Highlights in this Issue...

Joe H. & Tim K. Memorial Scholarship

Family Camp
The Painted Turtle

2014 Camps!

Camp Red Sunshine

NACCHO

Inhibitor Camp at Victory Junction

ANNUAL CAMP ISSUE!

2014 Bleeding Disorder Camp Listing on page 14
The MISSION of Matrix Health Group is to provide individualized, focused services to people with bleeding disorders nationwide.

Our VISION is to enhance the lives of those we are privileged to serve by providing the best pharmacy and support services possible.

The purpose of Matrix Health News is to provide an opportunity to connect with others in the bleeding disorder community by providing information such as current news within the community, upcoming events, educational matters, personal stories, and a variety of opinions and views on topics within the bleeding disorder community.

The information and opinions printed in this newsletter do not necessarily reflect the views and opinions of the partners, employees, others associated with Matrix Health News or that of Matrix Health Group.

Health related topics found in Matrix Health News are for informational use only and are not intended to take the place of treatment or medical advice provided to you by your health care professionals or hemophilia treatment center. Please consult with your health care professionals when medical questions arise.
<table>
<thead>
<tr>
<th>CONTENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Note from the Editor . . . page 4</td>
</tr>
<tr>
<td>Joe Holibaugh &amp; Tim Kennedy Memorial Scholarship Program! . . . page 5</td>
</tr>
<tr>
<td><strong>Camp Ailihpomeh: Freedom and Camaraderie</strong> . . . page 6</td>
</tr>
<tr>
<td>Camp Rocks! . . . page 7</td>
</tr>
<tr>
<td>Inhibitor Family Camp The Painted Turtle . . . page 8</td>
</tr>
<tr>
<td><strong>ADVANCE HEMOPHILIA</strong> . . . page 10</td>
</tr>
<tr>
<td>Camp Bloodstone . . . page 12</td>
</tr>
<tr>
<td>2014 Camps Across Our Nation! . . . page 14</td>
</tr>
<tr>
<td>What is Camp Hemotion? . . . page 17</td>
</tr>
<tr>
<td>Camp Spirit at Camp Boggy Creek . . . page 19</td>
</tr>
<tr>
<td>Camp Red Sunrise . . . page 19</td>
</tr>
<tr>
<td>Weekend at Kweebec! . . . page 20</td>
</tr>
<tr>
<td>My First Camp Experience . . . page 21</td>
</tr>
<tr>
<td>My First Year at Camp Hemotion . . . page 23</td>
</tr>
<tr>
<td>Camp and So Much More . . . page 21</td>
</tr>
<tr>
<td><strong>NACCHO</strong> . . . page 23</td>
</tr>
<tr>
<td>Inhibitor Camp Victory Junction . . . page 25</td>
</tr>
<tr>
<td>Upcoming Events . . . page 30</td>
</tr>
<tr>
<td><strong>Time for FUN!</strong> . . . page 31</td>
</tr>
</tbody>
</table>

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Visit us today to learn more about our specialty pharmacy and support services, read popular articles from **Matrix Health News**, view pictures, learn about our upcoming events and find information on the bleeding disorders community.

“Like” our page to see how we are **Dedicated to Making a Difference** in the lives of individuals with hemophilia, vWD and other bleeding disorders.

www.facebook.com/pages/Matrix-Health-Group/140849859422348
Attention TRICARE Patients

Matrix Health Group is a specialty pharmacy devoted to caring for those with bleeding disorders. We are dedicated, determined and committed to personalize your homecare experience with round-the-clock service and a comprehensive line of factor and ancillary supplies. We offer a unique team of compassionate Care Coordinators with top-notch pharmacy and reimbursement services. At Matrix Health Group, our goal is to make your life easier!

We offer:

- Experienced, compassionate Care Coordination Team with a personal contact assigned to you for your pharmacy, reimbursement and support services
- Specialized, knowledgeable pharmacy with a comprehensive line of factor products and complementary supplies
- Located in Weston, Florida and Bartlett, Tennessee - our services reach across the nation
- 24-hour delivery with emergency same-day shipments available
- Interactive physician relationships providing you with custom treatment plans
- Specialty team of Reimbursement Facilitators dedicated to assist you with private and government insurance reimbursement needs
- Informative quarterly newsletter, Matrix Health News

For more information regarding our services, please contact us at 877-337-3002

We look forward to hearing from you!

A Note from the Editor

Dear Readers,

Finally the chill in the air is starting to recede for many of us and with the beautiful sunshine beaming down on our faces, thoughts are turning to summer fun. And when thoughts turn to summer fun, memories and anticipation of bleeding disorder camps enter the conversation!

My boys are older now with summer jobs and extra college classes, so they haven’t been able to attend camp for a couple of years. They miss it terribly and eagerly look forward to the day they can return as counselors. Some of their best childhood memories were made at camp and they still recount the stories with smiles on their faces.

Please enjoy our special annual camp issue of Matrix Health News, which highlights the camps in our close-knit community. We hope to have listed all the available camps, but if you find we have missed one, please let us know for next year’s listing. Also, since plans often change, please be sure to contact your specific camp to verify camp dates and locations. We don’t want anyone to miss the fun!

Enjoy!

Maria

Maria Santucci Vetter
Editor-in-Chief, Matrix Health News
maria.vetter@matrixhealthgroup.com

Matrix Health Group
is pleased to announce
A Moment in Your Spectacular Life!

2014 Calendar
Our calendar highlights a fantastic collection of photos depicting the spectacular moments in the lives of people with bleeding disorders!

Just contact the Matrix Health Group Care Coordinator nearest you to receive your free calendar.

Please see page two for a list of Coordinators.

Available only while supply lasts

TRICARE APPROVED!
Matrix Health Group is pleased to announce the 2014 Joe Holibaugh and Tim Kennedy Memorial Scholarship Program!

At Matrix Health Group, 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.

Joe Holibaugh and Tim Kennedy demonstrated such convictions in their dedication to serving the bleeding disorder community. Both were tenured employees at Matrix Health Group. As part of our company and of the bleeding disorder community, the dedication they exhibited was unwavering. Each brought remarkable qualities and skills together in a way that truly touched the individuals and community they both deeply cared for.

The enthusiasm and positive attitudes they put forth to make a difference in the lives of people with bleeding disorders will not soon be forgotten. In memory of these two remarkable employees and in honoring our Guiding Principle of Enrichment, we are proud to continue offering the Joe Holibaugh and Tim Kennedy Memorial Scholarship Program.

This program will award two $1,000 scholarships to students with a bleeding disorder. Applications must be postmarked by August 1, 2014. A third party committee will review and determine the award recipients, who will be announced in late September.

To download the application, please visit our website at www.matrixhealthgroup.com

Time is limited so don’t delay!

Send your application in today!
Naturally, the word hemophilia has always meant a lot to me. After 18 years of hearing it, its familiarity resembles that of my own name. Flip the letters around and you’ll get Ailihpomeh (Ali-Pome-Ah), the name of Texas’ bleeding disorder camp. It is located on the Camp John Marc grounds outside Waco, and spans 170 acres of beautiful Texas hill country. But it is neither the size nor location that makes this place synonymous with home. I’m here to describe the freedom and camaraderie that this place creates, but doubt I can begin to do it justice.

My personal story with camp began at age seven. I think it’s safe to assume that many people with hemophilia haven’t spent more than a night or two at friend’s house before that age, let alone a week more than 200 miles away. To my seven-year-old brain, this trip might have well have been a one-way expedition to the other side of Mars. Understandably, I was anxious. As I hugged my mom like I would never see her blonde hair again, I clenched my Power Rangers pillow and stepped onto the enormous bus to embark on the most ambitious voyage I had ever been on.

A bumpy four hours later, we arrived.

A stone arch housed a sprawling white gate, which opened as soon as I laid eyes on it, beckoning us to enter, which I now see as a metaphor for the welcoming nature of camp. I stepped off the bus into a crowd of cheering strangers greeting me and it wasn’t long before I felt like I belonged, and met a guy who to this day is one of my best friends. For the next eight years, I continued to meet new people and forge friendships that I took with me as I left camp year after year.

At age fifteen, I was invited to join the Leadership Program. Leadership is in many ways the same as being a camper, but at the same time is something entirely different. Upon being accepted into Leadership, you are instantly granted more freedom and trust, and you are looked to as a leader. People begin to expect more from you than they did in the past. Suddenly, it’s no longer, “What do I want,” it’s “What do WE need?”

Transitioning from camper to counselor was something not even Leadership could fully prepare me for. The weight of the responsibility now on my shoulders...
didn’t hit me until I saw the first of my campers step off the bus. From here on out, it was the needs of my campers I had to consider before my own. Without knowing who I was, all of these kids’ parents entrusted me with the care of their children, and I recognized that. In my cabin, three out of the seven were first-year campers. My immediate objective was to make them feel as welcome as I felt my first year, and I believe I accomplished that. I was actually happy to see a lot less homesickness than I expected, not a surprise since campers are plenty busy throughout the week to keep their minds off of it.

The sacrifices made during the week seem small in comparison to the reward of seeing smiles as my campers rode a horse for the first time or caught their very first bass. Along with the fun camp activities, you are also there to learn. The camp’s Medical Education (MedEd) classes are given to teach age-appropriate information about their disorders as well as other issues in life.

Camp Ailihpomeh is not just a place to come have fun for a week. The lessons learned and experiences enjoyed here will stay with me for a lifetime. This place has helped me grow and mature, and has helped shape the man I am today. I couldn’t imagine not having camp to look forward to every year and so I am thankful for the men and women who dedicate their time to make things like this possible for us to enjoy.

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Camp Rocks!

By Matthew Stone, 12

Camp is really amazing! I remember the time when I was waiting to be old enough to go to camp. It seemed like it took forever, then finally it was time. My first camp week was with the Virginia Hemophilia Foundation’s Camp Youngblood at Camp Holiday Trails in Charlottesville, Virginia. I was very excited and not worried because some of my friends that I had met at different events were going too. I knew we were going to have fun. We got to go fishing, canoeing, swimming and had free time to just hang out with friends.

The counselors were really cool. They were like big brothers and sisters, and they played games with us and made sure everything was okay. Another fun activity was plotting our revenge on the other cabins as we tried to “one-up” the others with our good, ole-fashion camp pranks. It was so funny. I even earned the “Best Prankster” award one year.

When it was time to get my infusion, I would go to the med corner and the nurses would not only give me my infusion, they would show me how to do it and let me practice. I earned my First-Stick award the very first time I went to camp. I liked learning how to infuse at camp. The camp nurses were really good teachers. Sometimes I would go by myself, and other times my counselor, cabin mates and I would go together to support each other.

Summer is just around the corner and I will be going to camp again this year. One of my friends will be going for the first time and I know he will love it. I plan to show him around and will be there with him. I have made a bunch of friends at camp and that means a lot to me, especially since they are just like me. I am the only kid in my school with hemophilia and at camp I am just another kid. That’s pretty cool! Watch out camp... here we come!
In our travels, we have found Comprehensive Health Services and their wonderful staff, who like us, have family members who have experienced the trials, tribulations and complications of hemophilia and inhibitors.

They have brought the possibility of a place where families can escape the emotional, mental and physical roller coaster of everyday life living with this disorder. With their true heartfelt dedication, they have created a place for families to feel relaxed and accepted during such trying times, and for that, I am truly grateful for the opportunity to attend Inhibitor Family Camp.

Two years ago in my search for fun family things to do within the bleeding disorder community, I came across CHES and Inhibitor Family Camp. As I read about it I thought to myself, “Wow, really, a camp for families with children who have hemophilia and inhibitors? That’s unbelievable!” The minute I saw this, I was on a mission to figure out how to get our family there. I cannot begin to describe how excited I was.

When I received notification we were accepted and learned we would make the trip to Victory Junction in North Carolina, I was overjoyed with excitement and anticipation. We were going to be with other families who, like us, were going through the same things we were. It brought tears to my eyes, thinking about it and wondering what the possibilities could be. I thought, “Maybe we will meet some really amazing families, just bond and feel accepted and normal. Maybe we can share our experiences and bounce ideas off of each other. It’s going to be a wonderful experience, I just know it!”

Sure enough, we met some of the most wonderful staff, volunteers, counselors and families. Victory Junction, founded by the Petty racing family, was a wonderful place to allow children with life-threatening disorders to just be; to enjoy camp like a normal child. We literally left there feeling like we had an extended family with many memories to cherish.

This year when the opportunity arose to go to Inhibitor Family Camp at The Painted Turtle in California, there was no question that I had to make it happen. Tristan had a crazy beginning of the year with his first-ever port infection and an eighteen-day hospital stay, along with multiple elbow and ankle bleeds. I was determined to get a reprieve for us. We so needed the support
and a break from the monotony of treatments and sleepless nights. So without hesitation, we made the six-hour flight from the east coast to the west coast and the two-hour journey by bus through the foothills of the Angeles Mountains to The Painted Turtle in California.

The place was breathtakingly beautiful. The cabins and scenery made things feel like we could release the stress and just go with it, and we did! From the minute we arrived it felt like home. A weight was lifted off my shoulders. We were welcomed with open arms by the volunteers, staff and nurses, and instantly felt accepted. The kids were so excited to try activities like horseback riding, archery, boating, fishing, wood shop, arts and crafts, and teen bonding sessions. I was just excited to be able to relax for once and share experiences at the evenings’ parent café sessions.

Horseback riding became a challenge for Tristan as he ended up with the inevitable elbow bleed, at camp no less, and was not cleared to ride. He was extremely sad and angry because he was not able to do what his sister and everyone else was doing, which broke my heart. The camp staff saw this and made him feel extra special by bringing him into the horse stalls to meet and pet the horses. He even got to meet a movie horse, which warmed my heart and turned me into a blubbering mess! The staff was so attentive to Tristan’s feelings and found a way to make him feel special. I could tell he felt so much better about himself, which meant the world to me.

One afternoon after education sessions, camp provided its very own Pinewood Derby. Each family made pinewood cars to race. The kids’ cars were amazing! We were entertained all weekend by “Pun,” who was hilariously funny. I don’t think I had laughed that hard in a really long time! At the camp talent show, our family jammed to Ronny James Dio’s Rainbow in the Dark, while wearing goofy outfits. I don’t remember the last time my kids and I had so much fun.

There were dance sessions and singing during meals. YouTube would have loved our camp version of the Harlem Shake. At the end of our weekend as we watched a slide show of the recent days, all I could do was cry as I thought, “These pictures are beautiful; those people up there are our family and are some of the most amazing people I have ever met. We will miss them so much.” I tried so hard to hug everyone as we left that day feeling more relaxed and connected than ever.

As a single mom of a child with a serious life-threatening disorder, I want to make sure my children get to experience everything life has to offer, despite our life’s many hurdles. Life is too short. To our family, camp is a way to feel normal and to find solace within our much smaller, hemophilia community. Camp is a way to meet new friends, re-unite with old ones, network with other families going through what you may or are going through, teach and learn from each other, and socialize in an environment that feels safe.

We are like one big family from beginning to end. That’s what Inhibitor Family Camp is all about. It means you get to be normal among friends and your inhibitor family.
Carlos Isaac Medrano Ceja and Sarah Torchia are changing lives for people with bleeding disorders in Mexico. Their efforts, along with the non-profit organization Advance Hemophilia, which Carlos helped found in 2011, are making a difference by providing valuable education and support services in an area where there are very little. One staple resource their organization has provided is a summer camp program aimed at empowering campers to adapt and meet the challenges life with a bleeding disorder in Mexico presents.

Born with severe hemophilia A in Mexico, Carlos moved with his parents to the United States when he was four-years-old. The move enabled the family to take full advantage of the many resources available to the bleeding disorders community in this country. As a child, Carlos attended camp in both Colorado and Nevada, and as a young adult, he remained involved in the camps’ leadership programs. The experience left such an impression that he later became a full-time camp counselor at Rocky Mountain Village, an Easter Seals camp in Colorado. It was there that Carlos met Sarah. Their shared compassion for helping and empowering others made them a great team and soon Sarah was working alongside Carlos at Advance Hemophilia. With an upbringing surrounded by strong resources and support systems, and grounded by the leadership experience provided by camp, Carlos learned the great value a strong community plays for the bleeding disorder community. These lessons would factor strongly into the development of Advance Hemophilia.

When it came time for Carlos to attend college, he decided to pursue his degree in Mexico. Upon starting studies, he sought the connection and support of the local bleeding disorder community. It was then he learned there was no organization, no hospital or resources in the area to speak of. Determined to change this, Carlos and his family founded Advance Hemophilia. Since 2011, the organization has been providing support through frequent meetings offering education, leadership and team building for individuals and families affected by a bleeding disorder.

One of the most successful programs Advance Hemophilia has initiated is their camp program. The organization has hosted three very successful camps. Inspired by their experience in the U.S., Carlos and Sarah wanted to provide community members the same opportunity to get connected, learn from each other and meet amazing people. Sarah notes, “While working at the Rocky Mountain Village, I was highly impressed with the mentorship the senior campers provided the youth when it came to infusions. It became clear to me then that there was something much bigger happening than just camp. That image has stuck with me and has remained the vision we are replicating in Mexico with our camp program.”

In addition to fostering an environment for participants to mentor and learn from each other, Carlos and Sarah are working hard to prepare their campers to face the challenges life with a bleeding disorder presents. Sarah says, “The hard truth is there are huge obstacles when it comes to getting factor to the people who need it. One telling activity came when we asked campers to draw their greatest hope, their greatest fear and their greatest want. For the greatest want, each camper drew
factor.” Another huge problem facing the community in Mexico is a general lack of awareness. Many of the local hospitals are completely unprepared and lack the basic understanding of how to treat people with a bleeding disorder. Additionally, many of these individuals come from areas of extreme poverty, creating problems in accessing care and providing little opportunities for families to move forward.

Carlos, Sarah and Advance Hemophilia are working hard to help their campers meet and move past these challenges. In addition to teaching children how to self-infuse, many of the camp educational components are aimed at teaching children to know their body and identify bleeds early. Sessions are also aimed at creating positive emotional coping techniques when factor is not available. Camp also empowers participants to actively advocate and speak for their needs when dealing with hospitals who may lack knowledge of how to best treat their condition. Finally, the extremely successful Yo Creo (I Believe) program is teaching campers and their families how to be entrepreneurs. Each camper creates a product to sell, allowing them to turn a profit and spread awareness about bleeding disorders. Carlos explains, “Teaching our campers to be entrepreneurs, innovators and self-advocates in an age where these skills can make all the difference in one’s healthcare has been our greatest success. Seeing the success her son had, one mom started her own business based on the same model!”

In addition to all the great skills campers are learning, providing an environment for participants to just relax and have fun is very important. Sarah mentions, “Because of donations from local sponsors, we were able to host a ‘vacation’ themed camp which actually took place on the beach! For some families this was truly a vacation as they had never been to the beach before, despite living less than an hour away. It was amazing to see our campers have the opportunity to relax amidst the everyday struggles of living with hemophilia.”

The efforts of Carlos, Sarah and Advance Hemophilia are not going unnoticed. At this year’s NACCHO conference in Arizona, the two won the “NACCHO Cup” award for their Yo Creo program. They were awarded $1500 to use at their discretion toward their camp program! The money will fully fund next year’s camp and will allow the organization to reach out to other hospitals and families to help the camp grow. They also plan on investing in medical bracelets for campers, and are working to provide better access to the products and supplies that treat individuals with bleeding disorders. The two are always looking to the future. In Mexico, Carlos is seeking to obtain a physical building for campers and other people with disabilities to sell goods generated by the Yo Creo project. In the states, Sarah is working hard to partner with independent boutiques and other vendors to sell the products created by their campers. Additionally, Sarah will be hosting a barbecue fundraiser on World Hemophilia Day to benefit Advance Hemophilia.

Driven by a spirit and passion to help others, Carlos, Sarah and Advance Hemophilia are changing outcomes for individuals living with a bleeding disorder in Mexico. By taking on the problems the community faces head on, they are making a lasting positive impact. “Like” the Advance Hemophilia page on Facebook for updates and further information on how these remarkable individuals are providing opportunities and changing lives for the bleeding disorders community. 🍔

(www.facebook.com/advancehemophilia.ac?fref=ts)
“Guess we better be ready, huh?”
I remember stating as the bus pulled up in front of the dorm late on a Wednesday morning with kids all set for Camp Bloodstone.

Let’s backtrack a little bit to see how we got here. I have twin eight-year-old boys with severe hemophilia A. Many of you know the problems that can sometimes go along with that diagnosis. We try to give our kids as normal a routine as circumstances allow and I think my wife and I have done a great job of it; that is until the talk turns to the topic of SUMMER CAMP.

It’s not so much the kids saying they don’t want to go - we go camping every year with them - it’s Mom. The thought of anything happening to them while they are away from our care sets in panic, but I have it all planned out. We are going to stay at a nearby campground just to keep her calm. That’s the plan until the bleeding disorder foundation’s executive director mentions she wishes we could find a camp here in Maryland.

A few years back, I had mentioned I had access to a camp in Bel Air, Maryland - both nearby and affordable. It didn’t work out back then, but fast forward to July 2012 and we’re asked, “Hey could you look into that for us again?”

Since summer sessions were in progress at the camp, I decided to stop in and talk to the staff to see if any dates would be open for the next summer. Armed with a few names and numbers as well as a price list and open dates, I rushed off to let the foundation know what I had found out.

“This is great, Shawn,” the executive director said. “Can you reserve the dates in August? Oh, by the way, you’re the committee chair and camp director for this, just to let you know.” What? Chair? Director? I have never set up a camp, much less run one. Yeah, I went to a few when I was a kid, but setting one up from scratch? Okay.

That’s how it began, but now the challenge was how to make this camp different than the others. I was eager to make Camp Bloodstone a unique experience for every camper. Checklist please:

1. This will be a camp for just our foundation’s kids, so they will know everyone there.
2. Organize campers into teams and have them compete at some of the events.
3. Focus on outdoor activities such as a ropes course and canoeing. An archaeology dig would be awesome! Did I say archaeology dig? Yeah, more on that later.

Now it’s time to kick in and get the big activities lined up. We, the camp planners, are doing ourselves a favor and scheduling just a three-and-a-half-day camp. Being our first run at it, we do not want to push it. After many conference calls, site visits and plenty of hair-pulling, we now have
for the most part, put together the camp that has big promise.

We set activities into age-based categories. We have a ropes course and a Canoeing 101 class, which has some of the parents worrying... something about canoes flipping over. We have a “Stream-Doctor” class, which has the kids in boots tromping through water and mud, looking for what lives in the marshes and streams. We also have the one thing I think will make our camp just a little different... an archaeology dig site.

I called my friends at the Archaeological Society of Northern Chesapeake to see if they could help. While they loved the idea, they were understandably nervous. Young kids and short attention spans are not usually a good mix. After a few meetings, reassurances and a bit of dig site construction, we were ready for something different.

So now it is registration time and 19 kids sign up. That’s great, we can work with that. A week after registration, oh-by-the-way kids are added and we are now up to 22. Still no problem since I had already planned for extras in the food and sleep counts.

With only one month left before camp, I have daytime programs set, check; evening programs set, check. Oh, can we add another four kids? Check. 26 kids? Can we get more counselors?

Welcome back to the start of our story; ready or not, here come the kids for the first day of Camp Bloodstone. We wrangle them together into teams of Blue Fish, Turtles, Tigers and Zebras. Then GO! The camp is under way at such a blurring pace it’s hard to keep up. As camp director, I am everywhere as we have programs going on all over the campground. A few asked how I was managing to be in two and three places at once. Easy - run all the time and don’t ever, ever sit down.

With the close of each day around a roaring campfire, the kids bemoan the call for bedtime, especially the counselors-in-training. After the campers are all in the dorms (not in bed, per se), I make sure everything is ready for the next day and we have an idea of who needs to be where and when. Then I too, manage a few hours of sleep. As dawn breaks the morning sky, I am already up to make sure everything is in place.

At some point, I blink and suddenly it’s Saturday morning. The activities are done, the kids are talking about their favorite event, and all the bags are packed and waiting for the bus. Splash! A camper from Team Turtle is throwing stones into the koi pond. Someone ask him to stop, again, for real this time; seriously, he has just about filled the pond with stones in three days.

As we wait for the bus, everyone receives their camp medal and a bloodstone - for the one thing that binds us all together in this crazy-paced four days is our blood. One way or another, blood brought us to this camp and I made sure everyone left Camp Bloodstone with a reminder of that. A camp built on our blood with the sweat of many and... would someone please stop him from throwing stones at the koi? You get the idea... time to go save the fish!

Matrix Health Group would like to extend a warm congratulations to Mr. Shawn Nease, who was honored at the Hemophilia Foundation of Maryland’s (HFM) Annual meeting February 1, 2014 as the chapter’s Volunteer of the Year! Shawn is an active member of the HFM community along with his wife Carri and their two sons. Always looking for ways to make a difference in the community and inspired by his children, his service to the chapter along with the creation of a weekend camp designed for kids that are just a bit younger than the typical required camp age offered some excited pre-campers a fun and fantastic experience. The program was a great hit! Way to go Shawn for your continuing efforts and contributions to your community!
This spring we continue our tradition of bringing you the most comprehensive national bleeding disorders summer camp directory!

Use this updated list to identify a camp in your area. Most camps are directed to children between the ages of seven and fourteen years old. However, many camps also include a junior counselor leadership program and our listing also includes a number of family camps open to entire family.

Summer time is quickly approaching, so use this list to develop your camp “game plan.” Don’t miss out on the fun!

Although we have tried to include every camp across the nation, there is always the possibility we have missed one or two. If you are having trouble finding a camp in your area, be sure to check with your local chapter, hemophilia treatment center or a Matrix Health Group Regional Care Coordinator (list can be found on page 2), and we will help you locate a camp.

www.matrixhealthgroup.com
Camps Across Our Nation
1. Alabama Camp Clot Not
June 21-26, 2014
Open to: Boys & Girls with a bleeding disorder, Carriers
Ages: 6-18
Location: Children’s Harbor - Mariner’s Adventure Camp; Alexander City, AL
Contact: Vicki Jackson, ED, Hemophilia & Bleeding Disorders of Alabama, Inc.
334-277-9446
amandajackson@hbda.us, www.hbda.us

2. Alaska Camp Frozen Chozen
July 14-19, 2014
Open to: Boys & Girls with a bleeding disorder, Siblings
Location: Sutton, AK
Contact: John Palmatier, ED
907-212-6711 or 907-343-9232
alaskahemo@gmail.com
www.alaskahemophilia.com
Colleen Thorntley, Camp Director, Alaska Hemophilia Association and Treatment Center, 907-212-6700

3. Arizona Camp Honor
June 2-7, 2014
Open to: Boys & Girls with a bleeding disorder, Siblings
Ages: 8-17
Location: Prescott, AZ
Contact: Josh Traulsen, 602-955-3947
Josh@hemophilaz.org
Arizona Hemophilia Association
www.hemophilaz.org

4. Arkansas Camp Aldersgate
July 27 – August 1, 2014
Open to: Boys & Girls with a bleeding disorder, Carriers, Siblings
Ages: 6-16
Location: Little Rock, AR
Contact: Lara Lawrence
Arkansas Center for Bleeding Disorders, 501-364-5961
lawrencelaral@uams.edu

5. Arkansas Camp Nopokamee
July 27-31, 2014
Open to: Boys & Girls with a bleeding disorder, Carriers, Siblings
Ages: 8-18
Location: Arkansas
4-H Center; Ferndale, AR
Contact: Angie Clark, Camp Co-Director
501-470-3566
angie1315@wildblue.net
Angela Dickens, Camp Co-Director
479-414-0150

6. California Camp Hemotion
June 15-21, 2014
Open to: Boys & Girls with a bleeding disorder, Siblings
Ages: 7-14
Ages: 15-20 Junior & Assist. Counselors
Location: Coarsegold, CA
Contact: Merlin Wedepohl, ED
Hemophilia Foundation of Northern California, 510-658-3324
merlin.wedepohl@hemofoundation.org
www.hemofoundation.org

7. California Camp Arroyo Family Camp
January 17-19, 2014
Open to: All family members affected by a bleeding disorder
Ages: All ages
Location: Camp Arroyo, Livermore, CA
Contact: Merlin Wedepohl, ED
Hemophilia Foundation of Northern California, 510-658-3324
merlin.wedepohl@hemofoundation.org
www.hemofoundation.org

8. California HFNC BLeaders
May 16-18, 2014 Annual Retreat
Open to: Boys & Girls with a bleeding disorder, Siblings
Ages: 13-18
Location: Northern CA
Contact: Merlin Wedepohl, ED
Hemophilia Foundation of Northern California, 510-658-3324
merlin.wedepohl@hemofoundation.org
www.hemofoundation.org

9. California Camp Blood Brothers and Sisters
July 28 - August 2, 2014
Open to: Boys & Girls with a bleeding disorder
Ages: 7-16
Location: The Painted Turtle Camp; Lake Hughes, CA
Contact: Linda Corrente, ED
Hemophilia Foundation of Southern CA
www.hemosocal.org, 323-525-0440
correntel@sbcglobal.net

10. California Camp Pascucci
August 9-15, 2014
Open to: Boys & Girls with a bleeding disorder, Siblings, Carriers
Ages: 7-14
Ages: 15-17 Junior Counselors
Location: Big Bear, CA
Contact: Nooshin Kosar, ED
Hemophilia Association of San Diego County, 619-325-3570
info@hasdc.org, www.hasdc.org

www.matrixhealthgroup.com
11. Colorado Mile High Camp
July 20-25, 2014
Open to: Boys & Girls with a bleeding disorder, Siblings
Ages: 7-17, Siblings - Ages: 7-14
Location: Rocky Mountain Village at Easter Seals, Empire, CO
Contact: Amy Board, Camp Director
720-626-1263, info@cohemo.org
Colorado Chapter of the National Hemophilia Foundation
www.cohemo.org

12. Connecticut Hole in the Wall Gang Camp Hero’s Journey
Wilderness-based camp
July 2-8, July 11-17, July 20-26,
July 30 - August 5
Open to: Campers with hemophilia
Ages: 16-18 (not yet in college)
August 8-14, 2014 - Sibling campers
of summer program
Ages: 16-18 (Not yet in college)
Location: Ashford, CT
Contact: Greg Yeager
860-429-3444, ext. 226
greg.yeager@holeinthewallgang.org
www.holeinthewallgang.org

13. Delaware Camp Kweebec Family Camp
September 26-28, 2014
Location: Camp Kweebec
Schwenksville, PA
Contact: Ellen Kahil
Delaware Valley Chapter of NHF
215-393-3611
ellenk@hemophilia.org
www.hemophilia.org

14. Florida Camp Spirit
July 26-31, 2014
Open to: Boys & Girls
Ages: 7-16
October 17-19, 2014
Family Retreat
Open to: Families with a bleeding disorder
Location: Camp Boggy Creek; Eustis, FL
Contact: Fran Haynes, ED
Hemophilia Foundation of Greater Florida
800-293-6527
info@hemophiliasupport.org
www.hemophiliasupport.org

15. Georgia Camp Wannaklot
July 20-25, 2014
Open to: Boys & Girls
with a bleeding disorder
Ages: 7-12 Junior Camp
Ages: 13-17 Teen Camp
Location: Rutledge, GA
Contact: Kim Wilson
kawilson@hog.org
770-518-8272
Hemophilia of Georgia, www.hog.org

16. Hawaii Camp Koko Ohana
May 30 - June 1, 2014
Open to: Families of children with a bleeding disorder
Ages: All ages
Location: YMCA Camp Erdman
Waialua, HI
Contact: Jennifer Chun, Hawaii Hemophilia Foundation, 808-782-5506
hawaiihemophiliasupportfoundation@hotmail.com

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What is Camp Hemotion?

By Cathy Marquez, 18

Camp Hemotion is that magical place, where any child, teenager and adult can feel “normal” for a whole amazing week. It is a place where you don’t have to cover up your bruises or hide your bleeding disorder from anyone; it’s a place to be free.

I started going to Camp Hemotion when I was fourteen and immediately fell in love with the place. I fell in love with the caring staff, the amazing kids and the inspiring teenagers. Camp Hemotion has helped make me the person I am today.

At camp I learned to be myself, I learned to accept the life I live, and above all, I learned to accept I have a bleeding disorder: that it’s okay and I’m not alone. Camp is one of the best places to build your own support group and to meet extraordinary people who help you grow as an individual. I’ve been going to camp for four years now. As soon as the week is over, I climb in the bus and always think to myself, “I can’t wait for next year!”

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www.matrixhealthgroup.com
17. Idaho Camp Red Sunrise
June 26-29, 2014
Open to: Families affected by a bleeding disorder
Ages: All Ages
Location: Sawtooth Methodist Camp
Fairfield, ID
Contact: Taryn Magrini, ED
208-344-4476, tmagrini@hemophilia.org
Idaho Chapter of NHF
www.idahoblood.org

18. Illinois Camp Warren Jyrch
August 3-9, 2014
Open to: Boys & Girls with a bleeding disorder or diagnosed carrier status
Ages: 7-17
Location: Camp Benson
Mount Carroll, IL
Contact: Lily Schwartz
Bleeding Disorders Alliance Illinois
312-427-1495, lschwartz@bdai.org
www.bdai.org

19. Indiana Camp Brave Eagle
June 15-20, 2014
Open to: Boys & Girls with a bleeding disorder, Siblings, Carriers
Ages: 7-16
Location: North Webster, IN
Contact: Briana Vieke, Program Director
Hemophilia of Indiana, Inc.
800-241-2873, bvieke@hoii.org

20. Indiana Camp Independence
July 27 - August 1, 2014
Open to: Boys & Girls with hematological disorders
Ages: 8-18
Location: Bradford Woods, Martinsville, IN
Contact: Andrew Harner, LCSW
317-944-0115, aharner@iuhealth.org

21. Iowa Camp Tanager
June 22-27, 2014
Open to: Boys & Girls with a bleeding disorder and one guest per family
Ages: 6-17
Location: Cedar Rapids, IA
Contact: Karla Watkinson, RN or Michelle Krantz, RN, BAN University of Iowa Hospitals & Clinics 319-356-4277 319-356-4271 or 319-356-2890 karla-watkinson@uiowa.edu michelle-krantz@uiowa.edu or Hemophilia of Iowa, Sue Grant 319-730-7707, hemophiliaofiowa.com

21. Iowa Family Camp at Camp Tanager
August 9-10, 2014
Open to: Families with a child who has a bleeding disorder (ages 3-6)
Location: Cedar Rapids, IA
Contact: Michelle Krantz, RN or Karla Watkinson RN, University of Iowa Hospitals and Clinics, 319-356-4277 319-356-2890 or 319-356-4271 michelle-krantz@uiowa.edu karla-watkinson@uiowa.edu or Hemophilia of Iowa, Sue Grant 319-730-7707, hemophiliaofiowa.com

By Omar Wilson Cepeda, 9

Camp Boggy Creek is awesome! I am so excited to go again this summer! All my friends at camp also have a bleeding condition so we understand each other very well. I enjoy the outdoor and indoor activities: the sing-alongs by the campfire, art and craft shops, playing basketball at the gym, archery lessons, horseback riding, fishing, and kids night out where we play board games with the counselors and other campers, and last but not least, the talent show. That’s when I get to play the piano. One of my favorite outdoor activities is Messy Day, which means I get to roll in the mud, dunk my face in pile of noodles, and of course have a food fight! 🍔
Camp is Awesome! Why is that? Camp is the real life social network where we make lifelong friends. It is the classroom where we discover how we can make our life better. It is the arena where we train to overcome some of our biggest fears. Camp is the amusement park where we allow ourselves to enjoy every experience.

For those with bleeding disorders, camp is a time and place to spend with others facing similar challenges and learning together how to face those challenges. Our favorite part of camp is when a child or teen earns the Big Stick or Little Stick (for siblings or friends) awards. It takes courage to do something the first time, and earning those awards demonstrates courage.

Camp Red Sunrise is approaching its third year as a family camp for those affected by bleeding disorders in Idaho and surrounding areas. Organized by the National Hemophilia Foundation (NHF) Idaho Chapter, hosted at the Sawtooth United Methodist Camp north of Fairfield, Idaho, and supported by volunteers from the community and medical personnel from the St. Luke’s Hemophilia Treatment Center, Camp Red Sunrise promises to be an educational and fun experience in a beautiful mountain setting.

This year Idaho Chapter of NHF and Camp Red Sunrise are excited to introduce a program focused on boys with bleeding disorders ages 12 to 18. Growing up and maturing from adolescence to adulthood is hard enough, but a bleeding disorder makes that transition even more of a challenge. However, it is possible and there are many resources out there to help make the transition a success. To start the program, four events are planned throughout the year where teens get together to interact with each other and learn how to prepare for their future. Adults affected by bleeding disorders are at each event to share their experiences and provide mentoring. In January of this year, NHF Idaho Chapter and Camp Red Sunrise were awarded 5th place in the North American Camping Conference of Hemophilia Organizations 2014 NACCHO Cup in recognition of their plans designed for the teen program.

What makes camp and similar programs awesome is YOU! Whether you attend a camp just for kids or a family camp; whether you are there as a volunteer or as a camper, what really makes it a memorable experience is the people who attend. So, wherever you are, thank you for your support of camp (any camp) through being a sponsor or donor, a fund-raiser, a volunteer or just being a camper! 🌞
Weekend at Kweebec!

By Ellen Kahil

We had a blast of a weekend at Camp Kweebec in Schwenksville, Pennsylvania. It felt good to come back for our second year at this new site. Everyone had a wonderful weekend of great food, friendship, zip lines, arts and crafts, and so much more! We had a magic show on Saturday night provided by the magnificent Mike Miller! We thank the staff at camp Kweebec for providing such a great weekend for us!
My First Camp Experience

By Lino Garcia

In my birth country of Peru, being born with a bleeding disorder was very difficult. During my infant days, few if any doctors knew about von Willebrand Disease (vWD). Luckily, I had a doctor who had knowledge of how to stop my nosebleeds, but no factor. Stimate, which I now take to help stop my bleeding, was never presented to me until I moved to the United States when I was seven. A doctor here diagnosed me with vWD. He also referred me to Lucile Packard Children’s Hospital at Stanford University for better treatment care at the hematology clinic. Later that day, a social worker I met gave me information about the hemophilia foundation.

At age ten, I went to my first camp, Camp Hemotion. This experience was both exciting and frightful because I had never been away from home; yet, camp was amazing! Meeting people with similar bleeding disorders, making new friends along the way, learning more about other people and their experiences with hemophilia and vWD was a deeply bonding experience. Although we were not genetically related, we treated each other like blood brothers, which made all the difference to me. During my week at camp, I participated in many activities and did my first campfire skit, which was especially memorable to me since I had never been in front of an audience and I experienced stage fright for the first time. In the end when the buses came to take us back home, we all gave each other a hug and went on our way waiting for next year to see each other again.

When I reached the age of sixteen, I became a junior counselor. I enjoyed helping kids because it created good memories and experiences. Making kids laugh, going on hikes together and camping out on movie night was exciting to all of us, but the most special part of camp was knowing that you have a family who will support you when you need help. What makes the hemophilia foundation and camp so special is the group of family and friends we can talk to. We won’t feel alone no matter what kind of bleeding disorder we have.

Camp and So Much More

Last year, YMCA Camp Whittle was honored to host Camp Independent Firefly for a week of fun at the end of our summer camp season. Camp Independent Firefly is comprised of campers from the Candlelighters Childhood Cancer Foundation of Nevada and the National Hemophilia Foundation, Nevada Chapter. This group of rambunctious, fun loving, spirited kids was like any other camp. Traditional camp activities were played and campfires were surrounded by songs and dancing, but this group of campers all shared something unique in common, they are cancer survivors or patients with hemophilia, and their siblings.

During this special week, Camp Whittle was transformed into a place of connection and healing as these kids were able to do outdoor activities they usually only imagine. They met others who shared in their struggles and endurance as they live everyday in defiance of their medical issues. Feelings of isolation melted into camaraderie, friendships blossomed and support systems were formed. Possible roadblocks were not going to stop the Camp Independent Firefly staff from enabling a camper to attend; our Health Center was even used for medical treatments during the week.

YMCA Camp Whittle treasures the partnership we have with Camp Independent Firefly and their amazing team of dedicated doctors, nurses and camp directors who enable this group of kids to have the experience of a life-changing week at camp.
32. Nebraska Camp Coholo
Session I - Ages: 6-11
July 20-23
Session II - Ages: 12-17
July 23-27
TBA Siblings
August 22-24, 2014
Location: Eastern Nebraska 4-H Center; Gretna, NE
Contact: Anisa Hoie, RN 402-955-3950
ahoie@childrensomaha.org
www.campcoholo.com

33. Nevada Camp Independence
August 12-16, 2014
Open to: Boys & Girls living in Nevada with a bleeding disorder, Siblings
Ages: 7-17
Ages: 16-17 Leaders in Training Program
Location: Camp Whittle; Big Bear, CA
Contact: Anne McGuire 702-564-4368
amcguire@hemophilia.org
Nevada Chapter of the NHF
www.nhf.org

34. New England Hemophilia Association
22nd Annual Family Camp
July 23-26, 2014
Open to: Families with a bleeding disorder in New England
Location: Geneva Point Center Moultonborough, NH
Contact: Kevin Sorge, ED New England Hemophilia Association 781-326-7645
Ksorge@newenglandhemophilia.org
www.newenglandhemophilia.org

35. New Mexico Camp Sangre Valiente
June 9-14, 2014
Open to: Boys and girls with a bleeding disorder in their family
Ages: 7-17
Location: Fort Lonetree, Capitan, NM
Contact: Johanna Chappelle Sangre de Oro, Inc. Bleeding Disorders Foundation of New Mexico 505-341-9321
sdo@sangredeoro.org

36. New York Camp High Hopes
August 10-16, 2014
Open to: Boys with a bleeding disorder, their male siblings and male family members of women with a bleeding disorder
Ages: 7-17
Location: Lowville, NY
Contact: Kathy Mott, Camp Co-Director 315-396-5644, mottfam@twcny.rr.com
www.camphighhopes.org

37. New York BDAN Family Camp
October 11-13, 2014
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

38. New York Double H Ranch
Session I: June 25-30
Session II: July 3-8
Session III: July 11-16
Session IV: July 20-25
Session V: July 28-Aug 2
Session VI: August 5-10
Session VII: August 13-18, 2014
Open to: General Sessions for Boys and Girls with bleeding disorders
Ages: 6-16
Location: Lake Luzerne, NY
Contact: Tara Bogucki 518-696-5676 x222
tbogucki@doublehranch.org
www.doublehranch.org

39. North Carolina Camp Carefree
July 20-26
Open to: Boys & Girls with a bleeding disorder
Ages: 6-16
June 15-21
Siblings, well children with a chronically ill sibling
July 13-19, 2014 Well children with a chronically ill parent
Location: Stokesdale, NC
Contact: Anne Jones, 336-427-0966
carefreedirectors@gmail.com
www.campcarefree.org

40. North Carolina Camp Rainbow
June 15-21, 2014
Open to: Boys & Girls with a bleeding disorder treated by the Brody School of Medicine at East Carolina University
Ages: Kindergarten-18 years old
Location: Camp Don-Lee Neuse River near Arapahoe, NC
Contact: Jacquelyn P. Sauls, MS, CCLS 252-744-4102, SaulsJ@ecu.edu

41. North Carolina Victory Junction
July 16-10, 2014
Open to: Boys & Girls with a bleeding disorder
Ages: 6-16
Location: Victory Junction Randleman, NC
Contact: Rebekah Hampton 336-495-2019
hampton@victoryjunction.org
www.victoryjunction.org

42. Ohio Flying Horse Farms
Session I: June 24-29
Session II: July 8-12
Open to: Hematology and Oncology patients
Ages: 8-15
Sibling Camp: June 8-13
Open to: Siblings of children with diagnoses
Ages: 8-15
Location: Mt. Gilead, OH
Contact: Olivia Miller, 419-751-7047
olivia@flyinghorsefarms.org

43. Ohio Camp Njoyitall
July 6-11, 2014 Ages 13-18
July 13-18, 2014 Ages 7-12
Open to: Current Cancer and Blood Diseases patients in the Institute at Cincinnati Children’s Hospital Medical Center
Location: Camp Joy Clarksville, OH
Contact: Karen Martin, Child Life Specialist or Heather Binning, Administrative Asst. 513-636-6569 (NJOY)
cbd.lib.camp@cchmc.org

44. North Carolina Inhibitor Family Camp
October 24-27, 2014
Open to: Families with a child (age 6-18) with an active inhibitor
Location: Victory Junction Randleman, NC
Contact: Comprehensive Health Education Services, 781-878-8561
info@inhibitorfamilycamp.org
www.inhibitorfamilycamp.org

45. North Carolina Victory Junction
October 11-13, 2014  Well children with a chronically ill parent
July 13-19, 2014  Ages 7-12
Matrix Health Group was well-represented at NACCHO, the annual conference for summer camps in the hemophilia community. Bobby Wiseman and Justin Lindhorst and I all attended the seminar in beautiful Tempe, Arizona, with many strong ideas being traded between camps from all over the world.

By Ben Martin

As a member of the planning committee, Bobby spent much of the weekend operating behind the scenes while continuing to help develop camps in foreign countries to their programs off the ground. Justin attended for the first time and left with pages of ideas and plans to implement. I was a presenter in a breakout session on developing the future generations of camp leadership.

Though NACCHO stands for North American Conference for Camps by Hemophilia Organizations, in its 11 year history, the program has expanded to include organizations from all over the world, including Australia, Romania and Nigeria.

Personally, I have come away with something
to take back to Camp Hemotion in Northern California every year and this year, I came up with a great new theme idea (Secret Agents!) to incorporate into our camp this summer.

For those who have attended for several years, it has become like a second home for one weekend a year. We have been fortunate to stay at the same hotel each conference, allowing attendees to become familiar with the best spots to grab a bite to eat in between sessions.

NACCHO is the premiere training and brainstorming ground for excellence in hemophilia summer camps around the world. Summer camp professionals from across the world come together for a time filled with the exchange of knowledge, learning and an atmosphere of fun and enjoyment. Professionals learned how to boost their respective camping programs to the next level.

Volunteers were able to learn new skills and techniques to add essential functions to their programs so campers can have a wonderful, positive experience in the various programs. NACCHO is truly the training and learning field for hemophilia summer camps where participants learned to go BOLD to create effective, timely and relevant programs for all participants.

The four-day weekend was filled with aliens and explorers as a Star Trek theme carried throughout the 11th annual program.

My First Year at Camp Hemotion

By Max Goldman, 7 1/2

The bus ride is really long - it's four hours and you get pretty tired on the ride. Once we there we were introduced to our cabinmates and counselors. You get to meet a lot of new people there and it's fun to do lots of new activities like ropes course, arts and crafts (my favorite), swimming and a lot of other ones I forget. There's also archery which is really fun and on the last day of camp you get to do a really fun water fight - counselors against the cabins. We got free time, but we also had to have showers at the end of every day. Yuck! The meals are great; my favorite meal was breakfast because we got to have bacon, eggs, waffles and syrup - really good stuff!

After a few days, I began to feel homesick because camp is a week long and it was my first time away from home. I was almost going to cry, but I held my tears back. At every meal we got mail call and it made me feel better to get letters from my family. My counselor was really strict and we couldn't have pillow fights. Some of my cabinmates were just like me and got a little homesick, but I made lots of new friends who I see sometimes at other hemophilia events.

Next summer I'm looking forward to camp to see my old friends, do archery and more arts and crafts. Bye!
44. Oklahoma Camp Independence

June 23-27, 2014
Open to: Boys & Girls with a bleeding disorder, Siblings
Ages: 7-17
Location: Camp Bond, Tishomingo, OK
Contact: Bob Goodley, ED
Oklahoma Hemophilia Foundation
405-463-6634
bgoodley@okhemophilia.org
www.okhemophilia.org

45. Oregon Camp Tapawingo

August 3-9, 2014
Open to: Boys & Girls with a bleeding disorder, Siblings
Ages: 7-17
Ages: 17-19 Counselors in Training
Location: Falls City, OR
Contact: Marita Postma
Hemophilia Foundation of Oregon
503-297-7207
marita@hemophiliaoregon.org

46. Pennsylvania Camp Hot-To-Clot

August 3-9, 2014
Open to: Boys & Girls with a bleeding disorder, Siblings, Children of affected adults
Ages: 7-17
Ages: 15-18 Leaders-in-Training Program
Location: YMCA Camp Kon-O-Kwee; Fombell, PA
Contact: Dawn Rotellini
412-327-1923
drotellini@hemophilia.org
or Alison Yazer, ED, 724-741-6160
Alison@westpennhemophilia.org
Western Pennsylvania Chapter of NHF
800-824-0016

47. Pennsylvania Camp Dragonfly Forest

July 29 - August 3, 2014
Open to: Boys & Girls with a bleeding disorder
Ages: 7-14
Ages: 15-17 Teen Leadership Program
Location: Inhilt Farm; Valley Forge, PA
Contact: 610-298-1820
info@dragonflyforest.org
www.dragonflyforest.org

48. Tennessee Camp Freedom

July 12-18, 2014
Open to: Boys & Girls with a bleeding disorder and carriers
Ages: 7-17
Location: Brandon Springs Group Camp, Dover, TN
Contact: Tennessee Hemophilia and Bleeding Disorders Foundation
615-900-1486, www.tbhdf.org

49. Texas Camp Ailihpomeh

July 13-18, 2014
Open to: Boys with bleeding disorders
Ages: 7-14
Ages: 15-17 Leadershhip Program
Location: Camp John Marc; Meridian, TX
Contact: Sabrina Farina LMSW, Camp Co-Director, 713-500-8353
Sabrina.Farina@uth.tmc.edu

50. Texas Camp United Hands

July 13-18, 2014
Open to: Boys & Girls affected by a bleeding disorder and their siblings
Ages: 7-17
Location: Camp Twin Creeks Minnehaha Springs, WV
Contact: Anita Graham
304-293-1205
agraham@hsc.wvu.edu

51. Utah Camp Valor

August 4-8, 2014
Open to: Boys & Girls with a bleeding disorder
Ages: 8-13
Siblings, ages 10-11 only
Location: Camp Wapiti; Tooele, UT
Contact: Scott Muir
smuir@hemophiliautah.org
Jan Western
western@hemophiliautah.org
801-484-0325
Utah Hemophilia Foundation
www.hemophiliautah.org

52. Virginia Camp Youngblood

July 20-25, 2014
Open to: Boys and Girls with a bleeding disorder, Siblings, living in Virginia
Ages: 7-17
May 16-18, 2014 Family Camp
Location: Camp Holiday Trails Charlottesville, VA
Contact: Kelly Waters, ED
Virginia Hemophilia Foundation
800-266-8438, www.vahemophilia.org
434-977-3781
www.campholidaytrails.org

53. Washington Camp I-VY

July 21-25, 2014
Open to: Children affected by a bleeding disorder and their siblings
Ages: 7-16
Location: Camp Huston; Gold Bar, WA
Contact: Luke Phifer, Camp Director
Bleeding Disorder Foundation of Washington
206-533-1660, www.bdfwa.org
general@bdfwa.org

54. West Virginia Camp HemoVon

June 16-20, 2014
Open to: Boys & Girls affected by a bleeding disorder or diagnosed carrier status
Ages: 7-14 (Age exceptions will be made on a case-by-case basis)
Location: Camp Lakotah
Wautoma, WI
Contact: Karin Koppen
Great Lakes Hemophilia Foundation
414-937-6782
kdaniels@glhf.org
www.glhf.org
www.campklottypine.org

55. Wisconsin Camp Klotty Pine

July 27- August 1, 2014
Open to: Boys & Girls with a bleeding disorder or diagnosed carrier status
Ages: 7-14 (Age exceptions will be made on a case-by-case basis)
Location: Camp Lakotah
Wautoma, WI
Contact: Karin Koppen
Great Lakes Hemophilia Foundation
414-937-6782
kdaniels@glhf.org
www.glhf.org
www.campklottypine.org
When Kelly and her family returned from their first Inhibitor Family Camp at Victory Junction in North Carolina, it was obvious the camp had a profound effect on her entire family. Others noticed it as well, "Family members who saw our pictures could not believe how happy and stress free we looked. They said Brian was a different kid... It’s like all the joy, happiness and fun that was stolen from him was restored. Brian was able to be a kid for the first time in a very long time," Kelly shares.

Across the country, local camp programs for families dealing with a bleeding disorder help provide a fun, safe environment where kids, parents and siblings alike get to meet other families faced with the same challenges. Until recently, there was not a family camp directed at meeting the unique needs for those faced with the added complication of inhibitors. Since 2010, Inhibitor Family Camp has provided not one, but two uniquely focused camps strictly for families living with an inhibitor. With camps located on both the east and the west coasts, the goal is to provide camp opportunities nationwide.

For many families, finally having the opportunity to connect and download with others in the same shoes is a game changer. "It gave my husband and me a chance to connect with other adults that deal with the financial, emotional and social aspects of this disease. For four days we felt 'normal.' Our lingo was understood, our day-to-day life and struggle was validated and I gained some hope again!" Kelly exclaims.

For others, Inhibitor Family Camp is an opportunity to reach out, share experiences and help families like Kelly’s. For Renee and her family, who have been attending camp since its inception, "We want to help others who are navigating what we have already been through. There is no pressure to share if you are not ready to do so. It’s a relaxed atmosphere that gives you the opportunity to connect with other families who are dealing with similar circumstances.”

Parents and children alike have the opportunity to get to know each other and bond over traditional camp activities such as horseback riding, archery and even a talent show. Special accommodations are made so every camper can participate. Renee tells us, “The modifications provided by the camp are wonderful in helping our son participate even when he is experiencing a bleed.”

For Kelly’s son Brian, “The activities gave him a huge self-esteem boost. It showed him there are other kids exactly like him. It was amazing to see him smile, really smile. He learned he was good at things like archery, horseback riding and bowling. My son finally has something to talk about, brag about, feel good about.”

Renee recalls one of her most memorable moments with her son at camp, “He hit a bulls-eye in archery after years of having a target elbow joint.” In addition to the numerous traditional camp activities, educational sessions and infusion seminars are offered to provide hands-on training, as well as news and updates relevant to patients living with an inhibitor.

Inhibitor Family Camp is providing a venue for families tasked with the additional burden of an inhibitor a relaxed environment to connect, learn and grow. From combating isolation, boosting self-esteem and just providing a setting for families to have a good time, these camps are helping people learn to better manage their condition and cope with the challenges that come with it. Kelly affirms, “It was a phenomenal experience. It showed us how to stop treating hemophilia and reminded us to start living with it!”

For more information on Inhibitor Family Camp visit: www.comphealthed.com/index.php/inhib/
In keeping with our long and successful tradition of grass roots advocacy, more than 300 members of the National Hemophilia Foundation traveled from every state across the country to convene in Washington, DC for Washington Days on February 26-28, 2013, calling on their representatives to discuss issues that matter to them. Proudly contributing and lending their voices to the cause from Matrix Health Group were David Burgeson (Florida), Matthew Compton (California) and Terry Stone (Virginia).

There is one thing you can count on, and that’s change. Although the needs of the bleeding disorders community over the years have changed and improved, it is so important to stay vigilant with regard to laws and policies that affect our healthcare accessibility and affordability. Two of the concerns discussed with legislators during Washington Days are of great concern to the community at large.

First was to rally support for H.R. 480, which addresses the recent and continuing shift of some insurance companies to move expensive biological products like clotting factor under newly created specialty tiers. Instead of a flat-rate copay, these new tiers require patients to pay a percentage range from 20% to 30%. Patients shared their monthly EOBs to explain that 20% or 30% of bills for clotting factor is just not manageable particularly with balance due statements of $30,000 or more per month.

Secondly, members asked to simply preserve the current funding from two sources that together provide critical support. Therefore, it is extremely important to maintain what we have as it is needed to help fund our hemophilia treatment centers across the country, supports surveillance of the blood supply and date collection, and funds important programming through NHF such as First Steps, Victory for Women and others, which have made an impact to so many affected by a bleeding disorder.

After the meetings wrapped up, representatives and legislative aides from across the country had a better understanding of our needs. The final sessions of Washington Days provided training to members, so they could keep this momentum going in their own states by learning how to make their state advocacy days successful and effective.

To help, NHF chose Washington Days to launch its newest tool to streamline advocacy information and make it user friendly. Advocacy.hemophilia.org is a new a website designed to keep members informed with the issues and where our voices are needed. This is yet again another way that NHF strives to help us help ourselves and stay involved. After all, when we share our stories, put our faces to our concerns and speak from the heart with great conviction and experience, together we are better! 💕
Matrix on the Move!

Tennessee
David Tignor, Stephen Lawrence and Donna Garner

Matrix Health Group was pleased to partner with Pfizer for a program on Exploring Emotional Well-Being in the Hemophilia Community. Many of our friends from the community gathered at The Butcher Shop Steakhouse in Cordova, Tennessee on December 3, 2013 to hear the presentation led by Linda Pollhammer, RN, Certified Nurse Educator. Together we learned to recognize many signs of depression and anxiety, how they affect our care and daily activities, and ways to cope and work through these feelings. This added great insight to the support roles and in some cases, gave an opportunity for the patients to hear it is okay to share feelings and that they are not the only ones who need an outreach. Many caregivers and family members quickly formed an impromptu support group among themselves.

Andrew Berkowitz, Hemophilia Specialty Manager, discussed many of Pfizer’s programs such as their trial program, gap coverage and copay assistance program, and its first mobile logging app, HemMobile. Andrew also demonstrated the ease of factor reconstitution with Xyntha’s Solofuse.

In addition to the presentations, the evening also provided a chance for blood brothers of all ages to share wisdom about health issues including ways to improve mobility and work through bleeds.

Blood sisters took the opportunity to ask about and discuss their own unique issues. Many also participated in lively discussions about insurance with the Matrix Health Group representatives while others raised questions regarding various medic alert jewelry and I.C.E. apps for smartphones.

Virginia
Terry Stone

So what happens when you get a group of women from the Virginia Hemophilia Foundation (VHF) together for Women’s Night Out in December? Well, you have some wild and crazy times, and that’s because the women are wildly fond of one another! The ladies were treated to a delicious dinner at the Lemaire Restaurant in the Historic Jefferson Hotel in Richmond on December 4, 2013. What a great location to gather, particularly since it was festively adorned with the most exquisite holiday decorations second to none! Hosted by CSL Behring, guest speaker and vWD advocate, Diane Rankin discussed ways to create a successful women’s initiative in our own community while sharing her personal story.

Following great conversation and dinner, the ladies of VHF ventured out and about aboard their James River Bus sleigh ride and viewed some
of the most brilliant and over-the-top holiday light displays Richmond has to offer. It was an obviously popular event as neighborhood streets were crowded with thrilled spectators ready to kick off their holiday mood. The displays were all certainly worthy of local news coverage! The ladies didn’t have to light up the town; the town was lit up for them!

After a lovely ride through the city, the group returned to the hotel and will be looking forward to new women’s events in the New Year, but this one will be difficult to top!

California
Marina Vera
The Hemophilia Foundation of Southern California schedules a Family Retreat and Holiday Party every year in Malibu, California and this year was no exception. December 7, 2013 began with a chilly downpour, canceling all outside activities. Indoor fun was still to be had until the sun returned brightly shining in the afternoon. With the outdoor activities back on schedule, the families were able to enjoy rock climbing while others escaped the brisk air and warmed up with soothing hot chocolate being served all day in the dining area.

Matrix Health Group had many of the children busy at our very popular arts and crafts table. We provided fabric Christmas ornaments in fun shapes and let the kids go crazy decorating them. Even some of the parents joined in making the arts and crafts! We are eagerly looking forward to next year’s retreat – who knows what activity Matrix Health Group will plan for 2014!

Idaho
Liselle Easto
On the snowy morning of December 7, 2013, members of the Idaho Chapter National Hemophilia Foundation came together for the Annual Family Conference and Holiday Party at the Hilton Garden Inn - Boise Spectrum in Boise, Idaho. Community members arrived from all areas of the state for education, good food and to wish each other a happy holiday.

Once registration was completed, attendees were given time to spend with vendors to hear about the latest and greatest in the industry. Following a taco buffet lunch, the children were escorted across the street to the Edwards Cinema to watch the movie Frozen. While they were entertained, the adults were treated to remarks by Taryn Yates, Executive Director, and Shane Bell, Board President. An interactive seminar in Communicating Assertively was followed by a session on Behavioral and Psychological Issues with Bleeding Disorders. Introduction of the St. Luke’s Pediatric Hematology staff came next with an announcement that the center had received an NHF grant to add a mental health professional to the team. Camp news was next, then dinner was served followed by more activities and holiday gifts for the children. Many chapter members commented this was one of the best conferences ever hosted by the chapter!

Virginia
Terry Stone
How better to herald in the holiday season than to share lunch with friends from the Hemophilia Association of the Capital Area (HACA) at the historic Mount Vernon Inn. We enjoyed a tour of Mount Vernon, home of George Washington, and time to explore the many exhibits and artifacts that chronicle the life and times of our nation’s first president.

It was like stepping back in time when the holiday season was aglow with the magic of simpler days. We modern-day observers were treated on December 7, 2013 to a journey back to the days of George Washington and the legacy he built. He thought of himself as a farmer, although he cultivated so much more during his life. During our lunch of turkey potpie, we listened to an historical interpretation from Dr. James Craik, George Washington’s personal physician, as he
regaled stories of the day and put to rest some of the interesting tales that have been floating around for many years. Did George Washington cut down that cherry tree? Were his false teeth really made of wood? Hmmm?

After enjoying our colonial fare, we made our way over to the magnificent home for a group tour. Our members, young and old alike, had many great questions for the docents and everyone seemed to learn interesting new facts about George Washington! Who said history isn’t fun? Well, no one from this group!

After spending a bit of free time exploring the grounds and the museum, we said our goodbyes and spread good tidings of the holiday season with one another, just like the colonialists would have done. It’s always a wonderful day when HACA members get together - another joyful day shared among friends!

California
Marina Vera
On December 14, 2013, Zito’s Pizza in Orange, California was the venue for the Hemophilia Foundation of Southern California’s Annual Hemophilia Holiday Party. The reserved party room kept the sports fans content watching the big screen televisions broadcasting football, soccer and basketball games while everyone got their fill of the delicious food. The children had a great time decorating gingerbread men with icing and candies at the arts and crafts table provided by Matrix Health Group. I enjoyed every moment of watching the smiling faces of the children as they created their edible art. The highlight of the party was of course, the surprise visit from Santa. It’s always fun to watch little faces light up with such glee!

South Carolina
Peggy Gay
Fortunately, rainy weather did not keep families from attending the South Carolina Hemophilia Chapter’s The Lights Before Christmas Holiday Celebration on December 14, 2013 at the Riverbanks Zoo and Gardens in Columbia, South Carolina. Along with music and raffles, the festive evening included a special visit from Santa with gifts for the children.

Sue Martin, Chapter President, entertained the children with a reading of The Elf On the Shelf, a popular story of an elf sent to the North Pole to help sort through the naughty and nice lists. The book was then raffled to one of the lucky families. Everyone had a wonderful time visiting and
reminiscing about the past year as a delicious dinner was relished.

**Virginia**  
**Terry Stone**  
The holiday season is a time where families come together to celebrate in their own special way. The Virginia Hemophilia Foundation family is no exception, hosting three gatherings across the state making it easy to get together and share holiday cheer - The Ramsey United Methodist Church in Richmond, Children’s of the King’s Daughter HTC in Norfolk and the Vinegar Hill Café in Charlottesville.

All events were infused with great food, fun and a visit from the jolly man himself. Kids were delighted with gifts wrapped with care and teenagers were treated to the most awesome and coolest gifts ever... gift cards!

It was a nice opportunity to take a break from holiday shopping and the hustle and bustle of the malls, and just hang out with special friends to enjoy all the blessings of great friends and a community we appreciate. As the year came to a close, thoughts of what a wonderful year it was were ample... happy kids that went to camp, many social gatherings, educational seminars and lots of fun! Many thanks to Kelly Waters, Executive Director, and Heather Conner, Chapter Administrator, for their dedication to raising this chapter to new heights and striving to make each year better!

**Illinois**  
**Eva Kraemer**  
Greg McClure, founder of the Marcus McClure Big Dreams Foundation, and Bayer hosted an Educational Program on Saturday, December 21, 2013 in Sauk Village, Illinois. Greg focused on nutrition - something that people with or without a bleeding disorder could really “sink their teeth” into. Since the holidays were well underway, the importance of eating a well-balanced meal, including a variety of fruits and vegetables, helped us all make better choices and start out 2014 on a healthier path. The welcoming environment as well as the expertise with which the program was presented set a perfect stage for discussion. I was honored to be invited and take part in a relevant program surrounded by warm and wonderful people.

**Maryland**  
**Terry Stone**  
The Super Bowl was not the only game in town during the first weekend in February 2014! The Hemophilia Foundation of Maryland hosted families from across the state on the eve of the Super Bowl game for dinner and their Annual Meeting at the BWI Hilton Hotel in Baltimore, Maryland. While the children had their own fun with games and activities, the adults shared time together mingling over dinner and listened to a great program of speakers as well as several award announcements for service to the chapter. Emma Miller, Executive Director, and Jamie Edwards, Foundation Administrator, worked hard to ensure a fun and informative evening for all.

Matrix Health Group was there to support the chapter and share information. Since it was Super Bowl weekend, a tailgating theme was in full effect at the Matrix Health Group booth complete with tailgater cookbooks and wooden spoons along with great information on how we make a difference for all we serve. So whether it’s caring for your pharmacy needs, or making sure you have a great recipe for the big game, we’re here for you! Go Team Matrix!

**Virginia**  
**Terry Stone**  
There is no better feeling than when you participate in your State Advocacy days sharing your voice and your story to bring awareness and make a difference. For the
members of the Virginia Hemophilia Foundation (VHF), they know that feeling well after they rallied together to call on their legislators over Martin Luther King weekend January 20, 2014 in Richmond, Virginia. The VHF families united and together they addressed issues that affect the bleeding disorder community. They came with their loved ones, their concerns and their insurance explanation of benefits (EOBs) ready to explain why their issues are so important and how it affects their family.

Issues to share this year were ones that reach beyond the bleeding disorders community and affect other patient groups as well. The first was to address the recent practice of some insurance companies moving expensive biological drug to a newly created Tier IV on the pharmacy benefit formulary. Rather than pricing for this tier at a flat rate, some plans are charging a coinsurance of 20% to 30%. The goal of House Bill 304 would limit the cost of this tier IV to a flat rate not to exceed $150.

Also on the docket were Senate Bill 201 and House Bill 308, which ask for 60-day notification of a plan that decides to move a particular drug from one tier to another. There have been instances where a patient has gone to refill a prescription only to find out during dispensing that the drug has been moved to another tier with an extremely high cost, leaving patients to come up with the extra at the register or forego their medicine. The final issue was to discuss how important it is for Virginia to expand Medicaid and keep people insured.

The visits were well received. Such advocacy is part of our culture. There were patients, parents and siblings who came to meet with their representatives. The teens, however, were a force worthy of their own mention. The chapter has made it their mission to empower our youth to carry the message forward that this community will continue to be the grass roots leader to ensure laws that affect access, affordability and fair practices with our healthcare is, and always will be, their focus.

Becky Bowers-Lanier, VHF’s Advocacy Consultant, led the training for the adult attendees. The teens had their own training and then enjoyed some great activities at G Force such as laser tag, go-cart racing, and a chance to work with a chef at Mise En Place cooking school where they rolled up their sleeves and tried their hand at prepping and cooking their own meal.

For those who participated in Richmond Days, keep the feeling of a job well done with you. For those thinking of joining and sharing your voice with your own chapter’s advocacy days, do it! Your voice makes all the difference!

Illinois
Lisa Miller and Eva Kraemer

The Twenty-Fifth Annual Spring Gala to support the Bleeding Disorder Alliance Illinois (BDAI) was held on March 1, 2014 at the Marriott Chicago O’Hare. Platinum sponsors, Bayer and Pfizer, along with over 150 elegantly adorned guests helped raise urgently needed funds for BDAI to help improve the quality of life for persons affected by hemophilia and other bleeding disorders.

Bob Robinson, Executive Director, and Ramona Towner, Board President, set the mood for the evening as guests indulged upon Amish chicken and bourbon braised
short ribs. Dessert did not disappoint with a baked cherry almond tart with a white chocolate straw to sip up every tasty bit. The night featured silent and live auctions of incredible values, as well as raffles, music and dancing. Generosity was in full swing and merriment was had by all. Matrix Health Group was proud to be a sponsor for such a worthy cause!

New York
Terry Stone
Certainly a trip to the Big Apple is exciting all by itself, but add the arrivals of factor IV folks with an eagerness to share, learn and rekindle friendships, there is no better recipe for a great weekend as families from across the country were once again welcomed to the Coalition for Hemophilia B Annual Fundraising Dinner and Symposium.

The weekend of March 8-9, 2014 started with a fundraiser dinner aboard the beautiful Atlantica Yacht Friday evening. A great time was had by all as new friends were made and old friends caught up. The next morning everyone got down to business as Dr. Christopher Walsh of Mt. Sinai Hospital in New York spoke about what’s new in hemophilia care. He also discussed that not only will there be different companies coming to market with longer lasting products, but there will even be choices given different scientific approaches as to how to achieve sustainability. Science and new technologies continue to evolve and this community will certainly benefit from better therapies and disease management as a result.

Val Bias, CEO of the National Hemophilia Foundation shared the current initiative called My Life, Our Future: Genotyping. He discussed the importance of having the data concerning each of our unique genotype as it relates to hemophilia. Science is getting so specific and to continue to drive a better understanding of our genetic scenario and develop research that is targeted, it is of critical importance to have data not only from the patient, but from the family as well. The genotyping is available through our network of hemophilia treatment centers.

Other presentations included a well-balanced program of helpful information from insurance updates and the Affordable Care Act, a self-help workshop on developing positive assertiveness skills, overcoming life challenges at various stages of life, infusion class for those who want to just watch or to learn new tricks to stick, and some break-out sessions divided by the sexes for their own time to rap. While the adults were having a great day, the children, tall and small, had great activities to keep them equally happy. The children started their day with Chris Monda, Pro Bowler with hemophilia B, then were off to the Discovery Times Square, a Getting’ in the Game session and a program called Designing Your Future, along with a teen break-out session.

Time was available throughout the day to visit with the many exhibitors like Matrix Health Group who were there to support the efforts of the Coalition and meet the families who wanted to know all about the many products and services available. The day came to a close with a big Hemophilia B family dinner at Clyde Frazier Restaurant in the heart of the city.

Matrix Health Group gives a warm and heartfelt THANK YOU to Kim Phelan, VP of the Coalition, along with her dedicated team, President Wayne Cook, Dr. David Clark, and all of the hard working volunteers and sponsors who made the weekend so informing, fun and memorable for all.

Answers to the puzzles on page 35

**Camp Trivia!**

4. b - Heart surgery
5. a - NACCHO
6. b - Camp Needle Poke
7. c - Hemophilia backward
8. a - Michigan
9. d - a, b and c

1. a - Michigan
2. b - 1969
3. d - a, b and c
Cycling Across America to Support Save One Life!

Barry Haarde is ready to roll again--this time through Old Dixiel Wheels for the World 2014: Big Wheels Keep On Turnin' will take Barry 2,904 miles through nine southern states. This 27-day ride will begin in Costa Mesa, California on April 19 and end in Savannah, Georgia on May 17. Why does he do this amazing, crazy thing? Barry's going to raise $45,000 with your help for Save One Life!

Barry made history when he became the first person with hemophilia to bike across the USA in 2012. From Oregon to New Hampshire, Barry covered 3,667 miles in 50 days. In 2013 Barry completed a second cross-country challenge: Wheels for the World 2013: FAST & FURIOUS! From southern California, he rode 3,456-miles in just 33 days, averaging an astounding 120 miles a day, to end in Massachusetts.

Help us raise $45,000 with Barry!
Visit www.SaveOneLife.net and make a donation today.

All proceeds go to support the operations and programs of Save One Life.

Save One Life is an international nonprofit that provides direct financial aid to more than 1,100 impoverished people with bleeding disorders in twelve developing countries. In addition to direct sponsorship, it also provides funding for camps, scholarships, micro-grants and support to locate patients in rural areas.
Upcoming Events

April 11, 2014 Ohio
Northern Ohio Hemophilia Foundation
216-834-0051, www.nohf.org
Black & Blue Ball Masquerade Style!
Ritz-Carlton; Cleveland, OH
Contact: Susan Moore 330-472-2289

April 12-13, 2014 Illinois
Bleeding Disorders Alliance Illinois
312-427-1495, www.bdaoi.org
Statewide Fun & Education Weekend
Rockford Rock Tower Resort; Rockford, IL
Contact: Eva Kraemer 608-852-3777
(Habla español)

April 17, 2014 Tennessee
TN Hemophilia & Bleeding Disorder Found.
888-703-3269, www.thbdf.org
FF & E Golf Tournament
Windyke Country Club; Memphis, TN
Contact: Shannon Cassada 423-241-9356

April 26, 2014 Texas
Texas Central Hemophilia Association
972-386-3865, www.texcen.org
Denim & Diamonds Gala
Austin Ranch; Grapevine, TX
Contact: Tammy Davenport 936-524-4907

April 19, 2014 California
Hemophilia Foundation of Northern CA
Hemophilia Walk
Cesar Chavez Park; Berkeley, CA
Contact: Bobby Wiseman 415-726-6187

April 27, 2014 Virginia
Virginia Hemophilia Foundation
800-266-8438, www.vahemophilia.org
Wine Tasting Event
C’est Le Vinwine Bar & Art Gallery
Richmond, VA
Contact: Terry Stone 703-795-6269

April 28, 2014 Tennessee
TN Hemophilia & Bleeding Disorder Found.
888-703-3269, www.thbdf.org
Music City Golf Tournament
West Haven Golf Course; Franklin, TN
Contact: Shannon Cassada 423-241-9356

May 3, 2014 California
Hemophilia Foundation of Southern CA
323-525-0440, www.hemosocal.org
Family Information Day
Los Angeles Zoo; Los Angeles, CA
Contact: Marina Vera 323-252-8682

May 3, 2014 Florida
Florida Hemophilia Association
305-235-0717, www.floridahemophilia.org
3rd Annual Walk In the Jungle
Jungle Island; Miami, FL
Contact: Hector Heer 954-940-1248
(Habla español)

May 3, 2014 Tennessee
TN Hemophilia & Bleeding Disorder Fnda
888-703-3269, www.thbdf.org
Be a Factor 5K
Loudon High School; Loudon, TN
Contact: Shannon Cassada 423-241-9356

May 5, 2014 North Carolina
Hemophilia of N.C. Chapter
800-990-5557, www.hemofoundation-nc.org
Annual Meeting Educational Day
Location: Omni Charlotte Hotel
Charlotte, NC
Contact: Peggy Gay 864-275-0246

May 7, 2014 California
Hemophilia Council of California
916-448-7444, www.hemophilica.org
Future Leaders/Legislative Day
Sacramento, CA
Contact: Bobby Wiseman 415-726-6187

May 12, 2014 California
Hemophilia Foundation of Northern CA
Board of Directors Meeting
HFNC office; Emeryville, CA
Contact: Bobby Wiseman 415-726-6187

May 17, 2014 Washington, DC
Hemophilia Assoc. of the Capital Area
703-352-7641, www.HACAcares.org
Educational Seminar
Madame Tussauds; Washington, D.C.
Contact: Terry Stone 703-795-6269

May 12, 2014 Ohio
Tri-State Bleeding Disorder Foundation
513-961-4366, www.tsbdf.com
Search for the Holy Grail
Fundraising Scavenger Hunt
Holy Grail Restaurant; Cincinnati, OH
Contact: Rania Salem 513-470-5500

May 20, 2014 California
Hemophilia Assoc. of San Diego County
619-325-3570, www.hasdc.org
Annual Golf for a Cure Tournament
The Crosby Club; San Diego, CA
Contact: Heath Messerly 619-787-0916

May 24, 2014 Kentucky
Kentucky Hemophilia Foundation
Family Zoo Day
Louisville Zoo; Louisville, KY
Contact: Rania Salem 513-470-5500

May 30, 2014 Florida
Matrix Health Group and Foundation Hope & Life
Bonaventure Country Club; Weston, FL
Contact: Hector Heer 954-940-1248
(Habla español)

June 2, 2014 Virginia
Hemophilia Assoc. of the Capital Area
703-352-7641, www.HACAcares.org
15th Annual Golf Tournament
Old Hickory Golf Club; Woodbridge, VA
Contact: Terry Stone 703-795-6269

June 7-7, 2014 South Carolina
Hemophilia of SC Chapter
Meeting & Upstate Education Day
Embassy Suites Golf & Conference Center; Greenville, SC
Contact: Peggy Gay 864-275-0246

June 6-8, 2014 Wisconsin
Great Lakes Hemophilia Foundation
414-256-0007, www.glhf.org
Bleeding Disorders Conference
Kalahari Resort; Wisconsin Dells, WI
Contact: Eva Kraemer 608-852-3777
(Habla español)

June 7, 2014 Maryland
Hemophilia Foundation of Maryland
410-661-9007, www.hfmonline.org
5K Race to Stop the Bleeding
Quiet Waters Park; Annapolis, MD
Contact: Terry Stone 703-795-6269

June 7, 2014 Texas
Texas Central Hemophilia Association
972-386-3865, www.texcen.org
TexCen Annual Meeting
Dallas-Fort Worth, TX
Contact: Tammy Davenport 936-524-4907

June 13-15, 2014 Tennessee
Tennessee Hemophilia and Bleeding Disorder Foundation
888-703-3269, www.thbdf.org
Tennessee Annual Meeting
Embassy Suites Nashville SE Murfreesboro, TN
Contact: Cyndy Coors 251-243-1623

June 17, 2014 Illinois
Bleeding Disorders Alliance Illinois
312-427-1495, www.bdaoi.org
Driving fore Hemophilia Golf Tour.
Ruffed Feathers Golf Club
Lemont, IL
Contact: Lisa Miller 630-698-8775

June 20-21, 2014 Virginia
Virginia Hemophilia Foundation
800-266-8438, www.vahemophilia.org
Annual State Meeting
Location Omni Hotel; Richmond, VA
Contact: Terry Stone 703-795-6269

June 20-22, 2014 Ohio
SW Ohio Hemophilia Foundation
937-298-8000, www.swohiohemophilia.org
Family Fest
Higher Ground Retreat Center
Brookville, Indiana
Contact: Rania Salem 513-470-5500

June 28, 2014 Ohio
Tristate Bleeding Disorder Foundation
513-961-4366, www.tsbdf.com
Summer Education Program
Coney Island; Cincinnati, OH
Contact: Rania Salem 513-470-5500
Hi Kids!
Here's a little camp trivia quiz. See how many you can answer correctly! Answers are on page 32.

**Camp Trivia!**

1. Where was one of the very first hemophilia camp held?
   a.) Michigan  b.) Arizona  c.) Florida  d.) New Mexico

2. What year was the first hemophilia camp held?
   a.) 1937  b.) 1969  c.) 1980  d.) 1949

3. Which of these awards are given to first-time self infusers?
   a.) Big Stick Award  b.) Butterfly Award  c.) Little Stick Award  d.) a,b & c

4. Illinois' Camp Warren Jyrch is named after Warren C. Jyrch. What is he famous for?
   a.) Donating the camp grounds in Illinois
   b.) First person with hemophilia in Illinois to have open-heart surgery
   c.) Having the fastest time on the climbing wall at camp
   d.) Being the first camper to get poison ivy

5. Which organization is responsible for the training and education of leadership for bleeding disorder summer camps?
   a.) NACCHO - North American Camping Conference of Hemophilia Organizations
   b.) HCT - Hemophilia Camp Trainers
   c.) HFA - Hemophilia Federation of America
   d.) NHF - National Hemophilia Foundation

6. Which of these is NOT a bleeding disorder camp?
   a.) Camp Nopokamee  b.) Camp Needle Poke
   c.) Camp Wannaklot  d.) Camp Notaclotamongus

7. Where did the Texas camp name “Camp Ailihpomeh” come from?
   a.) Scrabble letters left on a board  b.) In honor of camper Tommy Ailihpomeh
   c.) Hemophilia spelled backwards  d.) A typing error

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**SuDoku!**

Fill in the grid so that every row, every column, and every 9 by 9 box contains the numbers 1 through 9.
Our Vision and Mission are realized through the value we place in five guiding principles. These values represent our commitment to our employees, patients, and the community, driving our organization to excellence. These core beliefs define our culture and provide a means for us to measure our success. By using these principles as a standard for excellence, we become the logical choice for consumers with specialty pharmacy needs. These attributes represent the very best of what our company stands for and they remain at the forefront in all we do.

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.

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