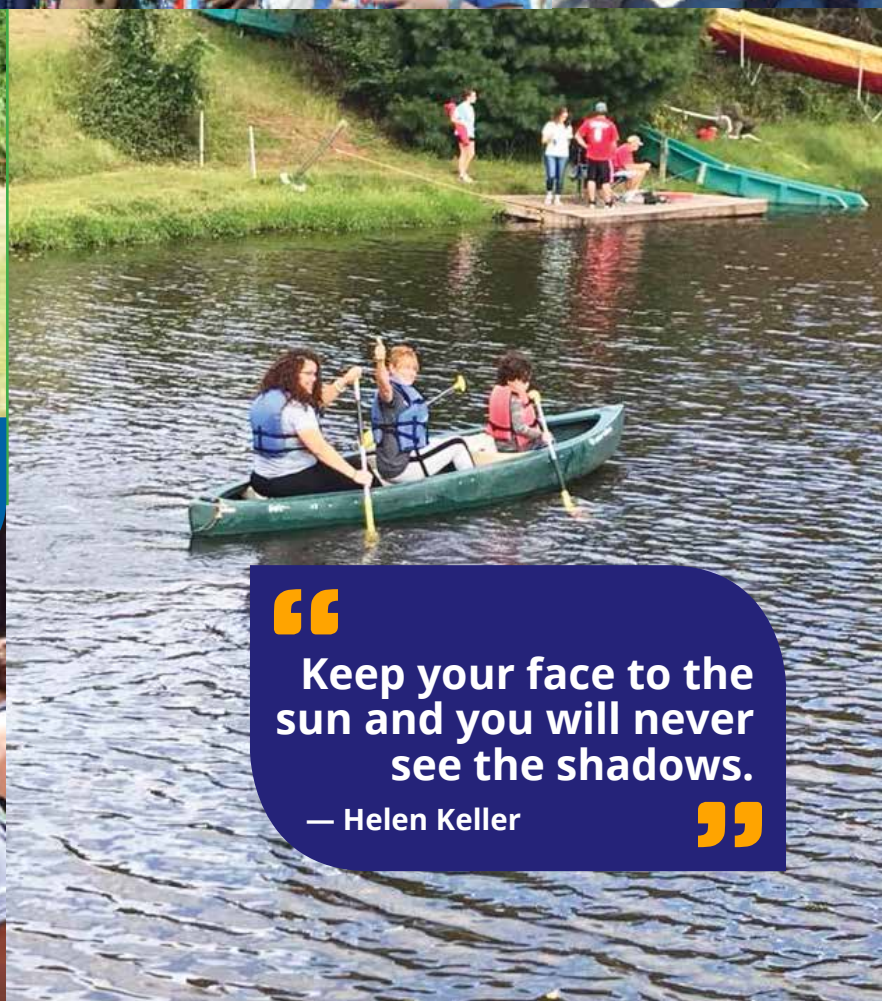
BioMatrix SpRx

NEWS

DEDICATED TO MAKING A DIFFERENCE

SPRING 2019
VOLUME 14 | ISSUE 2



> **Keep your face to the sun and you will never see the shadows.**
>
> **— Helen Keller**

VOLUME 14 | ISSUE 2
SPRING 2019

ABOUT BIOMATRIX SpRx

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 provide an individualized clinical approach to specialty pharmacy services that improve health outcomes and empower patients to live each day to its fullest potential.

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

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.

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

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

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

FINE PRINT

Editor-in-Chief: Maria Santucci Vetter
Editors: Susan Moore and **Justin Lindhorst**

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

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

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A NOTE FROM THE EDITOR

Dear Readers:

As we have for the past 10 years, our spring issue highlights bleeding disorder camps across our great country. In addition to a list of locations, session dates and contact information, you will find heartwarming camp related articles throughout. As adults and children alike attend camp this summer, consider sharing your experiences with our readers. We, at BioMatrix News, welcome your articles and photos!

Lastly, if we missed your local camp, please let us know and we'll be sure to include it next year.

As the days begin to warm this wonderful spring season, turn your faces and your smiles to the sun! Enjoy our special spring issue!

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

Now Accepting Applications for the 2019/20 School Year!

BIOMATRIX MEMORIAL SCHOLARSHIP PROGRAM

APPLY ONLINE!

http/bit.ly/2019-BioMatrix-Scholarship

The BioMatrix family of companies offers six $1500 educational scholarship opportunities to students diagnosed with hemophilia or von Willebrand Disease, and in the case of two of the scholarships, immediate family members may also apply.

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

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

Apply online by visiting:
http://bit.ly/2019-BioMatrix-Scholarship

The application may also be accessed by visiting:
https://matrixhealthgroup.com/scholarships/
or
scholarships@hemophiliafed.org

Joe Holibaugh (1971-2006)
$1500 Scholarship
For MEN and WOMEN with hemophilia AND an Inhibitor

Tim Kennedy (1962-2011)
$1500 Scholarship
For MEN with hemophilia

Millie Gonzalez (1953-2001)
$1500 Scholarship
For WOMEN with hemophilia or von Willebrand Disease

Ron Niederman (1950-1999)
$1500 Scholarship
For MEN with hemophilia or VWD and their immediate family members

Mike Hylton (1945-1998)
$1500 Scholarship
For MEN with hemophilia or VWD and their immediate family members

Mark Coats (1956-1963)
$1500 Scholarship
For MEN and WOMEN with hemophilia

BioMatrix Partners with NHF and Audaire To Improve Care For Patients With Bleeding Disorders

Innovative Digital Platform Increases Transparency and Accountability for Patients and Providers

BioMatrix Specialty Pharmacy is participating in a pilot program with National Hemophilia Foundation (NHF) and Audaire Health, Inc. (Audaire) focused on reducing administrative burden, increasing patient adherence, and lowering healthcare costs. Pilot participants include a small group of select pharmacies and Hemophilia Treatment Centers (HTCs) who will utilize Audaire's innovative data tracking tool demonstrating how the system can reduce cost of care and improve outcomes. Andrew Berg, CEO at Audaire asserts, "We are thrilled to announce our partnership with NHF and BioMatrix. It's a pleasure to find two partners as dedicated to simplifying the patient experience as we are. Our goal was to find pharmacy partners who value transparency, accountability, and driving better patient outcomes. BioMatrix is most definitely that partner."

The Audaire Platform allows patients to instantly record infusions by utilizing their smart phone (at home or on the go) or a small electronic device kept in the home. The HIPAA-compliant system offers treatment reminders and passive logging capabilities that instantly transmit infusions to the patient's care team. This "real time" reporting provides opportunities for early intervention, preventing unnecessary and costly emergency room visits and/or hospitalizations. The Audaire Platform is unique in comparison to other logging devices. The system provides a nearly passive data input solution designed to ease reporting burden for patients and pharmacy providers. By capturing multiple data points including prescription, dispensation, pharmacy/clinic touch points, reported bleeds and other medication administration information, the Audaire Platform provides more robust capabilities than current logging systems. "NHF believes that following prescribed treatments is a key to lowering costs and improving quality of life for people with bleeding disorders," said Val D. Bias, CEO of NHF. "We hope this program can make a real difference in people's lives."

"BioMatrix has a history of leveraging unique digital health technology producing positive outcomes for patients and reducing healthcare costs," BioMatrix Chief Clinical Officer Marc Stranz shares. "This program demonstrates our commitment to providing the tools and support that make managing a chronic condition easier." Data from the pilot will be evaluated to identify the number of meaningful interventions resulting in cost reductions and or avoidance, changes in patient adherence and reporting rates, and improvements in assay and inventory management processes. The program is limited to patients on service with providers participating in the pilot. Initial findings will be shared at relevant industry symposia in 2019.

ABOUT BIOMATRIX

BioMatrix Specialty Pharmacy offers comprehensive, nationwide specialty pharmacy services and digital health technology solutions for patients with chronic, difficult to treat conditions. Our growing family of companies unites leaders in the specialty pharmacy industry to improve health and empower patients to experience a higher quality of life.

ABOUT THE NHF

Established in 1948, National Hemophilia Foundation (NHF) is a national nonprofit patient advocacy organization dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. NHF is a leader in supporting innovative solutions to help people with bleeding disorders and their families manage their disorder and improve their quality of life.

ABOUT AUDAIRE HEALTH

Audaire Health, Inc. is a healthcare technology company that focuses on facilitating transparency and accountability between payer, provider, pharmacy and patient. On the front end, Audaire's patent pending platform allows patients to seamlessly log medication adherence and exacerbations in real time. On the back end, all stakeholders (payers, providers, pharmacies) have real time insight into patient behavior, physician behavior and pharmacy dispensations. The end result is more informed providers, better performing pharmacies, and better patient outcomes.

Why can't I?

Don't you trust me?

I know how to take care of myself!

By Gary McClain, MS, PhD, LMHC

CHRONIC COMMUNICATION AT HOME:
ENCOURAGING KIDS TO BE MORE INDEPENDENT

If you are the parent of a child with a chronic condition, you have probably heard this from your child a few times, if not many. Based on what my clients tell me, knowing how to respond is not easy.

All children, especially teens, want to have a measure of independence. While resolving the conflicts that arise around independence is never easy, this process can be especially challenging for parents of children with bleeding disorders. Children with a chronic condition like a bleeding disorder may be feeling frustrated about their own limitations and responsibilities, as well as guilty about how these limitations affect other family members, which may result in being that much more intent on being independent. They also struggle with being perceived as different.

Parents carry the burden of maintaining responsibility for keeping the home together with all fears and uncertainties that go along with the job. In the midst of these challenges, an elephant is wandering around. An elephant that everybody is stepping around but not talking about. Its name is "fear."

It is only human to have lots of fears around your child's bleeding disorder. After all, part of your job as a parent is to be aware of and actively preventing the "what ifs." Chances are, you've already experienced some of them, or have come close.

Fear can keep you motivated to do everything you need to do to stay on top of your child's care. However, fear can also cause you to hold the reins so tightly that you may risk stifling your child's self-confidence and keep him or her from getting actively involved in their own care.

When kids with bleeding disorders aren't encouraged to develop independence, the result is stress. First,

not making your child a partner in their care leaves it all on you, and you need the help. Second, when kids feel unfairly restricted by their parents, they don't feel normal and can rebel, placing their health at risk and causing tension at home. And third, a young adult trying to make it on their own, and who has not learned to manage their own bleeding disorder with confidence, is at great risk.

You, Your Child, and Independence: Finding the Middle Road

It's not easy for a loving and concerned parent not to want to watch their children like a hawk. And I'm not asking you to take unnecessary risks. However, I do think there is a middle road that can keep you feeling confident your child is adequately protected, while your child can also feel more confident and in control.

Here are some suggestions to help you help your child with a bleeding disorder become more independent:

Face your own fear

It's only human to have fears regarding your child's health. Acknowledge your fear. Don't judge yourself for how you feel or try to make it go away by ignoring it. This is the first step toward coping with your fear.

Encourage your child to express his/her feelings

Start the conversation by simply asking how your child is feeling and offer reassurance that you want to hear whatever it is they want to tell you - even the scary stuff. Give a few extra hugs and supportive words.

While you're at it, let your child know how you're feeling

Make your home a safe place to talk about emotions.

Set boundaries but offer choices

Children with bleeding disorders often feel as if they are bound by limitations, which can contribute to a sense of feeling "less" than other children. Provide your child with a sense of control by allowing for some choices in daily routines, in diet and in self-care. Explain the options and reasonable boundaries, share information, and listen to your child's concerns and preferences. Where possible, come to decisions together. Where appropriate, bring brothers and sisters into these discussions to make them more aware of his or her perspective and to give them an opportunity to make suggestions - don't forget that siblings have needs of their own.

Teach all children to be advocates

Children with bleeding disorders need to learn to speak up for themselves so that teachers, employers and other adults outside the home are aware of any needs and limitations. They also need to learn to deal with the questions and comments that will inevitably come their way, as do their brothers and sisters. Teach your chronically-ill child how to be a self-advocate through role-playing at home.

Consider attending camp together

Some great camping experiences are available for children living with bleeding disorders and their families. At camp, you and your children can learn from the experts on the latest knowledge and treatment of bleeding disorders. Kids can have fun with other kids who are also living with bleeding disorders, while you share experiences with other parents. Camp is also a great opportunity for kids to learn how to be more independent, even to get started on infusing themselves. Camps are held around the country. Attendance is almost always free, and even transportation may be subsidized.

Remember that not everything is a medical issue

Children are human beings, not medical conditions, and communications don't all have to revolve around your child's chronic condition. Many of the issues that come up with kids and teens are developmental.

Remember: The worst thing that can happen is not always the worst thing that can happen

It's easy to get caught in the trap of "catastrophizing," making every situation that comes up feel like an emergency. Take a step back and ask yourself: Am I looking at this through the lens of fear? Is this causing me to create the worst possible scenario that may not even be realistic? When your child pushes back on a limitation, keeping this in mind may help you realize that, well, it might just be time to relax.

Take care of yourself

Families facing a chronic condition like a bleeding disorder are constantly at risk for stress. Make sure your own needs are being met. Take care of your own physical well-being and find a safe place to talk about how you are feeling, even the bad stuff.

Parenting a child with a bleeding disorder can be challenging, but don't let the fear factor keep you from helping your child build confidence and independence. Be patient. Take it one day at a time. Create an atmosphere where all family members communicate with honesty and compassion.

About Gary McClain

Gary McClain, MS, Ph.D., LMHC, is a therapist, patient advocate, and author in New York City, who specializes in working with individuals diagnosed with chronic and catastrophic medical conditions, their caregivers, and professionals. He maintains a website, www.JustGotDiagnosed.com

THE BENEFITS OF KINESIO TAPING: ASK THE *HEMODOC*

By Dr. Michael Zolotnitsky, PT, DPT

Ever rolled your ankle or bumped your knee forcing you to limp around a few days, use a brace, crutches or even a wheelchair?

How about a jammed finger, twisted elbow or wrist bleed that made you avoid using your arm making simple things like shaving seem so challenging? The question lies in what you do when this happens. Do you rest, or do you move?

Growing up with severe hemophilia, I woke to countless mornings not being able to walk because of insidious thigh bleeds. I cautioned myself during basketball to avoid another jammed finger that would inhibit me from closing my hand for days. At a young age, I was unsure of how to manage persistent bleeds aside from my prophylactic treatment. Upon completion of my doctorate in a physical therapy program, I made it my mission to educate the bleeding disorders community.

It began with aquatic physical therapy, alternatives to pain management, safe sports and safe exercises. Then I discovered elastic therapeutic tape, also called kinesiology tape, Kinesio tape, k-tape, or KT, an elastic cotton strip with an acrylic adhesive used to treat pain and disability caused by athletic injuries or other physical disorders. Using this helps control pain and support weak muscles. Two years ago, I delivered my first kinesiology taping presentation teaching individuals with bleeding disorders how to properly apply Kinesio tape. The results? Individuals with joint issues found pain relief and could move more quickly and comfortably.

Kinesio tape provides the support of a brace, but with flexibility to prevent limited range of motion and reduce muscle contractures. It can also facilitate weaker muscles or inhibit tight muscles from firing. One of the most effective taping techniques helps reduce swelling by draining lymphatic fluid or draining synovial fluid.

Without proper instruction, applying Kinesio tape can cause more harm than benefit. For those who are unable to work with me in person, a YouTube channel (hemodoc) is available as an online resource. My goal is for every individual to live life to their fullest and not allow their medical condition to define their ability!

Individuals are not created equal and it's difficult to have a "one size fits all" solution. My advice is to first consult with your physician or hemophilia treatment center, ask about the use of Kinesio taping in your individual case and check out my YouTube videos for guidelines on how to effectively apply Kinesio tape to help alleviate painful joints.

CAMP, TO GO OR NOT TO GO... A MOTHER'S DILEMMA

MY NAME IS TERRY.
MY KID WOULD LOVE CAMP.
I DON'T WANT TO SEND HIM.
KID IS SAD.

DON'T BE LIKE TERRY.

Yes, I am (or was) one of THOSE parents. I feel like the decision to send my sweet little precious angel baby son with severe hemophilia to camp was like a meme.

By Terry Stone

Why should I send him? He's perfectly happy here with me. There's lots of stuff to do here. No one will take care of him like I do. What if he has a bleed or is lonely or scared. I braved and survived family camp with him when he was 7 thinking that's all the camp he'll ever need. He'll be so happy we went as a family. He'll agree with me and not want to go back over the summer by himself. I braved the camp mattresses, camp songs and camp food for him. Now I was sure he would be done with the idea of summer camp. After all, how could I live without him for a week?!

Well, I was wrong, so wrong! For one, those camp mattresses weren't *that* bad. Singing around the flag pole brought back fond memories of my own girl scout camp experiences. And the camp food - it was great!

So why was I dragging my feet? Who needs to grow up here? Why didn't I send my son to camp the first year he was old enough to go? I had no excuse other than it was time for me to grow up. Yes, my worries and insecurities got the better of me. My son was ready. He wanted to go.

Fast forward to 2019, Matt's last year of camp. He has loved every minute of camp from day one when he was 9 years old. He has made lifelong friends and credits his yearly camp pilgrimage as relief from the mundane - enough to give him a true mental break from everyday life that he really needed. Camp helped him be who he is today; a confident, smart and empathetic young man who just finished high school a year early and is ready to create his future.

Off to camp with a few summer camp experiences under his belt.

Camp is somewhat of a rite of passage. It's where kids learn to socialize on their own, much different from the family reunion where you push your child forward as you say, "Honey, go hug your Aunt Joyce." Sure, he loves his Aunt Joyce, but forced socializing is something kids NEVER forget. Don't let that be their "remember when" story at the Thanksgiving dinner table. Trust me, you'll regret it. Remember the meme, don't be like Terry, send your kid to camp!

Beyond this cabin door ghost stories will be told, cabin pranks will be plotted, and lifelong memories will be made!

Matt, the experienced camper, with his happy dad. See ya!

Every year my son came home from camp his voice sounded a little deeper, as he narrated tales of great adventures, recanted best songs sung around the flagpole that never made Billboard's top 100, and told us about new friends, that through the magic of camp have become their own tribe. All are welcome, all are accepted. I watched my son blossom, each year a little wiser, a little more confident, and most importantly, very happy.

Child development professionals recognize camp as profoundly valuable to help children mature emotionally, socially, intellectually, morally and physically. In the bleeding disorder community, there are camps offered by regional chapters across the country and attendance is usually free.

As a parent, we are continually making decisions to care for our children. Camp checks many of the experiences children need in their overall development.

So, as the meme says... don't be like Terry and delay an experience that will feed your child's needs and soul, send them as soon as THEY are ready – they'll let you know! Camp is magical and an experience that will profoundly nurture your child and the lessons and love will last a lifetime.

2019 BLEEDING DISORDER CAMPS ACROSS THE NATION!

For the 11th year running, we continue our tradition of bringing you an extensive directory of national bleeding disorders summer camps! While most camps are for children between 7 and 14 years old, there are many that also include a junior counselor leadership program. Additionally, many weekend camps are open to the entire family!

Summertime is quickly approaching, so it's time to develop your camp game plan. Use this list to identify a camp in your area and don't miss out on the fun! We try to include every camp across the nation, but there is the possibility we may have missed one or two. Please let us know of any camp that should be included and we'll be sure to add it next year. If you are having trouble finding a camp in your area, check with your local chapter, hemophilia treatment center or a BioMatrix Regional Care Coordinator and we will help you locate a camp!

1. Alabama Camp Clot Not

June 15–20, 2019 Ages: 6–18
Open to: Boys and girls with a bleeding disorder, carriers
Location: Children's Harbor Mariner's Adventure Camp; Alexander City, AL
Contact: Amanda Jennings, Consumer Relations Manager, 334-478-7822
amandajennings525@gmail.com
Hemophilia and Bleeding Disorders of Alabama, Inc., www.hbda.us

1. Alabama Camp Harvest Family

October 25–27, 2019 Ages: All ages
Open to: Active HBDA families with a parent or child with a bleeding disorder
Location: Children's Harbor – Harbor Lodge; Alexander City, AL
Contact: Amanda Jennings, Consumer Relations Manager, 334-478-7822
amandajennings525@gmail.com
Hemophilia and Bleeding Disorders of Alabama, Inc., www.hbda.us

2. Alaska Camp Frozen Chosen

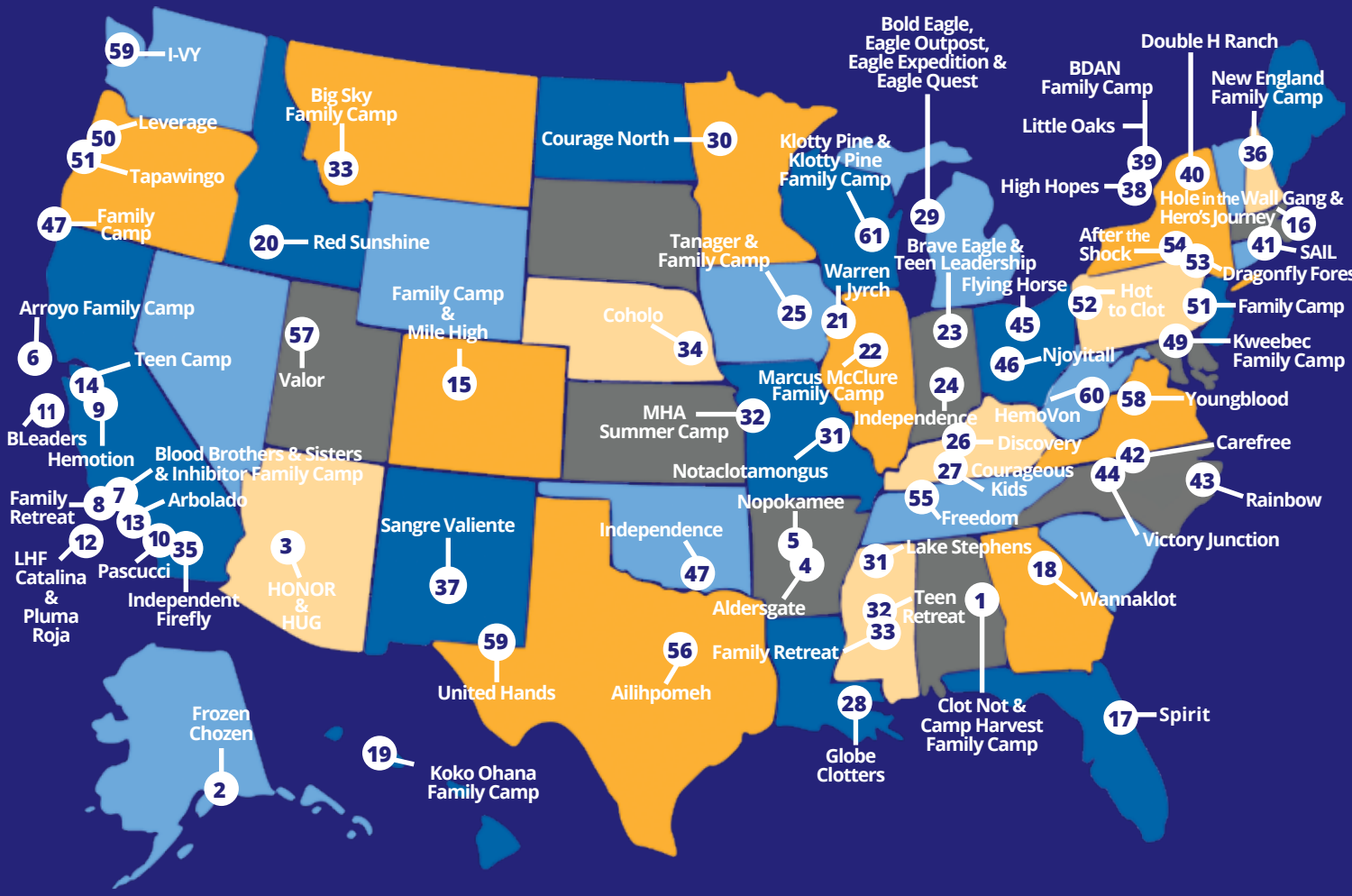
June 3–8, 2019 Ages: 7–18
Open to: Boys and girls with a bleeding disorder, siblings welcome based on availability. Theme-based: *Camp 907–Focus on Alaska!*
Location: Wasilla, AK
Contact: John Palmatier, ED
907-212-6711; 907-343-9232 or
Michelle Palmatier, Camp Director
907-229-6017, Alaska Hemophilia Association and Bleeding Disorder Center of Alaska, alaskahemo@gmail.com

3. Arizona Camp HONOR

June 12–17, 2019
Ages: 8–17
Open to: Boys and girls with a bleeding disorder, siblings and children of an affected parent
Location: Prescott Pines; Prescott, AZ
Contact: Vickie Parra, 602-955-3947
vickie@arizonahemophilia.org
Arizona Hemophilia Association
www.arizonahemophilia.org

3. Arizona Camp HUG

October 18–20, 2019
Ages: All ages
Open to: AZ families with a parent or child with a bleeding disorder
Location: Prescott Pines; Prescott, AZ
Contact: Vickie Parra, 602-955-3947
vickie@arizonahemophilia.org
Arizona Hemophilia Association
www.arizonahemophilia.org



4. Arkansas Camp Aldersgate

CAMP ALDERSGATE
COMMON GROUND FOR EXTRAORDINARY PEOPLE

July 28–Aug. 2, 2019 Ages: 6–18
Open to: Boys and girls with a bleeding disorder, carriers and siblings
Location: Camp Aldersgate
Little Rock, AR
Contact: Kara Burge, 501-364-6662
burgekb@archildrens.org
Arkansas Center for Bleeding Disorders
www.campaldersgate.net

5. Arkansas Camp Nopokamee

July 21–25, 2019 Ages: 8–18
Theme: *Medieval*
Open to: Boys and girls with a bleeding disorder, carriers and siblings (space permitting)

Location: C.A. Vines Arkansas 4H Center
Little Rock, AR
Contact: Laura Barnhart, 501-428-5754
toliveasruth@yahoo.com
Hemophilia Foundation of Arkansas
arkhemofoundation.org

6. California Camp Arroyo Family Camp

January 18–20, 2019 Ages: All ages
Open to: All family members affected by a bleeding disorder
Location: Camp Arroyo; Livermore, CA
Contact: Bryan Anderson, 510-658-3324
bryan.anderson@hemofoundation.org
Hemophilia Foundation of Northern California, www.hemofoundation.org

7. California Camp Blood Brothers and Sisters

July 23–28, 2019 Ages: 7–16
Open to: Boys and girls with a bleeding disorder
Leader-in-Training, **Ages:** 17–18
Volunteers **Ages:** 19+
Aug. 9–13, 2019–Sibling Camp **Ages:** 7–16
Open to: Siblings of boys and girls with a bleeding disorder
Location: The Painted Turtle Camp
Lake Hughes, CA
Contact: Cynthia Chavez, 626-765-6656
cynthia@hemosocal.org
Hemophilia Foundation of Southern CA
www.hemosocal.org

7. California Inhibitor Family Camp

Sept. 27–30, 2019
Open to: Families of a child age 6–19 managing an active or previously-active inhibitor within 1 year. Those who have tolerized greater than a year will be accepted, space permitting.
Location: The Painted Turtle Camp
Lake Hughes, CA
Contact: CHES, 781-878-8561
info@ches.education
www.ches.education/inhibitor-family-camp

Inhibitor Family Camp
CHES
INSPIRATION THROUGH EDUCATION

8. California Hemophilia Found. of Southern CA Retreat

June 7–9, 2019
Open to: Anyone with a bleeding disorder and their immediate family
Location: Pali Mountain Retreat
Running Springs, CA
Contact: Michelle Kim Esq., ED
626-765-6656, michelle@hemosocal.org
Hemophilia Foundation of Southern California, www.hemosocal.org

9. California Camp Hemotion
June 16–22, 2019 Ages: 7–14
Open to: Boys and girls with a bleeding disorder, siblings
Jr. and Assist. Counselors – **Ages:** 15–20
Location: Coarsegold, CA
Contact: Bryan Anderson, 510-658-3324
bryan.anderson@hemofoundation.org
Hemophilia Foundation of Northern California, www.hemofoundation.org

10. California Camp Pascucci
June 23–28, 2019 Ages: 7–14
Open to: Boys and girls with a bleeding disorder; siblings and carriers, space permitting
Jr. Counselors – **Ages:** 16–17
Counselors/General Staff–**Ages:** 18+
Location: YMCA Camp Oakes
Big Bear, CA
Contact: Nooshin Kosar, ED
619-325-3570
info@hasdc.org
Hemophilia Assoc. of San Diego County
www.hasdc.org

CAMP PASCUCCI

11. California HFNC BLeaders Annual Retreat
July 26–28, 2019 Ages: 13–18
Open to: Boys and girls with a bleeding disorder, siblings
Location: Bay Area, CA
Contact: Bryan Anderson, 510-658-3324
bryan.anderson@hemofoundation.org
Hemophilia Foundation of Northern CA
www.hemofoundation.org

12. California LHF Catalina Camp
April 12–14, 2019
Open to: Latino bleeding disorders families
Location: Campus by the Sea Avalon, CA
Contact: Jorge Catedral, 626-427-2735
jacatedral@gmail.com
www.hemolatino.org

12. California LHF Camp Pluma Roja Kids Camp
June 10–14, 2019 Ages: 7–16
Open to: Latino boys and girls with a bleeding disorder
Location: Catalina, CA
Contact: Jorge Catedral, 626-427-2735
jacatedral@gmail.com
www.hemolatino.org

L H F

13. California LHF Camp Arbolado
Sept. 13-15, 2019 Ages: 7-16
Open to: Latino bleeding disorders families
Location: YMCA Camp Arbolado
Angelus Oaks, CA
Contact: Jorge Catedral, 626-427-2735
jacatedral@gmail.com
www.hemolatino.org

14. California Teen Camp
July 6–10, 2019 Ages: 14–17
Open to: Boys and girls with a bleeding disorder; siblings and carriers space permitting
General Staff – **Ages:** 21+
Location: South Fork – American River; Lotus, CA
Contact: Nooshin Kosar, ED
619-325-3570, info@hasdc.org
Hemophilia Association of San Diego County, www.hasdc.org/events

15. Colorado Family Camp
May 4–5, 2019
Open to: Adults with bleeding disorders and their families; Families with a child with a bleeding disorder too young for camp, and young adults
Location: Rocky Mountain Village at Easter Seals
Empire, CO
Contact: Kelly Ryan, Camp Director
646-499-0684, kryan@hemophilia.org
Colorado Chapter of the NHF
www.cohemo.org

COLORADO CHAPTER NATIONAL HEMOPHILIA FOUNDATION
FAMILY C•A•M•P

15. Colorado Mile High Camp
July 14–19, 2019
Ages: 7–18
Open to: Boys and girls with a bleeding disorder, siblings
Location: Rocky Mountain Village at Easter Seals; Empire, CO
Contact: Kelly Ryan
Camp Director, 646-499-0684
kryan@hemophilia.org
Colorado Chapter of the NHF
www.cohemo.org

mile high summer C • A • M • P

16. Connecticut The Hole in the Wall Gang Camp
General Sessions:
June 14–20, June 23–29, July 12–18, July 21–27, Aug. 9–15, 2019
Ages: 7–15
Open to: Boys and girls with bleeding disorders and other serious illnesses
August 18–24, 2019 – Sibling Session
Open to: Siblings of campers attending the summer program or Hero's Journey
Location: Ashford, CT
Contact: 860-429-3444
admissions@holeinthewallgang.org
www.holeinthewallgang.org

THE HOLE IN THE WALL GANG CAMP
a seriousfun camp

16. Connecticut The Hole in the Wall Gang Hero's Journey Program
Adventure-based wilderness search and rescue program in the woods of CT
General Sessions: June 14–20, June 23–29, July 2–8, July 12–18, and July 21–27, 2019
Ages: 16–18
Open to: Adolescents with bleeding disorders and other serious illnesses
July 31–August 6, 2019 – Sibling Session
For siblings of campers attending the summer camp program or who have attended Hero's Journey
Ages: 16–18
Location: Ashford, CT
Contact: Greg Yeager, 860-429-3444 x226,
greg.yeager@holeinthewallgang.org
www.holeinthewallgang.org

THE HOLE IN THE WALL GANG CAMP
a seriousfun camp

17. Florida Camp Spirit

July 19–24, 2019 Ages: 7–16
Open to: Boys and girls with a bleeding disorder
Sept. 20–22, 2019 – Family Retreat Weekend
Open to: Families with a bleeding disorder
Location: Camp Boggy Creek; Eustis, FL
Contact: Fran Haynes, ED, 800-293-6527
info@hemophiliaflorida.org
Hemophilia Foundation of Greater FL
www.hemophiliaflorida.org

18. Georgia Camp Wannaklot

July 21–26, 2019
Ages: 7–12: Junior Camp
Ages: 13–17: Teen Camp
Open to: Boys and girls with a bleeding disorder
Location: Rutledge, GA
Contact: Kim Williams
770-518-8272, kawilliams@hog.org or
Liz Hernandez, 770-518-8272, lhernandez@hog.org
Hemophilia of Georgia, www.hog.org

19. Hawaii Camp Koko Ohana Family Camp

June 7–9, 2019 Ages: All ages
Open to: Families or individuals with a bleeding disorder
Location: Camp Moluke'ia
Waialua, HI
Contact: Donald "Ziggy" Douglas, ED
808-782-5506, ddouglas@hemophilia.org
Hawaii Chapter-NHF, hawaiinhf.org

20. Idaho Camp Red Sunrise

June 19–20, 2019 Teen Camp **Ages:** 13–18
Open to: Boys and girls with a bleeding disorder, siblings
June 20–22, 2019 – Family Camp
Open to: Families affected by a bleeding disorder
Location: Sawtooth Methodist Camp; Fairfield, ID
Contact: Marlyn Walker, 208-344-4476
mwalker@hemophilia.org
ID Chapter of NHF, www.idahoblood.org

THE VERY BEST PLACE TO BE!

By Colby S.

I'm 14 years old and live with severe hemophilia A. I go to Camp Tampawingo in Falls City, Oregon. I've been going to camp since I was 10 years old. At camp, we do all kinds of cool things – kayaking, gaga pit, swimming, arts & crafts, the blob, campfire, capture the flag, fishing, river walk, movie night and archery. The river walk is my favorite activity because on a hot day you are in the water hanging out with friends, climbing over rocks, exploring and having lots of fun.

To me, camp means having the best time of your life – that truly is what it's all about. I develop friendships, learn how to work with others, discover team building, and at last year's camp, I had a cool counselor who taught me some excellent magic tricks with cards.

My advice to someone who has never been to camp is to put yourself out there and make friends. It's a place where you can relax, have a great time with others and become close with those people. You get out of your comfort zone and meet people who live with a bleeding disorder too. Camp changes every year, the activities become more fun and it's an awesome time. It's one of the best places to be. Just go to camp and find out yourself! It's fun!

MAGICAL MEMORIES

By Patsy Gibson

My 10-year-old son, Kaleb, has been attending Camp Boggy Creek since he was 8. He's made close friendships with kids at camp who understand having a medical condition sometimes limits them in doing some things other kids their age typically can. I believe this understanding has helped Kaleb not just cope with his bleeding disorder, but to thrive.

At camp, he has been taken under the wings of older campers. He has made friendships that will most likely last his whole life. I keep in touch with their parents on Facebook and at local events, while he talks with his friends through video games.

Magical memories are made during his week at summer camp as well as during bleeding disorder family retreats. He gets to participate in all sorts of activities, and I have peace of mind knowing a hematologist and medical staff are on hand to keep him safe. Dedicated volunteers make sure my son and the other campers are engaged with one another and help create one of the best weeks of each summer for all the kids. He's enjoyed being able to do things with kids like fishing, woodworking and playing basketball while at camp. Also, surprisingly to me, he expressed enjoying family retreat talent shows and shared that they have similar shows at camp. Camp has really helped him to break out of his comfort zone and try new things like dancing (now I can't get him to stop!)

I am so thankful to Hemophilia Foundation of Greater Florida for giving my son the opportunity to participate in camp and for my family to spend quality time together at the retreats. These experiences help us to find hope and happiness in our situation.

21. Illinois Camp Warren Jyrch

August 4–10, 2019 Ages: 7–17
Open to: Boys and girls with a bleeding disorder or diagnosed carrier status
Location: Camp Benson
Mt. Carroll, IL
Contact: Lily Schwartz
312-427-1495, lschwartz@bdai.org
Bleeding Disorders Alliance Illinois
www.bdai.org

22. Illinois Marcus McClure Family Camp

June TBD, 2019
Open to: Families of children ages 6–10 with a bleeding disorder,who have not yet attended summer camp
Location: Timber Pointe Outdoor Center
Hudson, IL
Contact: Lily Schwartz, 312-427-1495
lschwartz@bdai.org
Bleeding Disorders Alliance Illinois
www.bdai.org

23. Indiana Camp Brave Eagle

June 9–14, 2019
Ages: 7–16
Open to: Boys and girls with a bleeding disorder, siblings, carriers
Location: North Webster, IN
Contact: Angel Couch, Community Outreach Coordinator, 800-241-2873, acouch@hoii.org
www.campbraveeagle.org
Hemophilia of Indiana, Inc., www.hoii.org

24. Indiana Camp Independence

June 23–28, 2019
Ages: 8-18
Open to: Boys and girls with hematological disorders
Location: Bradford Woods; Martinsville, IN
Contact: Marri Hampton
317-948-3111, rileyhemnurse@iuhealth.org
www.bradwoods.org/campriley/index.html

25. Iowa Bleeding Disorder Summer Camp at Camp Tanager

June 23–28, 2019 Ages: 6–17
Open to: Boys and girls with a bleeding disorder and one guest per family
Location: Camp Tananger; Mount Vernon, IA
Contact: Hanna Beary, Hemophilia of Iowa, Inc.
319-393-4007, hemophiliaofiowa.org or
Hemophilia Nurses at 319-356-4277
Iowa Hemophilia and Thrombosis Center

25. Iowa Family Camp

August 3-4, 2019
Open to: All Iowa bleeding disorders community members
Location: Camp Tananger
Mount Vernon, IA
Contact: Hannah Beary, 319-393-4007
Hemophilia of Iowa, Inc.,
hemophiliaofiowa.org or
Michelle Krantz, RN, 319-356-2890
michelle-krantz@uiowa.edu
or Karla Watkinson, RN, 319-356-4271
karla-watkinson@uiowa.edu
IA Hemophilia and Thrombosis Center

26. Kentucky Camp Discovery

July 14–18, 2019 Ages: 7–15
Jr. Counselors in Training – **Ages:** 16-17
Open to: Boys and girls with a bleeding disorder, siblings (space permitting)
Location: Cedar Ridge Camp
Louisville, KY
Contact: Ursela Kamala, ED
502-456-3233
Kentucky Hemophilia Foundation
info@kyhemo.org
www.kyhemo.org

27. Kentucky Center for Courageous Kids

June 9–13, 2019
Ages: 7–16
Open to: Boys and girls with bleeding disorders (hemophilia, vWD, ITP, SCA)
Location: The Center for Courageous Kids; Scottsville, KY
Contact: 270-618-2900
bchandler@courageouskids.org
www.courageouskids.org

28. Louisiana Camp GlobeClotters

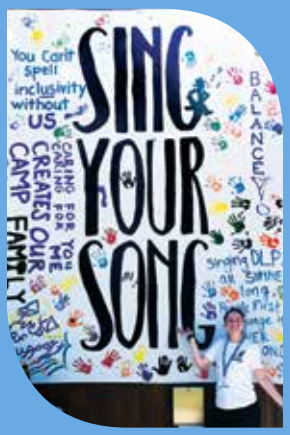
May 26–30, 2019
Ages: 7–16
Open to: Boys and girls with a bleeding disorder and siblings (space permitting)
Location:
Camp Istrouma
Baton Rouge, LA
Contact: Erica Simpson, 225-291-1675
director@lahemo.org or
Becky Doucet, outreach@lahemo.org

CELEBRATING 40 YEARS OF MEMORIES PAST... AND YET TO COME!

CAMP BLOOD BROTHERS AND SISTERS

From July 23-28, 2019, Hemophilia Foundation of Southern California (HFSC) will sponsor 120 youth ages 7-16 with bleeding disorders to attend its 40th Annual Camp Blood Brothers and Sisters held at The Painted Turtle in Lake Hughes, California

Campers will have a blast participating in many activities including archery, fishing, horseback riding, wood shop, ropes course with zipline, talent show and of course, the famous Silly Olympics! HFSC will award Big Stick Awards and a new category called "All-Star Access Award" for those learning to give themselves a subcutaneous injection! We also welcome our Leaders in Training for teens ages 17-18 to become leaders in our community. We look forward to an amazing week!



For more information, contact:
Cynthia Chavez, 626-765-6656
cynthia@hemosocal.org or
Michelle Kim, Esq., Executive Director
626-765-6656, michelle@hemosocal.org
www.hemosocal.org

29. Michigan Camp Bold Eagle
June 30–July 6, 2019 Ages: 13–17
July 14–18, 2019 – Ages: 6-9
July 20–26, 2019 – Ages: 10–12
Open to: Boys and girls with a bleeding disorder
Location: Holton, MI

Michigan Eagle Outpost Traveling Camp
August 4–10, 2019 Ages: 14–15
Open to: Boys and girls with a bleeding disorder
Location: Throughout Michigan

Michigan Eagle Expedition
July 30–August 7, 2019 Ages: 16+
Open to: Youth from MI, IN, OH
Location: Northern California

Michigan Eagle Quest Backpacking Excursion
June 8–14, 2019 Ages: 18+
Location: North Manitou Island in Lake Michigan

Contact: Tim Wicks, 734-961-3507, twicks@hfmich.org or
Anthony Stevens, 734-961-3510 astevens@hfmich.org
Hemophilia Foundation of Michigan
www.hfmich.org

30. Minnesota Camp Courage North
July 7–12, 2019 Ages: 7–17
Open to: Boys and girls with a bleeding disorder
Location: Camp Courage North Lake George, MN
Contact: Jim Paist, ED, 651-406-8655 info@hfmd.org
Hemophilia Foundation of Minnesota/ Dakotas, www.hfmd.org

31. Missouri Camp Notaclotamongus
June 5–8, 2019
Ages: 7–17
Open to: Boys and girls with a bleeding disorder
Location: Camp Wyman; Eureka, MO
Contact: Bridget Tyrey, 314-482-5973 info@gatewayhemophilia.org
www.gatewayhemophilia.org

32. Missouri Camp Wilderness
July 29–Aug. 2, 2019 Ages: 7–17
Open to: Boys and girls with a bleeding disorder, carriers
Location: Lake Doniphan Retreat Center Excelsior Springs, MO
Contact: Luke Saulsberry, Camp Director 816-315-7308 mhacampdirector@gmail.com
Midwest Hemophilia Association
www.midwesthemophilia.org

33. Montana/Wyoming Big Sky Family Camp
June 14–16, 2019
Open to: Families or caregivers managing a bleeding disorder
Location: Fairmont Hot Springs; Anaconda, MT
Contact: Brad Benne, ED 406-586-4050 brad@rmhbda.org
Rocky Mountain Hemophilia a Bleeding Disorders Assoc., www.rmhbda.org

34. Nebraska Camp CoHoLo Children's Cancer Camps of Nebraska
July 21–24, 2019
Ages: 6–11
July 24–28, 2019
Ages: 12–17
Open to: Boys and girls impacted by cancer or blood disorders
Location: Eastern NE 4H Center Gretna, NE
Contact: Berta Ackerson, Camp Director 402-707-2154 director@campcoholo.com
www.campcoholo.com

WHAT I LIKE ABOUT CAMP

By Alexander Newcomb

What I like about camp is making new friends and looking forward to seeing those same people year after year. There are a lot of activities at camp like relay racing, fishing, boating, biking and sometimes we also go off campus. Once we went to a bowling alley, and another time to a zipline park.

Each year, the theme at camp is different and the activities match the theme. We've had a medieval theme and a Harry Potter theme and a few others. For the medieval theme, we had catapults to knock down the other team's blocks and had to hit multiple targets using water balloon slingshots. Since I had a lot of fun at camp, I would like to be a Counselor-In-Training so I can help give other campers the best experience possible.

IN THE MIDDLE OF NOWHERE, BUT NOT ALONE

By Shelby Smoak

Syrus O. lives in the middle of nowhere: Castine, Maine. With a population of under fifteen hundred, excitement here involves watching snow banks accumulate in the winter and, so the town website claims, walking Main Street in the summer. But outside of his hemophilia, Syrus is not much different from other boys in other more populated places. He loves playing sports and video games, and spending time with his friends. He cherishes learning, observing, analyzing and just plain "existing" so he says. He also loves bleeding disorders camp.

Syrus has been attending Family Camp at Lake Winnipesaukee in New Hampshire since he was a toddler. Though his memory is vague, thoughts of that time and camp conjure up "very positive" feelings, especially of a particular playground he always adored. In fact, Syrus' act of fervent rebellion was sneaking away from his mother just to go swing on that swing. Camp has always been a welcoming and inclusive space for him. Even when he was little, there was always something for him to do and a place for him to be.

While his struggles with a bleeding disorder have presented some unique challenges in other aspects of his life, camp, Syrus says, hasn't done anything to exacerbate that. If anything, it's done the opposite and given him a place to vent about life issues related to having a bleeding disorder, a thing that his non-bleeding disorder friends "just wouldn't get."

He is also thankful he can seek advice from those who've experienced similar problems. For Syrus "camp is an amazing support network."

Syrus describes the camp community as "welcoming and warm" and "full of entertaining, intelligent, charismatic, empathetic, respectful, authentic, resilient individuals." Camp is home. The community has helped him develop as an individual to the point that, without camp, he feels he wouldn't be so considerate, so empathetic, so caring and, so understanding. "I look forward to camp every year. Some of my best friends come from that community," he enthuses.

From camp, he's learned "what it feels like to be unconditionally accepted and loved." Camp is, Syrus says, "my family." He encourages all his blood brothers and sisters to join him at camp. "You'll definitely get something out of it, and so will everybody else in the process of meeting you," he says. He adds, "Please - be part of the family. We'd love to have you!" So if Family Camp at Lake Winnipesaukee is your area camp, sign up! Go! And say "hey" to Syrus when you get there!

35. Nevada Camp Independent Firefly

June 11–15, 2019 Ages: 7–17
Leaders in Training **Ages:** 16–17
Open to: Boys and girls living in NV with a bleeding disorder, siblings
Location: Camp Whittle; Big Bear, CA
Contact: Maureen Salazar-Magana
702-564-4368
mmagana@hemophilia.org
Nevada Chapter of NHF
www.hfnv.org

36. New England Hemophilia Association Annual Family Camp

June 26–29, 2019
Open to: Families with a bleeding disorder living in New England
Location: Geneva Point Center; Moultonborough, NH
Contact: Heather Case, Program Director, 781-326-7645
hcase@newenglandhemophilia.org
New England Hemophilia Association
www.newenglandhemophilia.org

37. New Mexico Camp Sangre Valiente

June 3–8, 2019
Ages: 7–17
Open to: Children with a bleeding disorder and siblings
Location: Fort Lone Tree Capitan, NM
Contact: Alfonso Jaramillo, 505-901-7315
alfonso.jaramillo@sangredeoro.org
Sangre de Oro, Inc., Bleeding Disorders Foundation of New Mexico
www.sangredeoro.org

38. New York Camp High Hopes

July 28–Aug. 3, 2019
Ages: 7–17
Open to: Boys with a bleeding disorder, male siblings and male family members of women with a bleeding disorder
Location: Lowville, NY
Contact: Matt Palmeri, Camp Co-Director
607-644-6969, badlands056@gmail.com
www.camphighhopes.org

39. New York Camp Little Oak

July 28–August 3, 2019 Ages: 7–17
Open to: Girls with a bleeding disorder, carriers, sisters of boys with a bleeding disorder
Location: Aldersgate Camp and Retreat Center; Grieg, NY
Contact: Hannah Russell, Camp Director
425-770-1801
hannah.m.russell.p@gmail.com

NACCHO 2019!

The 17th annual NACCHO conference, funded by grants from Pfizer and Sanofi and hosted by the Arizona Hemophilia Association, was held January 17-20 in Phoenix, Arizona. This conference brought together camp directors and counselors from bleeding disorder camps across the country to learn from experts, share with one another and collaborate on new programs and activities for camp. We continued our efforts by inviting attendees from across the globe to participate in this conference. More than 160 attendees came from across America, Canada Turkey, Romania, Puerto Rico, Nigeria, Netherlands, Nicaragua, Egypt, Australia, and India.

Directors participated in a pre-conference which included sessions on Policies & Procedures, Outside Grants, Bullying and How to be a Better Facilitator. GutMonkey, a camp community favorite led by Patrick Torrey, opened the general conference where participants built *Fortlandia*! This year's theme was RISE UP (Resilient, Independent, Strong, Engaged, Unique, Potential). Attendees shared how they RISE UP at camp and encouraged other staff and campers to RISE UP. Our global participants presented *World at Camp* that allowed attendees to see what camps look like in other countries. The conference agenda was full of sessions with information that participants will be able to take back and use in the upcoming camp season!

To learn more about NACCHO, contact Vickie Parra at 602-955-3947, vickie@arizonahemophilia.org or visit NACCHO's Facebook page at: www.facebook.com/nacchoconference/

FORTLANDIA!

39. New York BDAN Family Camp

October 12-14, 2019
Open to: Families and Adults with a bleeding disorder
Location: Aldersgate Camp and Retreat Center; Greig, NY
Contact: Bob Graham, 315-396-2944
bobgraham04@msn.com, www.bdaninc.org

40. New York Double H Ranch

June 22–27, June 30–July 5, July 8–13, July 17–22, July 25–30, August 2–7, August 10–15, 2019 Ages: 6–16
Open to: Boys and girls with a bleeding disorder
Location: Lake Luzerne, NY
Contact: Tara Bogucki, 518-696-5676 x222
tbogucki@doublehranch.org, www.doublehranch.org

41. New York Camp SAIL (Self Advocacy, Independence & Leadership)

March 29–31, 2019 Ages: 13–18
Open to: Boys and girls with a bleeding disorder, carriers and siblings in New York State. One parent mandatory for each attendee under 18.

Location: Camp Quinipet
Shelter Island Heights, NY
Contact: Tyshawn Constantine, Program Director
212-682-5510
tconstantine@hemophiliany.com
Hemophilia Association of New York
www.hemophiliany.com

42. North Carolina Camp Carefree

July 21–27, 2019 Ages: 6–16
Open to: Boys and girls with a bleeding disorder
June 16–22, 2019 Ages: 6–16
Open to: Well children with a chronically ill sibling
July 14–20, 2019 Ages: 6–16
Open to: Well children with a chronically ill parent
Location: Stokesdale, NC
Contact: Rhonda Rodenbough
336-427-0966
directors@campcarefree.org
www.campcarefree.org

THAT BIT OF MAGIC

By Matt Delaney

I always tell people if someone ever has something good to say about me, that it comes from the experiences I've had at Double H Ranch. When I went to my first summer camp at age 8, I would never have guessed the impact it would have on my life.

While the days of camp were just seen as "fun" for me as a kid, I didn't really start appreciating the more nuanced effects it had on me until I was in my teenage years. Growing up with von Willebrand Disease and Glanzmann thrombasthenia, both rare bleeding disorders, I always had to tell my friends "no" or "that's probably not a good idea." It left me with a feeling that I was different or an outcast, which, in a kid's younger years is one of the most terrifying things possible.

Towards the end of my time as a camper, I knew I wanted to give back to camp for all that it gave me. Camp was like a secret little utopia where everyone just "got it." Being kind, treating others the way you want to be treated, and cherishing people for their strengths are things that don't always happen in the real world. Camp provides people with experiences that make you a better person. Some of my best friends, who I consider more like family, are from Double H. Our common ideas of kindness and acceptance make us all better humans. It's hard to describe Double H to the average person because it's impossible to describe something that made you who you are and who you strive to be.

To anyone considering Double H, I can't say anything but yes! You are family at camp and already belong, even before you sign up for the summer. It's a place that not only provides safe fun but provides what I call an "emotional fill up" of love and kindness that will last you all throughout the year until the next summer. Once you go that first time, you will never stop wanting to go back to experience that bit of magic!

43. North Carolina Camp Rainbow

June 9–15, 2019 Ages: 6–18
Must have completed Kindergarten.
Open to: Boys and girls with a bleeding disorder treated by the Brody School of Medicine at East Carolina University
Location: Camp Don-Lee Neuse River near Arapahoe, NC
Contact: Jacquelyn Sauls, MS, CCLS
252-744-3304, saulsj@ecu.edu

44. North Carolina Victory Junction

June 23–27, 2019 Ages: 6–16
Open to: Boys and girls with bleeding disorders or other serious illnesses
Location: Victory Junction; Randleman, NC
Contact: Camper Recruiter, Casey Roche,
croche@victoryjunction.org
www.victoryjunction.org

45. Ohio Flying Horse Farms

July 16–21, July 27–August 1, 2019
Ages: 8–15
Open to: Hematology and Oncology patients
Aug. 5–10, 2019 – Sibling Camp
Ages: 8–15 – **Open to:** Siblings of diagnosed children
Nov. 8–10, 2019 – Adolescent and young adult camp – **Ages:** 16–19
Open to: Adolescent and young adult Hematology and Oncology patients
Sept. 13–15, Sept. 27–29, Oct. 11–13, Oct. 26–28, Oct. 25–27 – Family Camp
Location: Mt. Gilead, OH
Contact: Olivia Miller, 419-751-7077
olivia@flyinghorsefarms.org
www.flyinghorsefarms.org

46. Ohio Camp Njoyitall

July 14–19, 2019 Ages: 12–16
July 21–26, 2019 Ages: 7–12
Open to: Current patients of the Cancer and Blood Diseases Institute at Cincinnati Children's Hospital Medical Center
Location: Camp Joy; Clarksville, OH
Contact: Kelly Range, Camp Director or Heather Binning, Admin. Assistant
513-636-NJOY (6569)
cbdi.camp@cchmc.org
www.cincinnatichildrens.org/service/c/cancer-blood/patients/camp

Summer Camp

By Andrew D.

Hi Everyone! I am 16 years old and in the 10th grade. I was diagnosed with severe hemophilia B at 9 months old. I love staying active, playing Fortnite, and hanging out with my friends. I've been going to bleeding disorders camp since I was 7 years old. I can remember the first time I went to camp – I felt free from worries and was the happiest I've ever been in my life!

At Hole in the Wall Gang Camp, I'm not alone! There are so many people there who love me! It's the best place on Earth! All my friends are there, and we get to play and are free to do whatever we want! Be kids! Be free! Be loved and cared for by the most amazing people! I always wonder why people in the real world can't act like the people at camp. Life would be easier for everyone.

My favorite part about camp is being with my friends who also have a bleeding disorder. The food is delicious too – yummy, I must say! Zipline and archery are my favorite activities. Camp helped me overcome many obstacles. I believe in myself and have more confidence. I know I will always have camp. Camp is not just camp. Camp is HOME. Camp is friends. Camp is family. It's a place where all my troubles go away. It's a place where I can rest my head. It's peace. It's so beautiful. It's comforting. It's where I feel I was born again. I'm a new me! I'm better, I'm stronger, I'm more caring and more understanding. I'm a kinder person because of camp. I can do anything I really want to do because camp made me believe. Believe in myself, my dreams, and my future.

I'm going out to the big world and be all I can be! I'm going to be me – Andrew! I take camp with me wherever I go because camp lives in me. Paul Newman and everyone at camp will always have a special place in my heart. Camp will always be here for me and all my journeys ahead. I couldn't do this on my own before, but I have camp with me now and forever!

47. Oklahoma Camp Independence

June 24–28, 2019 Ages: 6–18
Open to: Boys and girls with a bleeding disorder, siblings

Location: Camp Bond; Tishomingo, OK
Contact: Nathan Holloway, Camp Program Director Co-Chair
918-804-8184, nathan@okhemophilia.org
Lindsey Russell, Camp Admin Director Co-Chair, 479-306-8115
russell@okhemophilia.org
Kathleen Montgomery, ED
918-889-5166, www.okhemophilia.org
www.campindependence.org

48. Oregon Camp Tapawingo

Aug. 4–9, 2019 Ages: 8–15
Open to: Boys and girls with a bleeding disorder, siblings
Counselors-in-Training – **Ages:** 16–17
Location: Falls City, OR
Contact: Madonna McGuire Smith
541-753-0730
madonna@hemophiliaoregon.org
Hemophilia Foundation of Oregon
hemophiliaoregon.org

49. Oregon Family Camp

June 21-24, 2019 Ages: All ages
Open to: All families living with bleeding disorders
Location: Camp Myrtlewood
Myrtle Point, OR
Contact: Madonna McGuire Smith
541-753-0730
madonna@hemophiliaoregon.org
Hemophilia Foundation of Oregon
hemophiliaoregon.org

50. Oregon Leverage

Sept. 4–8, 2019
Open to: Adults ages 18+ with hemophilia and an active inhibitor within 3 years. Guests are not permitted.
Location: Camp Collins Gresham, OR
Contact: CHES, 781-878-8561
info@ches.education
www.ches.education/leverage

51. Eastern Pennsylvania Hemophilia Found. Family Camp

Sept. 20–22, 2019
Ages: All ages
Open to: Children with bleeding disorders in Eastern PA and their families
Location:
Camp Kweebec
Schwenksville, PA
Contact: Lindsay Frei
484-445-4282
lindsayf@hemophiliasupport.org
Eastern Pennsylvania Hemophilia Foundation, www.hemophiliasupport.org

52. Pennsylvania Camp Hot–To–Clot

August 4–10, 2019 Ages: 7–17
Leaders-in-Training – **Ages:** 15–17
Open to: Boys and girls with a bleeding disorder, siblings
Location: YMCA Camp Kon-O-Kwee
Fombell, PA
Contact: Katherine Bush or Kathaleen Schnur
412-209-7344
camph2c@itxm.org
www.hcwp.net
Hemophilia Center of Western PA
www.wpcnhf.org

53. Pennsylvania Camp Dragonfly Forest

July 21–26, 2019
Ages: 7–14
Open to:
Boys and girls with a bleeding disorder

July 14–19, July 21–26, 2019 Ages: 15–16
Teen Leadership Program
Location: YMCA Camp Speers in Pocono Mountains
Dingmans Ferry, PA
Contact:
Ryan Tressler
717-877-3817
ryan.tressler@philaymca.org
dragonflyforest@philaymca.org
www.dragonflyforest.org

A NEW PERSPECTIVE

By Mike Dague

I'm 43 and live with severe factor 8 hemophilia. I first attended bleeding disorders camp in 1983 when I was 7 years old. That's all it took – from then on, throughout the year, camp was all I thought about. I looked forward to being around others with hemophilia and to spend time with my blood brothers and sisters! As role models, some of the counselors made a profound difference in my life. I was able to see older men with hemophilia having "normal" adult lives.

1988

At camp, we enjoyed great food, swimming, canoeing, fishing, campfires and arts and crafts. But more than that, I formed bonds with friends that I still have to this day. My years at camp gave me a sense of self-confidence and taught me real-life skills. Being around others, kids and adults, living with a bleeding disorder, I saw people enjoying their lives, being physically active without fear. So I thought to myself, I can do that too. It gave me a new perspective. I grew more self-reliant after each year of camp.

Camp is almost a necessity for a young person with hemophilia as well as for the parents. Having a child at camp gives parents an opportunity to relax and be less protective. The child has the chance to be away from home, can understand he or she is normal, that they can get hurt and still get up and live.

I would say to a young camper or parent of a young camper is to relax, your child will make new friends, have plenty of fun and will come home excited about their week. The camp experience will stay with him or her for a lifetime.

54. Pennsylvania After the Shock (An Inhibitor Family Camp)

June 21–24, 2019
Open to: Families with a child (ages 0-18) managing a currently active or previously active inhibitor within 1 year. Those who have tolerized greater than a year will be accepted space permitting.
Location:
Camp Zeke
Lakewood, PA
Contact: CHES
781-878-8561
info@ches.education
www.ches.education/after-the-shock

55. Tennessee Camp Freedom

July 13–19, 2019 Ages: 7–15
Leaders–in–Training **Ages:** 16–17
Open to: Boys and girls with a bleeding disorder and carriers
Location: Brandon Springs Group Center Dover, TN
Contact: TN Hemophilia and Bleeding Disorders Found., 615-900-1486, www.thbdf.org

56. Texas Camp Ailihpomeh

July 14–19, 2019 Ages: 7–14
Leadership Program – **Ages:** 15–17
Open to: Boys with bleeding disorders
Location: Camp John Marc Meridian, TX
Contact: info@camp-ailihpomeh.org
www.camp-ailihpomeh.org

56. Texas Camp United Hands

July 8–13, 2019 Ages: 7–17
Open to: Boys and girls affected by a bleeding disorder, siblings
Location: Black River Learning Center; Carlsbad, NM
Contact: Yolanda Ortiz, 915-859-6688 or 915-204-4013, yortiz.hoep@gmail.com
Hemophilia Outreach El Paso
www.hemoelp.org

CHES INHIBITOR CAMPS

CHES understands at a personal level the obstacles and challenges that coincide with raising a child with inhibitors or being a young adult with an inhibitor. We strive to equip patients and families with valuable tools to navigate through everything from hospital stays to home infusion. Our programs are packed full of education and support. We offer nationwide camp programs to provide individuals, parents/caregivers, and families with hemophilia and inhibitors the support they truly need. Because of the generosity of its funders, all CHES programs are provided free of charge to qualifying participants including travel expenses, lodging and more.

AFTER THE SHOCK

Open to families of children with inhibitors of all ages, this program was created specifically to focus on newly diagnosed families who need extra care and guidance. This year's program will highlight *Pain Management, Chronic Illness, and the Family Unit.*

June 21–24, 2019
Camp Zeke
Lakewood, PA

LEVERAGE

The *Ultimate Inhibitor Adventure* is co-facilitated with GutMonkey, who has over a decade of experience in the bleeding disorder camping and adventure education fields. LEVERAGE delivers fun, interactive and challenging training for young adults Ages 18+ from around the USA living with an inhibitor.

September 4–8, 2019
Camp Collins; Gresham, OR

INHIBITOR FAMILY CAMP

Restricted to families with a diagnosed child ages 6-18, this program will zero in on *Pain Management and the Psycho-social Effects of Chronic Illness.* The entire, immediate family can play, learn, and grow while building stronger relationships.

September 27-30, 2019
The Painted Turtle
Lake Hughes, CA

To register, visit: www.CHES.education
For more information, call or email: 781-878-8561, info@ches.education

My Second Home

By Xander M.

My first experience at camp was nerve-wracking as I wondered if everyone would like me or if everyone would *be* like me. At the same time, I was also excited because I got to see how hemophilia affects others and how others have dealt with having it. The first couple times of going to camp, I made friends fairly easily and it was even easier knowing I didn't have to explain my bleeding disorder if I got hurt.

During this time, I learned how to how to talk to people and be social by myself without my mom or my older sisters to go to if situations got too stressful, and I'm happy for that. I was lucky because I got to see my sisters, Skylar and Taylor, have fun at camp for years before I was old enough to go. I had met their camp friends, so it was cool that some people already knew who I was. As I get older, I still seek to learn from new campers or maybe an older one.

I can understand the feeling of going to camp for the first time. So whenever I hear a new camper is coming, I get excited to teach them what I have learned from others when I was younger. I can be the person to encourage them to come to camp and be the friendly face when they arrive for the first time.

It is not only the campers and CITs (counselors-in-training) who I learn from, but it is also the counselors who basically become your older siblings. They are even my close friends outside of camp. I can't wait to get more involved in camp as a counselor when I get older! When I'm at camp, it's like going to a second home where I never feel homesick. I feel like I am right where I should be. Everyone at camp is part of my family, my BLOOD family!

57. Utah Camp Valor

August 5–8, 2019 Ages: 8–13
Children with a bleeding disorder, carriers
Ages: 10–11 Siblings of children with a bleeding disorder and children of affected parents
Location: Camp Wapiti
Tooele, UT
Contact: Jan Western, 801-484-0325
western@hemophiliautah.org
Utah Hemophilia Foundation
www.hemophiliautah.org

58. Virginia Camp Youngblood

July 7–12, 2019 Ages: 7–17
Open to: Children with inherited bleeding disorders, siblings and children of inherited bleeding disorder community members in VA and the Capital area.
Location: Camp Holiday Trails
Charlottesville, VA
Contact: Chris Shifflett, Family Coordinator
434-977-3781
campisgood@campholidaytrails.org
804-740-8643, vahemophilia.org

59. Washington Camp I–Vy

July 22–26, 2019 Ages: 7–15
Open to: Children affected by a bleeding disorder, siblings (space permitting)
Location: Camp Huston
Gold Bar, WA
Contact: Erica Duke, Camp Director
206-533-1660
general@bdfwa.org
Bleeding Disorder Foundation of Washington, www.bdfwa.org

60. West Virginia Camp HemoVon

June 10–15, 2019 Ages: 7–16
Open to: Boys and girls with a bleeding disorder
Location: Camp
Twin Creeks; Marlinton, WV
Contact: Anita Graham, 304-293-1205
agraham@hsc.wvu.edu
West Virginia University Medical Center

61. Wisconsin Camp Klotty Pine

August 5–10, 2019 Ages: 7–15
Age exceptions made on a case-by-case basis
Leader-In-training Program
Ages: 16–18
Open to: Boys and girls with a bleeding disorder, diagnosed carriers
Location: Campbellsport, WI
Contact: Karin Koppen, 414-937-6782
kkoppen@glhf.org
Great Lakes Hemophilia Foundation
www.glhf.org

61. Wisconsin Camp Klotty Pine Family Camp

October 4–6, 2019
Open to: Families of children with a bleeding disorder looking to learn more about the summer camp experiences or simply wanting to enjoy family camp.
Location: Campbellsport, WI
Contact: Karin Koppen, 414-937-6782
kkoppen@glhf.org
Great Lakes Hemophilia Foundation
www.glhf.org

SAY "I DO" TO CAMP!

Perhaps nobody is more grateful for bleeding disorders camps than Christy Tignor. After a history of bruising and nose bleeds, she was initially diagnosed with Type 1 vWD at age 9 and thereafter began her lifelong love affair with camp, and one camper in particular.

By Shelby Smoak

Following her diagnosis, Christy's hematologist connected her with the Kentucky Hemophilia Foundation, and to Land Between the Lakes Camp where at 10 years old, she attended for the first time. Land Between the Lakes was 4 hours from her home and had campers from Kentucky and Tennessee. Even though Christy admits she grew quite homesick that first year of camp, as the week wore on, fun took over so that by the end Christy was eager to go back the next year, and the next, and the next. And then there was David.

Since very few girls attended Christy's camp in the 1980s, boys could be found a-plenty. And one particular boy from Tennessee, David, took a special interest in Christy by giving her piggyback rides when someone ran off with her shoes or trying to snap her picture. So smitten was David with Christy that, as he himself admits, he even dragged a hair dryer and hair spray to camp to style his hair to look good for her. That's right: David's essential survival camp list included a sleeping bag, pillow, toothpaste, snacks, hairdryer and hairspray. The girls were able to ditch the hair dryer and hairspray for the week, but not David!

The budding romance soon flourished at Land Between the Lakes. Each year Christy yearned for camp where her excitement to see David and hang out with him as much as she could, grew into a full-blown crush. Then, at 22, Christy confessed her crush to a mutual friend and her concern that David did not feel the same way. She felt he had grown distant and aloof, and perhaps failed to reciprocate her feelings. Luckily their friend was a born matchmaker and quickly told David of Christy's crush, which spurred David into action. He called her. And their first conversation outside of camp topped at over 4 hours and concluded with plans for their first date. And it seems David really did have Christy at "Hello," because she claims that after that first call she knew she was going to marry him.

The next year they got engaged and the year after they tied the knot! And where better to sow the seeds of matrimony than, well, at camp! The day after camp was over, they married at Brandon Spring Group Camp, the spot where, 14 years earlier they had met. Two years after marriage, Christy and David welcomed their daughter, Lily, into the world. After Lily's birth, Christy found out that she actually has a platelet disorder rather than vWD. Their son Zachary soon followed.

"Even though I do not attend camp any longer, it still has a very special place in my heart," Christy says. "Not only did I meet the love of my life there, but I also made lifelong friends." Their daughter now carries on the tradition.

Each year, Lily looks forward to camp where she is a counselor alongside her father. And each year, the happy couple can only wonder what camp may give their daughter. Could a camp romance repeat itself? Is there something special in the water at Land Between the Lakes? Of course, Christy and David think so!

THE LAND OF LOVE

David Tignor, or "Tigger" as he is more fondly known, has been going to camp since 1981 when he was 6 years old. Today he is, well, an adult. Do the math. And his camp experience is extensive. He attended as a camper until age 17, when he transitioned to a junior counselor.

For the past 26 years, David has served at numerous camps in Tennessee and many other states as a counselor, Leader-in-Training Director and Activities Director, among other roles. David has brought his counselor experiences to hemophilia family camps in Maine, Montana, and Alaska as well as widely known camps like Tapawingo in Oregon and Hot-to-Clot in Pennsylvania. However, Tennessee's Land Between the Lakes will always hold a special place in David's heart because that is where he met Christy.

They met in 1985 when both were 10. Since there were very few girls at camp, David admits "they got a lot of attention from the fellas," but luckily, he — armed with a hair dryer and hair spray, camp essentials in his mind —was able to woo young Christy. That the two could also swim helped as they were allowed into the pool's deep end where David had exclusive conversation rights to Christy without interruption from other campers. Each year, they returned to their home states— David in Tennessee, Christy in Kentucky—their secret crush burned until summer returned.

In later years both serving as teen counselors and when in their early 20s, Christy was just about ready to give up since she felt Tigger was no longer interested in her. However, a mutual friend had the good sense to intervene. David made the call to set the situation straight and the rest is history; they dated, David proposed, they married at their beloved camp Land Between the Lakes, and soon their family grew. First came Lily, now 17 and a camp counselor having mild hemophilia herself, and Zachary, now 11; a loving son with special needs and a joy to all who know him.

For David camp is more than the educational and learning experiences. It moves beyond swimming, fishing, canoeing, archery, arts & crafts, or carnivals, tournaments, pool parties, and talent shows, or even Gold Rush, an event where campers find "fake" gold that they can spend at the general store and pizza parlor. The real gold for David is the ability to be around children and adults who also live with a bleeding disorder. "It opens doors to lifetime friendships," David says, and "demonstrates that living with a bleeding disorder is just a normal part of our lives."

Camp was extremely important to David as a child, but even as an adult, camp thrills him and he grows equally excited to go. "Camp Freedom opened doors to some very amazing experiences and learning opportunities," he says. "To this day, I still get butterflies when I drive onto the camp ground at Brandon Spring Group Center at Land Between the Lakes where I get to see my second family every year!"

A group of seriously good looking, interesting, intelligent and awe-inspiring people met in Florida for what can best be described as a huge family reunion! Boasting an intrinsic bond of being affected by hemophilia B, over 550 people gathered at the Renaissance Orlando at SeaWorld hotel for *The Coalition for Hemophilia B 2019 Annual Symposium* and basked in welcoming Florida sunshine from Thursday, March 14 thru Sunday, March 17. Everyone was ready for the warm climate, camaraderie, education, and healing.

THE COALITION FOR HEMOPHILIA B ANNUAL SYMPOSIUM

By Shelby Smoak

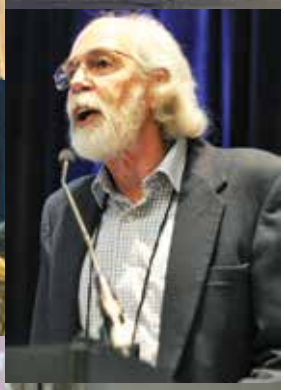
The event began with a *Family Breakfast*, followed by a *Meet & Greet* before lunch was served. The afternoon continued with intimate men's and women's sessions. The day ended with a welcoming dinner featuring a tease-performance from hemophilia B pickup cover band, The Bleeders.

The next morning opened with breakfast and an inspiring talk on *High Factor Levels and Your PK*, by Dr. Chris Walsh, HTC hematologist at New York's Mt. Sinai - a friend and frequent presenter at Coalition events.

Additional presentations throughout the day included an informative presentation on *The 411 on Medical Marijuana* with Dr. Michelle Witkop, *Financial Tools to Maintain Medicaid and Avoid Poverty* with attorney Donnie Akers, *Kinesiology Taping* with Dr. Michael Zolotnitsky, and *Mental Health First Aid* with Debbie de la Riva, LPC.

Friday's highlight, however, was the screening of *Bombardier Blood* where the provided Kleenex was well used to catch the tears brought on by this powerful and inspiring documentary by hemophilia B patient and mountain climber, Chris Bombardier. After the film ended and the clapping and cheering died down, Chris ran a Q&A, offering further insight into his struggles and achievements of being the first person with hemophilia to climb the highest mountain peaks of each of the 7 continents, including Mt. Everest. He also made history for holding the world record of highest elevation hemophilia infusion!

Saturday continued with another fantastic lineup of valuable sessions including *High Factor Levels and Your PK* with Dr. Lisa Boggio, *Hemophilia B Carrier Bleeding*



with Dr. Robert Sidonio, and *How to Work Out and Not Get Hurt* by Dr. Michael Zolotnitsky. The afternoon continued with more education on *Employment Rights* with Donnie Akers, a drumming program titled *What's so Funny?* with Robert Friedman, and an *Infusion Session* with Hope Woodcock-Ross, RN, BSN accompanied by Elizabeth VanSant with *Music Therapy*.

As with Friday, Saturday concluded with a bang! This time, the closing dinner brought all attendees together to continue sharing their experiences of living with or caring for someone with a bleeding disorder. Then *The Bleeders* hit the stage. Audience members describe the band as smokin', killer, with a young boy of 5 professing he was inspired to learn guitar. While he may be too young for a full-fledged Strat, his parents were convinced to consider a ukulele! It was a win for sure! The Bleeders blazed through renditions of Van Morrison's "Brown Eyed Girl," Aretha Franklin's "Chain of Fools," The Cars "Let the Good Times Roll," R.E.M.'s "The One I Love," and Modern English's "I Melt With You."

Sunday morning saw an end to an incredible weekend of education and friendship. BioMatrix was thrilled to have been a supporter of this event and we look forward to participating in the future!

The Coalition has grown immensely these past few years and the programming just gets better and better. A special THANK YOU to the Coalition's VP, Kim Phelan. She, her dedicated employees and devoted volunteers make organizing an event of this caliber look easy!

BioMatrix ON THE MOVE

VIRGINIA

Terry Stone and Michelle Stielper

Each year over Martin Luther King weekend The Virginia Hemophilia Foundation and the Hemophilia Association of the Capital Area conduct their state-wide advocacy days known as ***Richmond Days***. There is not a better or more profound time to come together as a community and call on elected officials to discuss legislative issues that matter. Proclaimed as a national day of service, MLK Day offers a great opportunity to march on Richmond to share our stories and advocate for change.

The event started Sunday afternoon, January 20th, with a briefing and advocacy practice for those who were participating for the first time. After dinner and fellowship at the Omni hotel, the group was ready to advocate after a good night's sleep and hearty breakfast.

These two Virginia chapters have impressive and committed advocacy chairs. Leaders Ann Kendall (HACA) and Krista Davidson (VHF), helped prepare the team for their visits on Monday. There to give insight and education was the chapter's long-time consultant Becky Bower-Lanier.

VA's hard working advocacy chairs, Ann Kendall and Krista Davidson.

On the docket:
HB 2515 & SB 1596 - Help for patients to afford out-of-pocket medical expenses. Require the insurance payer to count any payment made by them or a third party on their behalf to be credited to out-of-pocket due.

HB 2126 - Patients need transparency and consistency. This bill does not prohibit step therapy (fail first), though it puts in place an effective exception process that will assist patients with getting approval for their drug per doctor's orders.

Congratulations to the Virginia chapters for your strong advocacy efforts. You are consistent and impressive as you make our voices loud and proud.

NORTH CAROLINA

Xaviette Pointer-Kincy

Hemophilia of North Carolina (HNC) hosted its 12th annual ***Hearts for Hemophilia Casino Night*** at the Durham Convention Center. Arriving dressed to impress, 96 members were ready to play blackjack, craps, roulette, and Texas Hold'em Poker. Each player was presented with game chips and encouraged to compete in Vegas-style games to earn tickets for the live auction.

Xaviette Pointer-Kincy with Charlene Cowell, HNC Executive Director.

A silent auction was also held, allowing guests an opportunity to win bids on popular events, gift baskets, and other interesting and sought-after items. Several local businesses donated items in support of the live and silent auctions. This popular event is one of HNC's largest fundraisers of the year. Congratulations to HNC for hosting another successful event!

FLORIDA

Peggy Klingmann

BioMatrix and Octapharma came together January 29th to host a ***Ladies' Night Out*** at Painting with a Twist in Brandon. Attended by lovely women with bleeding disorders in the Tampa and surrounding areas, Sara Cesera, Patient Educator for Octapharma treated them to an inspirational and informative talk followed by a light meal. Then it was time to create a one-of-a-kind interpretation of a classic Monet painting. Thank you to our partners for this delightful evening!

MARYLAND

Terry Stone and Michelle Stielper

There was more excitement February 2nd than just groundhog Punxsutawney Phil not seeing his shadow! Groundhog Day was the kickoff to 2019 for the Hemophilia Foundation of Maryland with the first of many events for members to gather, learn and network. More than 200 assembled at Four Seasons Hotel in Baltimore for the chapter's ***Annual Meeting and Educational Dinner***.

Children were treated to crafts and fun of their own, while adults settled in for a dinner befitting a Baltimore visitor - crab cakes! After conducting some brief business including the chapter's year in review, Bioverativ - a Sanofi Company, took the stage and presented an interactive presentation, *Cognitive Conversations*. Industry was on hand to share updates and new information. The BioMatrix team enjoyed meeting people at our booth and signing books of our latest release, *This is My Something*, a heartwarming tale of a boy with hemophilia who finds acceptance and common ground with new friends. If you are interested in receiving a copy of the book *This is My Something* for your child, please call Terry Stone at 703-795-6269 or by email, terry.stone@biomatrixsprx.com and we will send you a copy!

Terry Stone and Michelle Stielper sign copies of *This is My Something.*

CALIFORNIA

Kelly Gonzalez

Surrounded by glistening lights of the European-themed ambiance of Tivoli Village, Nevada Chapter of NHF (NHFNV) held it's 4th annual ***Winter Wine Fest and Silent Auction*** February 8th. On the wrap-around patio of Brio at Tivoli Village Italian Grill in Las Vegas, a thoughtfully organized silent auction with creatively paired baskets and experiences, two wine stations with an array of Dreaming Tree Wines and 3 food stations generously sponsored by Brio

Christine, Kelly Gonzalez, Maureen and Betsy frame up for a super shot!

Tiffany and Maddie stopped to pose while Maddie participated in youth fundraising for camp!

Kelly Gonzalez and Elizabeth Pulley of Octapharma smile for the camera!

and stocked with appetizers and Pasta Brio. High top social tables were thoughtfully scattered to prepare for the nearly 200 attendees. Community members, industry partners, local supporters, and medical providers gathered to partake in Nevada Chapter of NHF's community event of the year!

The evening was filled with the common goal of gathering to support the members of Nevada's bleeding disorder community. Raising over $20,000 in two hours, funds will be used to support campers, patient assistance, educational programming and more for the Nevada community. Thank you to NHFNV and to all the industry and community partners for supporting this wonderful event!

OHIO

Shelia Biljes

Cupid's arrows were flying as BioMatrix teamed up with Bayer and the Northern Ohio Hemophilia Foundation (NOHF) February 8th to present ***Couples Night Out.*** The evening event was held at Brew Garden Restaurant in Strongsville and began with a warm welcome from Tanya Ricchi, NOHF's Executive Director. An overview of BioMatrix's services followed along with a presentation by Bayer's Doug Stewart on their newest antihemophilic factor, Jivi®.

Adding to the fun, each couple worked on Valentine trivia games in hopes of winning fun prizes. Over a delicious dinner, the trivia answers were revealed. Right after a cheesecake dessert, a couples' massage class ensued. Deanne Parnell, LMT, from *Get the Kinks Out,* presented tips on

Lisa and Jeff learn the fine art of massage from Deanne Parnell, LMT

how to massage your partner to relieve stress and tight muscles. Laughter filled the room as everyone followed the instructions and worked on their partner's kinks. The evening wrapped up with a chocolate rose presentation, but those without little ones to run home to stayed well after the end to mingle and further enjoy the evening.

CALIFORNIA

Kelly Gonzalez

The ***Annual Surf & Turf Crab Feed*** did not disappoint as over 515 attendees joined staff and volunteers of Central California Hemophilia Foundation February 9th at the Sacramento Elks Lodge #16 for this amazing event! A silent auction with over 100 items lined the perimeter of the room as a swing band entertained and amazing ROTC members served the community. Appetizers of nachos and bread were followed by salad, pasta and then onto prime rib and unlimited crab. Community members from all parts of central and northern California gathered to partake in this fun event and "feed" to their hearts' content! Proceeds benefit the many wonderful programs offered by CCHF.

VIRGINIA

Michelle Stielper and Terry Stone

What a splendid weekend to spend with splendid ladies! The Virginia Hemophilia Foundation (VHF) brought together women from the bleeding disorders community to share in fellowship and celebrate their strengths at their yearly Women's Retreat. We included the Bead Your Journey program for the ladies gathered at the Virginia Beach Founders Inn.

This program celebrated the journey each woman has had by living with or caring for someone with a bleeding disorder. It was beautiful to see how powerful it was to turn their personal journey into wearable art. The project entailed creating a necklace or bangle with individual beads that represent a multitude of common experiences in caring for someone with a chronic condition.

The project quickly turned into conversations around what the individual beads mean to each person. Immediately, stories about advocacy, education, relationship building, community support, first times at camp, courage and much more erupted from every table. We were extremely honored to have brought our program to such a strong and courageous group doing wonderful work within our community. We are thankful to VHF for allowing us to continue to provide the well-rounded impactful programming that we love.

Dynamic Duo: Michelle Stielper and Terry Stone

FLORIDA

Peggy Klingmann

BioMatrix and Kedrion came together to host a fun and educational event for the Tampa Bay bleeding disorder community at Tampa's Florida Aquarium. Our own Dr. Shelby Smoak gave an informative and timely presentation of *Hillbeat on the Move*, a relaxed session providing everyone with updated, relevant information and allowed an open forum discussion around those issues. It was enormously well received and appreciated by everyone. Lunch followed along with free time at the Aquarium to view spectacular sea life and enjoy fellowship. A great day was had by all!

CALIFORNIA

Kelly Gonzalez

Families arrived early morning at Pickwick Gardens in Burbank to prepare for fun and education at the ***EmPOWERment Forum*** hosted by Hemophilia Foundation of Southern California and sponsored by many industry partners. Although the area had received snow flurries a few days prior, nothing stuck and the day was beautiful, the venue grounds were stunning, and the community was ready to be empowered!

The day consisted of programs designed to encourage empowerment including emergency preparedness which very much interested Southern California families. A speaker from a local university discussed natural disasters and surprised us all when she talked about the quantity of water needed to maintain one person for 7-10 days.

Leticia, Julie and Kelly Gonzalez stop for a quick pic on the way to the Hemo History Jeopardy Game

We learned about the history of bleeding disorders in a competitive game of Hemo–History Jeopardy and aligned with the idea that if you don't know where you have been, you can't know where you want to go. As vested community members, learning our history is important so we are sure to continue what is successful, learn from past mistakes and avoid repeating them, and learn how to set goals and follow through.

Jeanne White-Ginder, mother of hemophiliac and HIV/HCV infected son Ryan White, tells Hemo SoCal about the journey from Ryan's diagnoses to his passing, the legacy he left behind, and the path to advocacy he paved for us all.

Another path to empowerment is through self-advocacy and community advocacy. Jeanne White-Ginder, mother of Ryan White, spoke with us about Ryan's journey from birth to his passing. The journey was such a rough one for Ryan and his family due to his very public battle with HIV and HCV due to contaminated blood products in the early years of factor treatments. Ryan and his mother faced horrific challenges yet stayed optimistic and empowered to change the stigma, not just for Ryan, but for all people affected by chronic conditions. We were so grateful to hear her testimony and every person in the room was touched emotionally.

The day ended with raffles for survival items such as 55 gallon water tanks, emergency kits, sustainable for 20+ years and much more. Thank you Hemo SoCal for recognizing the needs of the southern California bleeding disorders community!

PENNSYLVANIA

Tina McMullen

Balls were rolling and pins were falling at Eastern Pennsylvania Chapter of NHF's ***Bowling for a Purpose*** Saturday, February 23rd at Devon Lanes. All 24 lanes were filled with 144 participants. The day began with bowling and an opportunity to visit the display area, which also included an array of wonderful raffle items. Prizes were many: Autographed Philadelphia Flyers

Good friends Gianna and Bella bowl to their hearts content!

BioMatrix ON THE MOVE

Puck, 6 Reading Fightin Phils tickets, Asher's Chocolate basket, Panera bread for a year, a Trader Joe's basket, 4 tickets to the Philadelphia Art Museum, just to name a few! Attendees also enjoyed an array of sandwiches, snacks, and refreshments. It was a wonderful day for the community members of the Eastern Pennsylvania Chapter of NHF!

NEW JERSEY

Richard Vogel and Carolina Luna

When it comes to education, members of the Hemophilia Association of New Jersey don't let a little bad weather deter them. On February 24th, 150 members of the New Jersey bleeding disorders community made their way to iPlay America in Freehold Township for a ***Winter Gathering*** - education and a lot of fun! Free transportation was available for those who otherwise would have not been able to attend.

During a continental breakfast, guests were able to gather information from the exhibitors. They were then able to choose from a smorgasbord of breakout meetings; something for everyone from young scientists, self-infusing, branded sessions and some in Spanish.

Racavel, Devin, Steven and Shynese visit the BioMatrix booth.

While parents attended education sessions in the afternoon, children and young adults were able to play at one of New Jersey's largest indoor arcades. They chose from rides, bumper cars, and typical boardwalk games, made famous by the Jersey shore. It was an amazing day for all!

BioMatrix Care Coordinators Rich Vogel and Carolina Luna visit with community members Justin and Ellen (center).

ILLINOIS

Eva Kraemer

There are many changes affecting the community with regards to the Affordable Care Act such as the current administration's creation of alternative, non-ACA insurance plans that are attractive to healthy persons but fail to meet the needs of the chronically ill. This puts persons with chronic illness at a disadvantage by removing healthy people from the risk pool, thus driving up premiums for those who remain.

To better educate themselves on topics such as this, community members attended Bleeding Disorders Alliance Illinois' annual ***Advocacy Retreat*** March 2nd at the Crowne Plaza Chicago in Burr Ridge. Keeping abreast of insurance changes is extremely important as we endeavor to make our voices heard.

NORTH CAROLINA

Xaviette Pointer-Kincy

March 2nd at the Sheraton Airport Hotel in Charlotte was the place to be as Hemophilia of North Carolina hosted its ***2019 Annual Meeting***! This year's theme was *Moving the Community Forward*. Over 150 community members and supporters came together to learn new advances in research and treatment options. Dr. Steven Pipe educated everyone on shifting paradigms for hemophilia treatment and examined the exciting treatment options that will be made available to affected members. A screening of the popular documentary Bad Blood was shown to provide historical context for participants. Hats off to Executive Director Charlene Cowell and her team for creating a weekend full of education, advocacy, and community support!

Renita brings her smile to the BioMatrix booth!

NEW JERSEY

Richard Vogel

Whether you are a new parent, spouse, young or an old man (like me), living with or caring for someone with a bleeding disorder can be very stressful. The threat of a snowstorm did not deter community members March 3rd from learning the benefits of self-care in a fresh and creative way. The afternoon at the Hilton Newark Penn Station began with educational information on Eloctate®, a factor VIII extended half-life product.

Sarah Beaman, co-founder and art therapist of Indigo Art Therapy Studio then explained the healing power of art therapy. The process-focused, holistic approach helps individuals of all ages and abilities learn safe ways to express themselves, regulate emotions, work through traumatic memories and navigate sensory sensitivities.

The art project was a core value keepsake box. In a mindful moment, we concentrated on our core value and put that on a rock. The group then individualized their protective box around their core value. This was an interactive activity, and everyone went home with a meaningful piece of therapeutic art that will protect everyone's core values and remind everyone that "you are the eyes of the world."

FLORIDA

Hector Heer

Foundation Hope & Life USA presented an educational event for the bleeding disorders community March 9th. Foundation President Ana Calero, along with Vice President Norma Hernandez planned this ***2nd Annual Family Education Rally*** at Milander Park in Hialeah, where folks had a great time networking with other families, eating, and learning the day away. Everyone agreed the event was a success and are eagerly awaiting the next gathering!

Norma, Leonidas and Karina enjoy the beautiful day!

MAINE

Cheryl Ashmore

Still caught in the grip of a frigid winter, more than 200 people from New England's six states traveled to Portland March 9th for a day of high-level medical-based education at the ***Consumer Medical Symposium***. The New England Hemophilia Association (NEHA) set the bar for significant, relevant programming from experts in the medical, advocacy, insurance and legislative fields as they pertain to the bleeding disorders community.

Steve Pipe, MD, MASAC Chair delivered the keynote address *The Shifting Paradigms of Hemophilia Treatment*, a fascinating look into newly available therapies and those still in clinical trials. One of the more complex and most helpful sessions was *Ask the Experts: Insurance Trends and Barriers* facilitated by Joe Zamboni, Coordinator for NEBDAC (New England Bleeding Disorders Advocacy Coalition). Other sessions included a patient panel of women with bleeding disorders, vWD treatments and psychosocial issues. Finally, a panel comprised of Medical Science Liaisons from various pharmaceutical companies presented and then participated in round table discussions with small groups of patients. An astounding amount of information was shared, and the participants were impressed with what's in the pipeline for our community. Additional presenters included: Aric Parnes, MD, Boston Hemophilia Center; Glen Roy, RN, BSN, Maine Medical Center; Laurel McKernan, RN.

Because NEHA thinks of everything, the teen track was the Bomb(ardiers)! Chris and his wife, Jess, organized the kids into teams, asked them to memorize a pie recipe and make it from scratch blindfolded. Laughter and silliness ensued, and there were interestingly structured pies to admire and taste once the blindfolds came off. The kids were thrilled with Chris and Jess – one excitedly said, "I watched the updates on Facebook while Chris was climbing all the mountains. After he finished the seven summits, I got to watch Bombardier Blood. It was awesome to have such a great role model leading our session! Plus, Jess is really cool."

Kudos to NEHA for bringing their best game – the meticulously planned day's activities were well rounded and inclusive all ages. It was truly a pleasurable day and we can't wait to see what Executive Director Rich Pezzillo and NEHA have planned for us next!

VIRGINIA

Terry Stone or Michelle Stielper

When the community talks, the Virginia Hemophilia Foundation listens! Always welcoming feedback, the leadership of VHF heard the requests of many that more medically based learning opportunities would be welcomed. With great feedback driving this initiative, VHF created a new education event that addressed many hot topics of new and emerging therapies, gene therapy and how the near future looks. VHF proudly kicked off its first ***Medical Symposium*** March 9th at the Virginia Crossings Hotel in Glen Allen.

Many were delighted to welcome Dr. Louise Man, Assistant Professor of Medicine, University of Virginia Health System (UVA) Division of Hematology/Oncology as Keynote Speaker. Dr. Man is no longer new to the clinic at UVA hospital, but some have yet to meet her. She presented a comprehensive overview of longer half-life products, new delivery techniques and gene therapy. Science continues to progress and patients will see even more changes that may impact their care and their community.

Another great topic was presented by Jan Kuhn, RN, MPH, Program Manager, Central Virginia Center for Coagulation Disorders; *Clinical Trials* and if they are right for you. Jan led an honest discussion thanks to input from a panel consisting of a mom and a patient who spoke from their own experiences. Through the highs and lows of participating in a trial, the most hopeful message was that to participate is a way to pay it forward to others who may one day benefit from the knowledge gained.

Of course, you never have a great medical talk unless you include a dynamic chat about *Insurance Trends and Barriers*. Led by Becky Bowers-Lanier, VHF/HACA's Advocacy Consultant; Becky conducted a panel discussion that offered helpful information about coverage on the federal and state level, and how coverage will change as treatment evolves. Thanks to the panel of experts including our own Lauren Dunn, MSW, Central Virginia Center for Coagulation Disorders. The final session discussed the importance of having a medical home for your care, which is particularly important for patients with chronic illness and pediatric patients who are transitioning into adult care.

Industry sponsors were on hand for round table conversations about their services, and meals were lively with conversations among new and old friends. Reflecting on the day's hosts of expert presenters and range of topics that relate to our daily management of and support of life with a bleeding disorder, this unique Medical Symposium was a big hit.

CONNECTICUT

Richard Vogel

Amidst light snow, members of the bleeding disorders community arrived at West Dover's Mt. Snow for the 15th annual ***Connecticut Hemophilia Society Alpine Walk***. Held over St. Patrick's Day weekend March 15-17, this well-attended event brought together families to re-connect and share experiences. Upon arrival, everyone was free to gather product and service information from a variety of vendor exhibits. Movie night followed a buffet dinner, and everyone retired to rest up for the next day's outdoor activities.

Well-nourished after breakfast, dads and children bonded while snow tubing down the mountain. Moms and spouses had a chance to *Chill and Chat* and came away with some new insights.

Following a cozy pizza party, everyone donned snowshoes for the Alpine Walk on a private trail provided just for us. It doesn't get any better than walking at your leisure with family and friends in a beautiful setting all for a good cause. Coming in from the cold, everyone had the opportunity to enjoy the indoor pool and hot tub, go to the spa or just rest before the evening dinner and silent auction.

The weekend was warm with camaraderie and making new friends. If you find yourself in the northeast next March, come share the 16th annual Alpine Walk experience with CHS family and friends!

PENNSYLVANIA

Tina McMullen

The beautiful Chubb Hotel & Conference Center in Lafayette Hill was the picturesque setting for the Eastern Pennsylvania Hemophilia Foundation's (EPC) ***Annual Women's Retreat***. With around 30 women in attendance, the retreat was intimate, allowing an opportunity for many friendships to be formed.

The weekend began Friday evening with a relaxing opportunity to meet, converse and get to know each other. Saturday began with breakfast and time to explore the exhibit hall and visit industry reps. Educational programs were next and included topics such as *Utilizing the HTC for Best Possible Outcomes* by Melian Martin, L.C.S.W, Children's Hospital of Philadelphia, *Bleeding Disorders Overview* by Peter Cygan, MD, Penn State Hershey Medical Center HTC, and *Gynecological Issues for Women with Bleeding Disorders* by Tonya Wright, MD, Penn State Hershey Medical Center, Women's Health Division. BioMatrix held two sessions of *Putting on the Mask First* by our own Kelly Gonzalez, Educational Specialist. This is a very moving presentation, reminding us to take care of ourselves when caring for someone with chronic illness. There was laughing, crying and bonding between the women during the sessions. We experienced truly magical moments! Saturday evening the ladies enjoyed dinner and later more bonding in the lounge.

Robin (center) visits with Kelly Gonzalez and Tina McMullen.

(Back row left to right) Chris, Sue, Jen, Asmaa, Robin, Priscilla, Karen, and Deb. (Front row) Denise, Amy, Tina McMullen and Kelly Gonzalez.

Yoga with the one-and-only Kat Kocsi-Development Coordinator for the Eastern Pennsylvania Chapter and Certified Yoga Instructor kicked off Sunday morning. Breakfast was served and educational sessions followed: *Patient Self Advocacy Discussion* by Susan Cutter, ACSW, Hospital of the University of Pennsylvania HTC and *Iron Deficiency in Women with Bleeding Disorders* by Doug Drelich, MD, Thomas Jefferson University Hospital HTC.

When the event concluded on Sunday, hugs were shared all around. The splendid weekend offered the women of the EPC community an opportunity to learn, continue friendships and build new relationships. Thank you to Curt Krouse, Lindsay Frei and Kat Kocsi for a weekend we will never forget.

ANSWERS FOR PUZZLES ON PAGE 39.

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

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

1. Boy on right - Black camp logo is missing from shirt
2. Boy on right - Backpack on the grass is gone
3. Boy on right - Top part of his fishing pole is now yellow
4. Boy on right - Float from his fishing pole is gone
5. Boy on right - Number on shorts are now "00"
6. Boy on right - Socks are now blue
7. Boy on left - Word "EVEN" on his shirt is now blue
8. Boy on left - Fish he is holding is longer
9. Boy on left - Shorts are now maroon
10. There is a row boat in the water
11. Boy in the background is gone
12. Man in the background now has on black shorts

UPCOMING EVENTS

APRIL 12, 2019 CALIFORNIA
Latino Hemophilia Foundation
626-427-2735 or 323-369-4972,
hemolatino.org
Catalina Camp Luncheon
Cabrillo Bath House; San Pedro

April 12, 2019 Michigan
Hemophilia Foundation of Michigan
734-961-3506, hfmich.org
Community Nights
Merri-Bowl, Livonia

APRIL 13, 2019 ILLINOIS
Bleeding Disorders Alliance Illinois
312-427-1495, bdai.org
Annual Spring Gala – Black and White Masquerade Ball
Itasca Country Club
Itasca

APRIL 15, 2019 NEVADA
NHF Nevada Chapter
702-564-4368, hfnv.org
Golf Gets In Your Blood Tournament
Red Rock Golf Club; Las Vegas

APRIL 26, 2019 OHIO
Northern Ohio Hemophilia Found.
216-834-0051, nohf.org
Black and Blue Ball
Ritz Carlton; Cleveland

APRIL 26-28, 2019 MICHIGAN
Hemophilia Foundation of Michigan
734-961-3506, hfmich.org
SpringFest
Marriott at Eagle Crest, Ypsilanti

APRIL 27, 2019 PENNSYLVANIA
Eastern Pennsylvania Chapter
484-445-4282, hemophiliasupport.org
40th Annual Fashion Show
Normandy Farm Hotel and
Conference Center; Blue Bell

MAY 04, 2019 CONNECTICUT
Connecticut Hemophilia Society, Inc.
860-495-0006, cthemophilia.org
Annual Meeting
Sheraton Hotel; Rocky Hill

May 04, 2019 MISSOURI
Gateway Hemophilia Association
314-482-5973, gatewayhemophilia.org
Unite for Bleeding Disorders Walk & 5K
Forest Park Cricket Field, St. Louis

MAY 5, 2019 CALIFORNIA
Hemophilia Assoc. of San Diego County
619-325-3570, hasdc.org
Family Information Day, San Diego Zoo

MAY 7, 2019 PENNSYLVANIA
Eastern Pennsylvania Chapter
484-445-4282, hemophiliasupport.org
Annual Meeting
The Hilton City Avenue; Philadelphia

MAY 9, 2019 LOUISIANA
Louisiana Hemophilia Foundation
225-291-1675, lahemo.org
Louisiana Capitol Day
Baton Rouge Capitol Building

MAY 10 -11, 2019 CALIFORNIA
Hemophilia Found. of So. California
626-765-6656, hemosocal.com
Family Information Day
Knott's Berry Farm Hotel; Buena Park

MAY 11, 2019 MARYLAND
Hemophilia Foundation of Maryland
410-661-2307, hfmonline.org
Bull and Shrimp Roast
UAW Hall; Baltimore

MAY 11, 2019 NEW MEXICO
Sangre de Oro, Inc.
505-341-9321, sangredeoro.org
Unite for Hemophilia Walk & CINCO Event
Veterans Memorial; Albuquerque

MAY 18, 2019 KENTUCKY
Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org
Kentucky Zoo Day; Louisville Zoo

MAY 18, 2019 MAINE
Hemophilia Alliance of Maine
207-312-4448, mainehemophilia.org
Annual Meeting, Hilton Garden Inn,
Freeport

MAY 18-20, 2019 MARYLAND
Hemophilia Foundation of Maryland
410-661-2307, hfmonline.org
Women's Retreat
Gaylord; National Harbor

JUNE 7-8, 2019 SO CAROLINA
Hemophilia of South Carolina
864-350-9941, hemophiliasc.org/
Annual Meeting & Hello Conference
Embassy Suites; Greenville

JUNE 14-16,2019 OHIO
SW Ohio Hemophilia Found.
937-298-8000, swohf.org
Family Fest, Camp Higher Ground
West Harrison, Indiana

JUNE 15, 2019 TENNESSEE
Tennessee Hemophilia and Bleeding
Disorder Foundation
888-703-3269, thbdf.org
Race for Ian 5K
Trinity Baptist Church,
Jonesborough, TN

JUNE 17, 2019 ILLINOIS
Bleeding Disorders Alliance Illinois
312-427-1495, bdai.org
Driving fore Hemophilia Golf Tournament
Silver Lake County Club
Orland Park

JUNE 19, 2019 NEVADA
NHF Nevada Chapter
702-564-4368, hfnv.org
Couples Retreat
Hilton Garden Inn; Las Vegas

JUNE 21-22, 2019 VIRGINIA
Virginia Hemophilia Foundation
800-266-8438, vahemophilia.org
Annual Education Meeting
Natural Bridge Hotel and
Conference Center

JUNE 22, 2019 OHIO
Tri-State Bleeding Disorder Found.
513-961-4366, tsbdf.com
Family Education Day
Coney Island, Cincinnati

JULY 12-14, 2019 MISSOURI
Gateway Hemophilia Foundation
314-482-5973, gatewayhemophiliai.org
Family Education Weekend
Doubletree; Chesterfield

JULY 19-21, 2019 NEVADA
NHF Nevada Chapter
702-564-4368, hfnv.org
Northern Nevada Family Camp
Elko Convention Center; Elko

JULY 20, 2019 NEVADA
NHF Nevada Chapter
702-564-4368, hfnv.org
Unite For Bleeding Disorders Walk
Elko Convention Center; Elko

TIME FOR FUN!

HI KIDS!

Can you spot all 12 differences in these camp photos? Circle the changes when you see them. Look closely and good luck! Answers are on page 37.

MISSOURI CAMP WILDERNESS

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

Sudoku!

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

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

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11. Pennsylvania – Media
12. Tennessee – Bartlett
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