey, 314-482-5973

info@gatewayhemophilia.org

Host: Gateway Hemophilia Association

www.gatewayhemophilia.org

MONTANA | WYOMING

13. Mile High Summer Camp

In Conjunction with Colorado

Date: July 23-27, 2023

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

Ages: 7-18



13. Teen Leadership Weekend

In Conjunction with Colorado

Date: July 21-23, 2023

Open to: Teen boys and girls with a bleeding disorder

Ages: 14-18

Location: Rocky Mountain Village; Empire, CO

Contact: Hanna Beary, 646-499-0684

hbeary@hemophilia.org

Host: Rocky Mountain Hemophilia Bleeding

Disorder Association, www.rmhbda.org

and Colorado Chapter NHF, 720-545-0755

www.cohemo.org

Camp = Family

BY CAMERON

The first time I attended camp was when I was 12 years old. Camp Bold Eagle is in Michigan and about 6 hours from my home in Ohio. It was my first time away from home for an extended time.

My hemophilia chapter provided transportation. I was excited to go and didn't care how I got there but was a little afraid everyone would already have friend groups established. Those thoughts made it hard for me to put myself out there, but when I did, I made instant friendships.

The first thing that struck me about Camp Bold Eagle was how welcoming everyone was. A group of campers greeted me with open arms and hearts. They were excited to become friends and get to know the real me. These friendships blossomed, and I am forever grateful to have gotten to know them.

Camp friendships are inexplicably different from my school friendships. We have an understanding about each other's issues and pains. My campmates are some of my closest friends. Since most of them live in Michigan, I don't see them very often, but we stay in close contact. I am always happy to hear about everything they've been up to and how they are. I love when we can meet in person and just hang out. I cherish my time with them. There is always a lot to talk about, but sometimes we don't talk about anything at all, and it is a comfortable silence.

Camp is a place to be yourself, a place where you belong and are like everyone else there. It's a time to be silly and have fun along with getting to learn and do many activities. I am generally very quiet, but at camp I learned to open up with strangers and be loud enough to have my voice heard. It was the first time I felt I truly belonged. Being able to have this and share it with new campers is what keeps me coming back each year.



I continued attending camp and became a Counselor-in-Training in 2022. This was the year I learned to self-infuse and can now safely infuse myself. I am the oldest of six kids and five of us have a bleeding disorder. I would like to be trained well enough to help any of them in an emergency. Camp has taught me many useful skills to help my family.

My advice to parents is to let go. My mom had trouble letting me go. My uncle, who also has hemophilia, convinced her that it would be okay and would change my life. She listened to her younger brother, and he was right, camp changed my life.

For first-time campers, camp can be a scary thought, but everyone wants only the best for you. The adults and counselors are there to listen to you and see that you have an awesome, unforgettable experience. Just go! No one will judge you if you feel uneasy. Everyone will welcome you.

The final thing I have to say about camp is that it is like a family, which sounds cheesy. When so many people of different backgrounds come together and experience the same thing, it creates something beautiful, and I wouldn't trade it for the world! I love Camp Bold Eagle!

13. Montana and Colorado Chapter Family Camp

Date: June 10-11, 2023

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

Location: Highlands Presbyterian Camp and Retreat Center; Allenspark, CO

Contact: Hanna Beary, 646-499-0684
hbeary@hemophilia.org

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

NEBRASKA

32. CoHoLo Children's Cancer Camps

Date: July 16-19

Open to: Boys and girls impacted by cancer or a blood disorder

Ages: 6-11

32. CoHoLo Teen Camp

Date: July 19-23, 2023

Open to: Teens impacted by cancer or a blood disorder

Ages: 12-17

32. CoHoLo Sibling Camp

Date: September 10-12, 2023

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

Ages: 6-13

Location: Camp Fontinelle; Nickerson, NE

Contact: Sarah Jezewski
director@campcoholo.com

Host: Camp CoHoLo, www.campcoholo.com

NEVADA

33. Nevada Chapter Family Camp

Date: June 21-24, 2023

Open to: Immediate household family members of the NV Chapter

Location: Camp de Benneville Pines, Angelus Oaks, CA

Contact: Danielle Bell, 702-306-5513
dbell@hemophilia.org

Host: Nevada Chapter NHF, www.hfnv.org



NV Family Camp

NEW HAMPSHIRE | NEW ENGLAND

34. NEHA Annual Family Camp

Date: June 28-July 1, 2023

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



35. Men's Retreat

Date: April 21-23, 2023

Open to: People who identify as male with a bleeding disorder and caregivers, dads and grandfathers of children with a bleeding disorder

Ages: 18 and over

35. Women's Retreat

Date: August 11-13, 2023

Open to: Women with any type of bleeding disorder, carriers, and caregivers living in New England

Ages: 18 and over

Location: Stratton Mountain Resort, Stratton, VT

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

Host: New England Hemophilia Association, 781-326-7645, www.nehemophilia.org

36. BLeaders Teen Retreat

Date: March 3-5, 2023

Open to: People who identify as male with a bleeding disorder and caregivers, dads and grandfathers of children with a bleeding disorder

Ages: 13-18 (12 year olds may be considered on a case-by-case basis)

Location: Alnoba; Kensington, NH

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

Host: New England Hemophilia Association 781-326-7645, www.nehemophilia.org

NEW MEXICO

37. Camp Sangre Valiente

Date: July 9-13, 2023

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

Ages: 7-17

Location: Sacramento Camp & Conference Center; Sacramento, 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

38. Camp Little Oak

Date: July 23-29, 2023

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



38. Camp High Hopes

Date: July 23-29, 2023

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.
www.camphighhopes.org



38. BDAN Family Camp

Date: Oct. 7-9, 2023

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

39. Double H Ranch

Dates: Sessions June 21-25,

June 28-July 2, July 5-9,

July 13-17, July 20-24 and

July 27-31, 2023

Alumni Session August 3-7, 2023

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



BY ELIZABETH GARCIA

We are so grateful to the Inhibitor Family Camp for giving us the opportunity to attend this unique and wonderful camp!

Our family of four includes my husband, Jose, our 13-year-old son, Rob, who does not have hemophilia, and our two-year-old son, Alex, who has severe hemophilia B with an inhibitor. Alex was eight months old at the time of his diagnosis. As the mother of a newly diagnosed child, I felt terrible knowing my sweet boy has a bleeding disorder, and there was nothing in my power to change that.

Initially, I was so confused; I had no idea what hemophilia was. At times my mental health seemed to be constantly unbalanced, and I felt surrounded

by fear of the unknown. Oftentimes, I would find myself crying about the *what ifs*. Weeks passed, and we began to accept hemophilia as a part of our lives.

Four months later, Alex had his first bleed and fear surrounded my husband and I again.

When our hematologist recommended having a port placed to infuse factor more easily, our anxiety grew more intense. We finally decided to have Alex's port inserted with high hopes that our little boy would have a childhood close to any other child his age. He would have the freedom to be a one-year-old child, to run, play, and jump without worry of getting seriously hurt. Surgery went well; the plan was to infuse factor twice a week. Everything seemed so promising until the 7th day after surgery. Following his second infusion, he developed a huge hematoma at the port site. Sure enough, labs came back a week later with the detection of an inhibitor. Now we asked, "What is an inhibitor?" More to learn, more anxiety, more dread that dashed our hopes and dreams. An inhibitor was our terrifying enemy of the moment.

Factor was infused twice a week for ten weeks. Despite pre-medication for allergies, the allergic reactions were visible for most of every infusion. These are some of the allergic reactions Alex experienced: petechiae, hives, circumoral cyanosis, coughing, red/flushed skin with rash over his body, tachycardia, oxygen level dropping to 72%, swollen eyes and lips. Instead of waiting for his body to

respond to the clotting factor, we decided to stop trying. Unless they are affected with hemophilia and have an inhibitor, not many people understand bleeding disorder language. This often makes us feel alone. Being on social media, I joined a group of mothers with hemophilia children, where I learned about inhibitor camp and decided to attend.

CHES gave us the warmest welcome ever and made us feel we were not alone! At camp everyone spoke the same language when it comes to inhibitors. The support and compassion we received were unbelievable – something

we had not experienced anywhere else. The team was very attentive, understanding, caring and knowledgeable and made us feel part of the team.



Each educational session at camp was informative and supportive, from how to use Kinesio tape to how to speak with a doctor. Camp provided us with a better understanding of inhibitors while educating us on how to prepare ourselves for the many different situations we may encounter.

The campgrounds were beautiful, a peaceful place to spend time with the family, away from the pressures of daily life. The activities were fun and included amazing experiences with fishing, arts & crafts, aqua therapy, boating, cooking and teen activities. Everything was so wonderful! Meeting other parents and sharing our stories gave us hope there is light at the end of the tunnel. It reminded us there is much more to life than just living with fear.

My takeaway from attending camp was that *I am my son's voice, and I will learn to advocate on his behalf.*

We truly appreciate CHES for their time and willingness to serve community families like ours. I wish all parents who have a child with an inhibitor learn about the After the Shock Inhibitor Camp and have the opportunity to attend.

The quality of experiences offered proved to truly be a blessing – a weight was taken off our shoulders. I know there is much more to understand - we look forward to the next camp to continue to learn and interact with our inhibitor family.

40. Camp SAIL Teen Retreat

Date: September 22–24, 2023

Open to: Teen boys and girls with a bleeding disorder or a sibling in the same household as someone with a bleeding disorder) and 1 accompanying adult.

Ages: 13–18

Location: Frost Valley YMCA; Claryville, NY
Contact: Tyshawn Constantine
212-682-5510

tconstantine@hemophiliany.com

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



NORTH CAROLINA

41. Camp Carefree

Date: July 23–28, 2023

Open to: Boys and girls with a bleeding disorder

Ages: 6–16



41. Carefree Sibling Camp

Date: June 18–23, 2023

Open to: Siblings of children with a bleeding disorder

Ages: 6–16

41. Carefree Well Children Camp

Date: July 16–21, 2023

Open to: Well children with a chronically ill parent

Ages: 6–16

Location: Camp Carefree; Stokesdale, NC
Contact: Mary Kate Young, 336-427-0966
directors@campcarefree.org

Host: Camp Carefree
www.campcarefree.org



42. Victory Junction

Date: June 11–15, 2023

Open to: Boys and girls with bleeding disorders or other serious illnesses

Ages: 6–16

42. Victory Junction Family Weekends

Dates: Sessions March 3–5, March 17–19, March 31–April 2 and April 21–23, 2023

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

43. Camp Rainbow

Date: June 11–17, 2023

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; Arapahoe, NC

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

Host: East Carolina University HTC



OHIO

44. Camp Njoytall

Date: July 23–28, 2023 **Ages:** 7–12

Date: July 16–21, 2023 **Ages:** 12–17

Open to: Current patients of Cincinnati Children's Hospital Medical Center/Cancer and Blood Diseases Institute (By invitation only)

Location: Camp Joy; Clarksville, OH

Contact: Abbie Caplinger, 513-636-9736
cbdi.camp@ccchmc.org

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



Camper Andrew: Well, the thing I enjoy a lot about camp Njoytall would be the kind of atmosphere it has. It is very different compared to a field trip or something I could compare it to. It's something that makes you feel like you're a part of a family since you matter to everyone. Another thing I like a lot are some of the activities they give us to try. Camp distracts me from any stressful events going on in my life giving me a nice break, and it's nice.



45. Flying Horse Farms Family Camp

Dates: Sessions - April 21–23, May 5–7, Oct 13–15, Oct 27–29 and Nov 10–12, 2023

Open to: Children ages 7–15 with a serious medical illness and their immediate family members

45. Flying Horse Farms Hematology/Oncology Camp

Date: June 20–25, 2023

Open to: Boys and girls with a bleeding disorder or oncology patients

Ages: 8–15



45. Flying Horse Farms Siblings Camp

Date: July 31–August 5, 2023

Open to: Siblings of campers with a serious medical illness

Ages: 8–15

45. Flying Horse Farms Ranger Summer Program

Date: June 20–25, 2023

Open to: Teenagers with a bleeding disorder or hematology patients who have aged out of above camps. 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

OKLAHOMA

46. Camp Independence

Date: July 10–14, 2023

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

Ages: 6–18

Location: Camp Bond; Tishomingo, OK

Contact: Leisa MacDougall, 918-605-2579,

leisa@okbleedingdisorders.org

Host: Oklahoma Hemophilia Foundation
918-605-2579, www.okhemophilia.org



OREGON | PACIFIC NORTHWEST

47. Camp Tapawingo

Date: July 30–August 5, 2023

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

Ages: 8–17

Location: Camp Tapawingo; Falls City, OR



48. PNWBD Family Camp

Date: June 22–25, 2023

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

PENNSYLVANIA

49. Camp Dragonfly Forest

Date: August 6–11, 2023

Open to: Boys and girls with a bleeding disorder, sickle cell or asthma

Ages: 7–15 (grades 2–10)

49. Leadership Program

Date: July 30–August 11, 2023

Open to: Teens with a hematology condition or asthma

Ages: 15–17

Location: Camp Speers YMCA
Dingmans Ferry, PA

Contact: 570-828-2329

campers@philaymca.org

Host: Camp Speers YMCA

www.dragonflyforest.org



SOUTH CAROLINA

50. Camp Burnt Gin

Date: June 12-16, 2023
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: Marie Aimone, 803-898-0784

campburntgin@dhec.sc.gov

Host: South Carolina Dept of Health

<https://scdhec.gov/welcome-camp-burnt-gin>



TENNESSEE

51. Camp Freedom

Date: July 8-14, 2023

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 Amanda Wilson

amanda.wilson@thbdf.org

Host: TN Hemophilia and Bleeding

Disorders Foundation, www.thbdf.org



TEXAS

52. Camp Ailhpomeh

Date: July 16-21, 2023

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

info@camp-ailhpomeh.org

Host: Texas Bleeding Disorders Camp

Foundation, www.camp-ailhpomeh.org

www.campjohnmarc.org



Ailhpomeh

53. Camp United Hands

Date: July 10-14, 2023

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.hemolpaso.org>

UTAH

54. Camp Valor

Date: July 31-August 3, 2023

Open to: Children with a bleeding disorder and carriers

Ages: 8-14

54. Valor Sibling Camp

Date: July 31-August 3, 2023

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

Ages: 10-14

Location: Camp Wapiti; Tooele, UT

Contact: Jan Western, 801-484-0325

western@hemophiliautah.org

Host: Utah Hemophilia Foundation

www.hemophiliautah.org

54. Teen Weekend

Date: July 14-16, 2023

Open to: Teens with a bleeding disorder

Ages: 13-19

Location: Best Western Cotton Tree Inn Sandy, UT

Contact: Jan Western, 801-484-0325

western@hemophiliautah.org

Host: Utah Hemophilia Foundation

www.hemophiliautah.org



Valor

Valor



WASHINGTON

56. Camp I-Vy Jr. Family Camp

Date: April 22-23, 2023

Ages: 7-17

Open to: Newly diagnosed/young families with a child age 0-10 in Washington State

Location: Aloft Seattle Redmond Hotel Redmond, WA

Contact: Erica Duke, Camp Director

206-533-1660, general@bdfwa.org

Host: Bleeding Disorder Foundation of

Washington, www.bdfwa.org

WEST VIRGINIA

56. Camp Winaca | Camp HemoVon

Date: June 5-9, 2023

Ages: 7-17

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

Location: Camp Twin Creeks Marlinton, WV

Contact: Kristen Dansereau, 304-641-1413

kdansereau@hemophilia.org, West Virginia

Chapter NHF, 304-212-2616, www.wvnhf.org

Host: West Virginia University HTC



WISCONSIN

57. Camp Klotty Pine

Date: August 7-12, 2023

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

Ages: 7-15

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



VIRGINIA

55. Camp Youngblood

Date: July 16-21, 2023

Open to: Boys and girls with bleeding disorders, siblings, and children of members of the inherited bleeding disorder community residing within the VHF or HACA coverage area.

Ages: 7-17

Location: Camp Holiday Trail Charlottesville, VA

Contact: HACA, 703-712-2266

admin@hacacares.org or VHF

804-740-8643, info@vahemophilia.org

Host: HACA, <https://hacacares.org> and

VHF, <https://vahemophilia.org>

Camp Holiday Trails, 434-977-3781

program@campholidaytrails.org

<https://campholidaytrails.org/campers>



NATIONAL INHIBITOR CAMP

58. After the Shock

Date: June 23-26, 2023

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: nSpiration Foundation

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



NATIONAL INHIBITOR CAMP

59. Oregon Leverage

Date: Sept 10-14, 2023

Open to: Adults with hemophilia and an active inhibitor within 3 years

Ages: 18+

Location: Camp Collins Gresham, OR

Contact: Janet Brewer

jbrewer@ches.education

Host: CHES Foundation

www.ches.education/leverage



NHF'S WASHINGTON DAYS. 2023

MARCH 8 - 10



ADVOCATING ON *Capitol Hill*

Advocates in the bleeding disorders community descended upon our nation's capital March 8-10 to create awareness and press for better legislation against copay accumulator adjusters. This was part of the National Hemophilia Foundation's *Washington Days*, an event which had stalled during COVID and was virtual in 2022. This was the first full return of face-to-face advocacy with Congress in several years.

A top advocacy issue this year involved asking House Members to cosponsor H.R. 830, the *HELP Copays Act*. This act would require all copays (regardless of who contributes) to count towards a person's out-of-pocket maximum. Sixteen states and Puerto Rico currently have laws restricting an insurer's use of a copay accumulator adjuster, a policy where dollars provided by a third-party source (such as a manufacturer drug copay card) do not apply toward a patient's out-of-pocket amount. However, those laws only protect patients on those state's plans. The legislation would offer protection for people on employer-sponsored retirement and health plans, also known as ERISA plans, or large group plans.

Another advocacy issue included asking for continued funding of programs supported through NIH, CDC, and HRSA. NIH (The National Institutes of Health) is currently investigating the rise of inhibitors within the bleeding disorders community; the CDC (Centers for Disease Control and Prevention) provides funding to HTC's (Hemophilia Treatment Centers) for outreach and education; and HRSA (Health Resources and Services Administration) supports ancillary services within the HTC setting like physical therapy and social work. A reduction of these funds would negatively impact the current level of care persons with a bleeding disorder receive and would have consequences in the future as inhibitors and other issues become understudied.

After NHF training and a role-playing exercise to demonstrate the "Do's and Don'ts" of meeting with elected officials, the advocates felt prepared. The Advocacy Day began with a speech from Representative Earl "Buddy" Carter (R-GA-01) who is sponsoring H.R. 830, the bill the group was there to support. With his words of encouragement, the advocates headed out to descend upon the Capitol and meet with elected officials. Several BioMatrix members were there to support the advocacy efforts.

Richard Vogel with Team New Jersey was busy with five Congressional meetings. Starting with a visit to the office of Senator



Team New Jersey with Rep. Robert Menendez's Legislative Assistant, Artin Haghsheenas

Robert Menendez (D-NJ), advocates seamlessly interwove their stories into a cohesive narrative which started with the younger generation, moved on to women with bleeding disorders, and then concluded with those who have reached retirement age. New Jersey was fortunate to have with them for their advocacy Stephanie Lapidow, Executive Director and Amy LaPorta, Office Manager of Hemophilia Association of New Jersey.

Senator Menendez has been very supportive of bleeding disorder issues in the past; he sponsored the *Hemophilia Skilled Nursing Facilities Access Act (H.R. 5952, 116th Congress)*. Team New Jersey is hopeful he will introduce the companion legislation to the *HELP Copays Act* in the Senate, another bipartisan bill.

The team next went to the office of Senator Cory Booker (D-NJ). On the House side, the team met with Representatives Josh Gottheimer (D-NJ 05), Mikie Sherrill (D-NJ-11), and Bonnie Watson-Coleman (D-NJ-12), the latter already a cosponsor of H.R. 830. In their offices, the legislative aides expressed empathy and interest in supporting the cause.



Team New Jersey with Rep. Cory Booker's Legislative Assistant, Nadia Laniyan

For the full Capitol experience, the team was lucky enough to get passes to the House Gallery where they were able to watch democracy in action.

Shelby Smoak attended as an advocate for Virginia. He and Brenda Bordelon, fellow constituent and Chapter Director of Hemophilia Association of the Capitol Area, met with Representative Ben Cline (R-VA-06). The meeting was spirited, and Representative Cline seemed especially interested in H.R. 830 and the CDC funding, the latter of direct importance since he sits on the House Appropriations Committee which is responsible for making funding determinations.



Brenda Bordelon, HACA ED and Shelby Smoak with Rep. Ben Cline (center)



Dave Burgeson, Terry Rice, Felix Jaquez Garcia, Shelby Smoak and Richard Vogel



Felix outside Senator Luján's office



Team New Jersey – ready to hit the Hill with advocacy efforts!



Team Florida with Representative Moskowitz's Legislative Assistant, Harshitha Teppala



Friends meet up on the Hill to advocate! Justin and Reid

Representatives Rob Wittman (R-VA-01) and Morgan Griffith (R-VA-09) made time for staff to hear stories from the community and were asked to support our cause. On the Senate side, the offices of both Virginia Senators Tim Kaine (D-VA) and Mark Warner (D-VA) were receptive to the financial burdens endured by the community as explained by our group. They both took pride in being Senators from the state which was the very first to pass a copay accumulator ban.



New Mexico constituents meet with Claire Wengrod, Legislative Aide (2nd from left) for Senator Martin Heinrich

Felix Jaquez Garcia from New Mexico, teamed up with members from Puerto Rico to support them at their meeting with Representative Jenniffer González-Colón (R) of Puerto Rico. She was very receptive and immediately jumped in to work with the Puerto Rico chapter to protect access to HTCS.



Visiting with Kate Mertens, Legislative Aide (pink jacket) for Senator Ben Lujan

In his meeting with Senator Ben Ray Luján's (D-NM) staff, Felix was optimistic the Senator would sign on as a cosponsor to ban copay accumulators should a bill be introduced. Felix also connected with the staffer from Senator Heinrich's (D-NM) office, who also was willing to support a copay accumulator ban.

In the office of Representative Gabriel Vasquez (D-NM-02), the meeting with his staffer was productive as well as they were in support of the NHF initiatives.

Justin Lindhorst and Dave Burgeson attended from the state of Florida. Team Florida included nine advocates determined to help lawmakers understand the unique needs of the bleeding disorders community. While all five offices visited listened attentively to the concerns, the greatest victory came when meeting with Representative Bill Posey (R-FL-08). Rep. Posey was so inspired by the story shared by his constituents, he agreed on the spot to support H.R. 830 as a cosponsor. Congratulations to advocates Heather and Samantha for so eloquently sharing their story and securing support for the *HELP Copays Act*.

Terry Rice and two other constituents from Maine added their numbers to a larger New England contingency and made numerous congressional visits. Their first home state visit was with Senator Susan Collins (R-ME). Senator Collins listened to the concerns regarding access to affordable lifesaving prescriptions and the effect copay accumulators are having on patients and families living with a chronic illness that must be treated with expensive name brand medications that have no generic alternatives. She was supportive in finding a solution to deal with the accumulator adjustors, which have been crippling the financial and physical health of affected individuals and asked to be kept informed with the progress of H.R. 830 should a Senate companion bill is introduced. As the Ranking Member on the Senate Appropriations Committee, Senator Collins expressed support to continue HRSA and CDC funding of HTCS.

The team also met with Senator Angus King's (I-ME) office. Senator King's legislative assistant shared he has type-1 diabetes and was very aware of the detrimental effects of accumulator adjustors. He felt the Senator would support legislation to address the issue and was confident he would continue to support HTC level funding.

On the House side, the team left information with Representative Jared Golden (D-ME-02) and were able to meet with the legislative health aide to Representative Chellie Pingree (D-ME-01) who cosponsored accumulator adjustor legislation in previous years and would again cosponsor H.R. 830. The aide assured Representative Pingree would support continued HTC funding.

The meetings with the House and Senate offices set in motion the narrative of the burden our bleeding disorders community bears: financially, mentally, and necessarily, physically. To all the advocates from the nearly 50 states who joined the advocacy efforts, we say *thank you!* And to NHF, we also say *thank you* for organizing this energy on the Hill and aiding the community voices to be heard.

As nuanced as everyone's experience is of living with hemophilia, von Willebrand, or another factor deficiency – people with a bleeding disorder endure the costs of medications and the need for the protection H.R. 830 would grant; and even if not seen at an HTC, everyone benefits from the funding and support granted by our national institutions: NIH, CDC, and HRSA.

Real change has come from the efforts of *NHF Washington Days Advocacy* and hopefully, community members who shared their stories this year will impact further positive changes for the bleeding disorders community.



THE COALITION FOR HEMOPHILIA

17TH ANNUAL SYMPOSIUM

BY MICHELLE STIELPER AND TINA MCMULLEN

It really is SO fantastic to “B” together as no event encapsulates this feeling more every year than The Coalition for Hemophilia B Symposium. The 17th Annual Symposium took place March 16th–19th at the Renaissance Orlando at SeaWorld. The Coalition team pulls out all the stops when it comes to making an event feel like a family reunion. New families are embraced from the start and quickly find a home among their fellow hemophilia B community members.

Programming offered something for everyone from the young to the young at heart; Tai Chi classes, massages, medical talks, programming discussing emerging therapies, and men’s and women’s breakout sessions all brought the B community together while

programming for the youngsters and teens was pure magic. New friends were made, and existing friendships were nourished and flourished as the kids got crafty, had their face painted, made origami, hung out in the teen lounge, or went offsite for an airboat ride at Wild Florida Airboats, Gator and Safari Park.

BioMatrix Regional Care Coordinator, Shelia Biljes, led two sewing sessions co-sponsored by Medexus Pharma. Participants - pure beginners and master sewers alike - were welcome to share their personal journeys as they quilted beautiful tote bags as a keepsake of their special time together. Christian Harris, our B community fashion designer extraordinaire and Medexus speaker, discussed his path through the fashion industry, and how he created a line of clothing inspired by his personal journey with a bleeding disorder. The finished B bags Shelia helped participants make were marvelous, and everyone did a sensational job!

The entire event was energy-filled and buzzing with activity, and the BioMatrix booth was a busy beehive. BioMatrix Director of Advocacy and Education, Terry Rice, emceed





rousing rounds of Jeopardy in a battle of points between the guys and the gals. The gals won last year; the guys won this year. Prepare for a 2024 tie breaker!

At the booth we had information about our newly launched Patient Navigation Program, which can provide valuable assistance for families facing insurance obstacles and financial challenges to care. In addition to offering different promo items each day, we held raffles at the booth for a treasure chest gift basket and a beautiful, quilted table runner (thank you, Shelia!) to complement the bee-themed tote bag. Congratulations to our raffle winners!

We cannot forget to tell everyone about the final night party – a fabulous time spent making wonderful memories! The *Bleeders* band, featuring BioMatrix's very own "Doc of Rock" Shelby Smoak, played great tunes and brought the house down during dinner. Dancing and singing ringing throughout the evening in the atrium of the Renaissance. Everyone had a blast spending one last night together before heading home. It's always hard to say goodbye to our dear B's, but here's to another year! Before we know it, we will B together again!



THE COALITION FOR HEMOPHILIA B

NATIONAL NONPROFIT

MISSION



Our mission is to make quality of life the focal point of treatment for people with hemophilia B and their families through education, empowerment, advocacy, and outreach.

BECOME A MEMBER

Membership is **FREE**. Join our Coalition to receive timely information on hemophilia B products, resources, and emerging therapies in our news publications. Apply for patient & travel assistance grants. Learn more about our member benefits!

 hemob.org/subscribe

 Contact@hemob.org

 212-520-8272



BIOMATRIX] ON THE *Move*

Even with the lull of activities following the holidays, our Regional Care Coordinators and Education Team have been out in the bleeding disorders community live and in-person! In 2023, we will continue to offer on-line sessions with a wide and expanding variety of educational topics and fun activities to choose from. Interested in scheduling a session for your group of any size either in-person or virtually? Please contact your Regional Care Coordinator or message the Education Team at: education@biomatrixsprx.com.

MAINE

Rich Vogel

To get into the holiday spirit, there is no better place than the Samoset Resort in Rockport where the Hemophilia Alliance of Maine (HAM) held its **Winterfest** December 2nd-4th, 2022.



Sweater contest!

Following breakfast and before sessions started, there was time to visit and talk with industry and specialty pharmacies. When everyone settled in, Executive Director Tracey Gideon reviewed the accomplishments from the past year and highlighted what's in store for 2023.

Presentations followed and included a genetics counselor who spoke about how the hemophilia gene is passed on, a nutritionist who focused on the importance of balanced meals and a physical therapist who explained the benefits of staying active. After lunch, various rap sessions took place with something for everyone; moms, dads, aging with bleeding disorder and a session for partners and friends.

Due to the weather, most attendees opted for the Paint 'n Sip rather than brave the cold wet rain for a walk on the breakwater. Everyone reconvened for dinner and awards. Santa, an ugly sweater contest and dancing followed. After an industry session and breakfast the next morning, everyone said goodbye and we now look forward to what the new year brings!

Thank you to HAM for hosting this informative annual event!



Enjoying dinner!

PENNSYLVANIA

Tina McMullen

If you are a community member of the Brandywine Valley Hemophilia Foundation and were not at the Mendenhall Inn/Longwood Gardens for the Foundation's **Year End Event**, you truly missed a fantastic occasion! The December 4th, 2022 event began with a lovely buffet lunch including a tasty array of mini desserts. Foundation President Gail Novak gave a warm welcome and a recap of the past year's events. It is essential to know how the event sponsorships and community involvement helped raise funds for scholarships, grants, camp sponsorships, and other foundation programs.

Brandywine Vice President Jennifer Davis and Board Member Dr. Stephen Steinmetz led an educational "Jeopardy" game with prizes for each category. Year after year, Jennifer does a wonderful job coming up with games that the community loves, and Stephen had us all in stitches. To say the crowd had a great time would be an understatement!

The day concluded with each child receiving a gift, door prizes handed out, and attendees heading to Longwood Gardens to stroll around and take in the holiday lights and displays. Thank you to the Brandywine Chapter and to Board Member and Chair Kim Hamstead for organizing this festive holiday affair!



Dallas takes in the sights



Gail, Stephen, Jennifer and Kim were in a festive mood!



Jenn and Matt



Happy Family Fun! Delanie, Chris, Lauren and Patrick



Booth visitors! Walter, Rob, Tara and Arthur visit with Tina McMullen (far left)

DELAWARE

Tina McMullen

Mazzella's Italian Restaurant in Wilmington, Delaware was the venue December 17th, 2022, for Brandywine Valley Hemophilia Foundation's **Education and Cookie Decorating Event** – a lovely afternoon of education, great food, cookie decorating, and socializing!

Armed with a brilliant idea of a cookie decorating activity, Board President Gail Novak approached BioMatrix and Novo Nordisk to ask if we would like to partner as co-sponsors for this event. Of course, we said yes! BioMatrix was thrilled to provide the cookies and decorating supplies. Meanwhile during lunch, Novo Nordisk Mid-Atlantic Senior Community Liaison Dan Bull presented *Stop Waiting to Thrive: 6 Principles of Empowerment*. This interactive program was well received, and many attendees offered their thoughts and life experiences pertaining to the subject.

Cookie decorating followed with icings, gel glazes, sprinkles, sugar candies, candy eyes (a huge hit) and an assortment of homemade cookies. Children and adults got to work, and the imaginations of all were absolutely incredible!

This was such a fun occasion! Thank you, Gail Novak, for coming up with the idea and inviting BioMatrix and Novo Nordisk to co-sponsor this delightful family event!



Matt hams it up for the camera



The smiles say it all!
Becky and Gerald



Arthur is as sweet as a cookie!



Family time - Delanie, Chris, Patrick and Lauren

FLORIDA

John Martinez and Hector Heer

Every new year brings hope and fresh opportunities for our community to continue to grow and connect. And down in Florida, 2023 has begun with a BANG! On January 21st, the Hemophilia Foundation of Greater Florida hosted **Nuevo Año, Nuevo Tú (New Year, New You)**, their first Spanish Language, **Conferència Latino**.

Taking place at the Orlando Renaissance Resort SeaWorld, the conference drew over 100 participants eager to reunite with old friends and acquaintances. After visiting the registration table, attendees were able to browse and connect with representatives staffing the various industry booths set up in the hotel breezeway.

As the first presenter of the day, BioMatrix led our own version of Spanish JeoParody, which got everyone involved in the team-focused learning game. After separating into squads, participants were enthusiastically developing strategies to answer bleeding disorder questions all the while delivering energy that electrified the room. The competition remained high through the final question determining the winning team. Everyone celebrated as the winners were announced.

The conference continued with a men's session where they held an open discussion about the struggles of Latino men in our community. Stories were shared and everyone attending felt heard. A comprehensive list of topics for future conferences was also developed. In a separate women's session, a young lady described her struggles with bleeding symptoms and obtaining a proper diagnosis. An open discussion followed with other women sharing their stories as well. As the day came to a close, a wonderful dinner was served with a backdrop of lively Latino music and spirited dance, a fully enjoyable atmosphere!

BioMatrix has been invited to the HFGF Family Education Program at SeaWorld in June 2023, and we eagerly look forward to participating! BioMatrix is honored to partner with HFGF while continuing to support the bleeding disorders community in Florida.



We have the right answer!



Accepting the team trophy



Tearing up the dance floor with bleeding disorders friends!

OHIO

Shelia Biljes

We were feelin' the love in Northern Ohio as BioMatrix partnered February 10th with Bayer for the monthly **Educational Luncheon** at Tony K's in Berea. Bayer's Wendy Perkins presented Emergency Situations in Hemophilia. The ladies shared their own daunting stories and shared tips on how to navigate the emergency room.

After lunch, we tried a new, fast-paced activity – Plastic Wrap Ball Game! Using plastic wrap, a big ball is made by wrapping and laying little goodies tightly within. Each person tries to quickly unravel layers to get to the goodies while the next person is rolling the dice. Once the next person rolls doubles, the ball is passed to them for a turn at trying to unwrap prizes. We were all on our feet cheering for each other!



Fast Friends, June and Marie



Jen takes a selfie!

As always, the regulars mingled and welcomed the new attendees and found that the time to leave came too soon. Ending the lunch with a Valentine's card exchange, we went our separate ways with smiles on our faces.



The plastic wrap ball grows smaller

VIRGINIA

Terry Stone

Love was in the air and at the Lodge in Colonial Williamsburg as the ladies of the Virginia Hemophilia Foundation gathered for a **Women's Day Out** event February 11th to feed their soul, their tummy and for some well-deserved girl time and pampering.

RCC Michelle Stielper presented *Putting Your Mask on First*, which spoke to caregivers and the importance of self-care. Following the presentation, the ladies participated in a Valentine-themed Fiber Arts Program project where they created a unique garland for their home décor. From farmhouse to vintage valentine, and everything in between, each garland turned out beautifully. What a sweet keepsake to remember this time they shared as they display it through the years.



Crafting together: Alexandria with Michelle Stielper

Lunch and desserts were provided along with relaxing and invigorating hand massages by the Williamsburg Lodge Spa staff. The room was filled with hugs, fun, laughter, chatter, and a true feeling of love and sisterhood. Thanks to VHF for a lovely afternoon in historic Colonial Williamsburg.

FLORIDA

Peggy Klingmann and Marcy Foertsch

BioMatrix and Bayer presented an **Educational Evening** to the hemophilia community in Tampa February 23rd. Held at Seasons 52, the evening began with Bayer's program *Infusion Basics* given by Barbie Arebola, Bayer Hemophilia Community Advocate. Barbie discussed tips for venipuncture, infusion needs, and best practices for successful infusions.

Dr. Shelby Smoak, Advocate and Education Specialist for BioMatrix followed with *Financing a Chronic Illness*, which discussed the shifting burdens of healthcare costs onto patients and offered strategies to help patients maintain access to care through those financial obstacles.

The attendees offered wonderful feedback, asking questions and speaking among themselves afterward as they took the information to heart. The material was very relevant to our bleeding disorder community and the group was eager to learn more and expressed their plans to join us for additional programs throughout the year.

NEW JERSEY

Richard Vogel and Carolina Luna

On a mild New Jersey evening February 23rd, over 40 community members came to Spanish Tavern in Newark for some great food, informative education and to celebrate live, in-person programming. On this evening, BioMatrix partnered with Sanofi.

Laith Elkurd, a Sanofi Community Relations and Education Manager (CoRe) provided a detailed understanding of the importance of factor activity levels and why they matter in a slide presentation titled *Factor Fluency: Higher Factor Activity Levels Matter*. He talked about pharmacokinetics and explored why factor levels are more than just peaks and troughs. This was a prelude to introduce Altuviio, Sanofi's new once-a-week, long-acting FVIII product.

Terry Rice, BioMatrix Director of Advocacy and Education presented *Financing a Chronic Illness*. Terry discussed medical debt and how to navigate financial tools to maintain fiscal integrity and what to watch out for with copay and support programs (aka co-pay adjusters). He spoke about the difference between FSA and HSA plans. The group was very interested in his insight into life and auto insurance which drew many questions and "Wow, I didn't know that. I'll be calling my auto insurance tomorrow." Terry ended his presentation by touching on short- and long-term disability.

Everyone left well fed, well-educated, and happy to have seen old and new friends.

FLORIDA

Marcy Foertsch and Peggy Klingmann

On the evening of March 8th, BioMatrix and CSL Behring hosted an **Evening of Education** coupled with fun, camaraderie and tasty food! The dinner event began with everyone meeting at Cooper's Hawk Winery in Tampa. Rick Starks, Community Advocate for CSL Behring, spoke about his journey with a bleeding disorder. He relayed how fitness and addressing his mental health through martial arts and Tai Chi helped him become successful in life.



Josiah and Mom, Heather



Roger and Lynne



Thumbs up! Emily and Timothy

Following Rick's engaging presentation, BioMatrix led the group in four exciting rounds of *Bleeding Disorders Trivia* assembled by our education team. Did you know that water makes up 90% of our blood, or that factor concentrates were invented in 1967? Well, our audience does, and they found out the fun way: through our trivia game.

The remaining part of our time was spent sharing stories of living with a bleeding disorder and getting to know each other over dinner. It was a great evening of connecting and making our lives better with each other. Thanks to CSL for partnering with us. We look forward to the next time we gather!

OHIO

Shelia Biljes

Talk about dedication! Ladies from Northern Ohio braved the winter storm to spend time together as BioMatrix and Novo Nordisk joined March 10th to host our monthly **Educational Lunch Event** at Westlake's Bonefish Grill. As promised, it was a St. Patrick's Day extravaganza with plenty of green, leprechauns and pots of gold! Before lunch, Judy Doyle, Novo Nordisk Hemophilia Community Liaison, presented



Amber struggles to unwrap a candy Kiss



Shelia and Gloria show their inner Irish charm

Everyone is Irish! Mary, June and Marie

A Focus on Mental Well Being. The importance of this topic led to conversation about coping ideas for mental distress associated with having a family member with a bleeding disorder. Always looking for a laugh, the women took lots of group selfies sporting green mustaches. The women also enjoyed friendly competition with a race to open Hershey Kisses while wearing oven mitts. This joyful group of lovely ladies know how to have fun! With wishes for safe travels home, we headed back out into the snowy weather.



Bionca wins bragging rights!

VIRTUAL!

John Martinez, Gabriela Griffin, Eva Kraemer and Felix Garcia

BioMatrix provided a virtual opportunity March 11th for our Spanish speaking community to connect in an educational and entertaining manner. Families were excited for **Conectando en 2023** (*Connecting in 2023*) for the ever-important function of lifelong learning within the bleeding disorders community.

As participants joined the Zoom, each took a moment to introduce themselves and when everyone settled in, an overview of the national Medicaid Redetermination was discussed. BioMatrix also announced information regarding our *Patient Navigation Program* to assist families with general insurance issues including redetermination.

Following the educational component of our gathering, participants were dazzled by Chef Mike who led an interactive cooking demonstration of a distinct Baja Ceviche recipe, a shrimp salad on a tostada. Utilizing a variety of vegetables, spices and chili sauces Chef Mike created a tantalizing meal that had participants lamenting the lack of "smell-o-vision" on their computers. Chef Mike also created a traditional "agua fresca," a drink mixture of strawberries, lime, mint and sugar that had all on the Zoom meeting feeling quite thirsty. Chef Mike's witty charm added to the flavor of the event. Stay tuned for more programming coming your way!



¡Delicioso!



¡Refrescante!

Upcoming Events

NATIONAL EVENT!

APRIL 13–15, 2023 FLORIDA
'23 Symposium – Past. Present. Future.
Hemophilia Federation of America
<https://www.hemophiliamed.org>
Renaissance Orlando

APRIL 21–23, 2023 VERMONT
Men's Retreat
New England Hemophilia Association
781-326-7645
www.newenglandhemophilia.org
Stratton Mountain Resort; Stratton

MAY 03, 2023 NEW JERSEY
Fireside Chat
Sponsors: BioMatrix and Genentech
Contact: Rich Vogel, 732-991-7373
richard.vogel@biomatrixsprx.com
Bella Napoli; Bloomfield

MAY 6, 2023 TENNESSEE
12th Annual Be A Factor 5k
Tennessee Hemophilia & Bleeding Disorders Foundation
615-900-1486, www.thbdf.org
Loudon High School; Loudon

MAY 9, 2023 OHIO
"Celebrating Moms" Ladies Lunch
Sponsors: BioMatrix and Genentech
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Clementine's Tea Room; Olmsted Falls

MAY 19–21, 2023 DELAWARE
Men's Retreat
Sponsors: Country Boy Fishing, BioMatrix, Octapharma and Medexus
Contact: Richard Vogel, 732-991-7373
richard.vogel@biomatrixsprx.com
Atlantic Sands Hotel, Rehoboth Beach

MAY 23, 2023 PENNSYLVANIA
Educational Program and Dinner
Sponsors: BioMatrix and Takeda
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Bravo Cucina Italiana; Cranberry

MAY 31, 2023 MICHIGAN
Educational Lunch and Sewing Class
Sponsors: BioMatrix and Medexus
Contact: Moe Hoque, 313-258-6059
mohammed.hoque@biomatrixsprx.com
Kalamazoo Event Center

JUNE 1, 2023 OHIO
BioMatrix Ladies Lunch
Sponsors: BioMatrix and Novo Nordisk
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
TGI Fridays;
Brooklyn

JUNE 2-4, 2023 TENNESSEE
THBDF 53rd Annual Meeting
Tennessee Hemophilia & Bleeding Disorders Foundation
615-900-1486, www.thbdf.org
Embassy Suites;
Murfreesboro

JUNE 6, 2023 OHIO
Educational Dinner
Sponsor: BioMatrix, Octapharma and HEMA Biologics
Contact: Rania Salem, 513-470-5500
rania.salem@biomatrixsprx.com
TBA; Columbus

JUNE 7, 2023 OHIO
Educational Dinner
Sponsors: BioMatrix, Octapharma and HEMA Biologics with Northern Ohio Hemophilia Foundation
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
b.a. Sweeties; Cleveland

JUNE 8, 2023 PENNSYLVANIA
Fireside Chat and Dinner
Sponsors: BioMatrix and Genentech
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Juniper Grille;
Cranberry

JUNE 21, 2023 PENNSYLVANIA
EPBDF Annual Meeting
Eastern PA Bleeding Disorder Found.
Contact: Sarah Ross Pilacik, ED
610-770-5215, sarah@epbdf.org
www.hemophiliasupport.org
Sheraton Valley Forge Hotel;
King of Prussia

JUNE 23, 2023 DELAWARE
Blue Rocks Baseball
Sponsors: BioMatrix, Octapharma and Brandywine Valley Hemophilia Found.
Contact: Gail Novak, 302-598-4632
gvannicola@verizon.net
www.brandywinehemophilia.org
Daniel S. Frawley Stadium; Wilmington

JULY 23, 2023 OHIO
Family Education Day and Baseball Game: Cleveland vs Philadelphia
Northern Ohio Hemophilia Foundation
216-834-0051, <https://nohf.org>
Progressive Field; Cleveland

AUGUST 10, 2023 MARYLAND
Sunset Cruise
Sponsors: BioMatrix, Octapharma and Brandywine Valley Hemophilia Found.
Contact: Gail Novak, 302-598-4632
gvannicola@verizon.net
www.brandywinehemophilia.org
M/V Summer Breeze; Chesapeake City

AUGUST 12, 2023 TENNESSEE
17th Annual Pitchin' for Caleb
Tennessee Hemophilia & Bleeding Disorders Foundation
615-900-1486, www.thbdf.org
Centennial Park; Crossville

BIOMATRIX

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.

bit.ly/bd-patientnavigation



Hi Kids! Time for Fun!

Can you spot 9 differences between the photos? Check your answers on page 15! Good luck!



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

Sudoku!

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



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

BIOMATRIX

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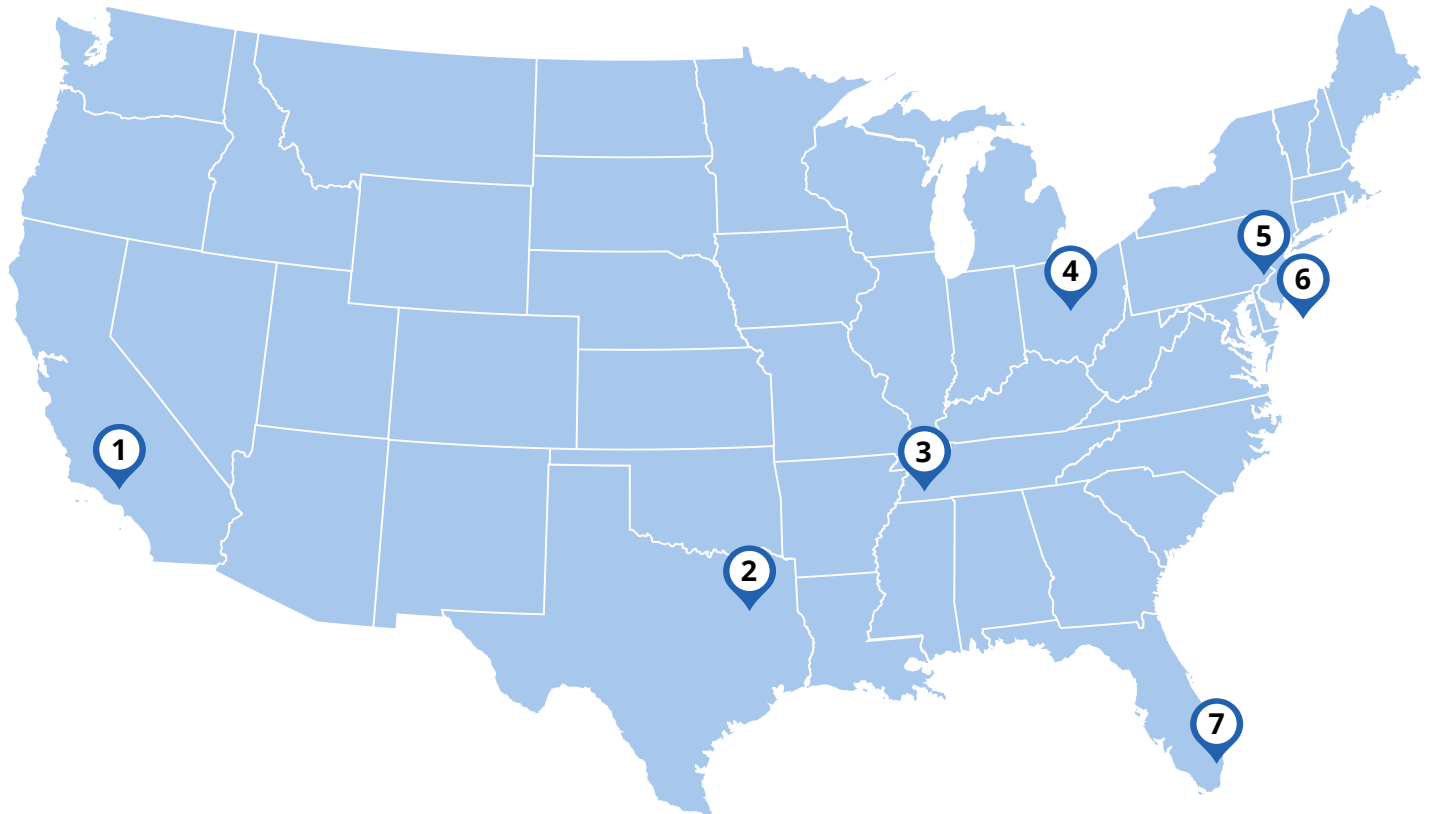
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DEDICATED TO MAKING A DIFFERENCE

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Pharmacy Locations

1. Canoga Park, California
2. Tyler, Texas
3. Bartlett, Tennessee
4. Dublin, Ohio

5. Garnet Valley, Pennsylvania
6. Totowa, New Jersey
7. Plantation, Florida



**BEST AND
BRIGHTEST
COMPANIES**
TO WORK FOR
IN THE NATION
2019, 2020, 2021, 2022