Matrix Health Group

A BIOMATRIX SpRx Company

NEWS

DEDICATED TO MAKING A DIFFERENCE

> **If you find a path with no obstacles, it probably doesn't lead anywhere.**
>
> ~ Frank Clark

WINTER 2018

VOLUME 13 | ISSUE 1
WINTER 2018

MISSION + VISION

The **MISSION** of Matrix Health Group is to provide individualized, focused pharmacy and support services to people with chronic conditions nationwide.

Our **VISION** is to enhance the lives of those we are privileged to serve.

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

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

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

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

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

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

FINE PRINT

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

The purpose of Matrix Health Group News is to provide information such as current news, upcoming events, educational matters, personal stories, and a variety of opinions and views on topics of interest to the bleeding disorders community.

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

Health related topics found in Matrix Health Group News are for informational use only and are not intended to take the place of treatment or medical advice provided by your healthcare professionals or hemophilia treatment center. Please consult with your health care professionals when medical questions arise.

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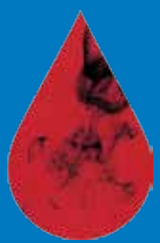

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A NOTE FROM THE EDITOR

Dear Readers:

Happy New Year! 2018 abounds with promise and new opportunities for the bleeding disorders community. New therapies and changing treatment paradigms are offering patients more options for managing their bleeding disorder.

We have some exciting changes of our own to share! This year, Matrix Health Group will formally unite under the name BioMatrix SpRx. BioMatrix SpRx was formed when Matrix Health Group merged with specialty pharmacy BiologicTx in 2015.

Our organization currently represents a growing family of companies who are committed to providing individualized care and support services focused on improving our patients' quality of life. Our promise and determination to provide our patients with the best service possible will never waiver. More information will be shared soon!

In the meantime, please enjoy this latest issue filled with articles addressing research, advocacy and a collection of personal stories as families share their experiences of having a child with a bleeding disorder.

We at Matrix Heath Group – soon to be BioMatrix SpRx – wish you peace, prosperity and happiness in the New Year!

Maria Santucci Vetter
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- Multifaceted team approach promoting adherence to treatment plans, resulting in positive health outcomes
- Informative quarterly newsletter, MATRIX HEALTH GROUP NEWS

MATRIX HEALTH GROUP TO BECOME

BioMatrix SpRx

What's in a name?

Matrix Health Group has provided exceptional pharmacy and support services for the bleeding disorders community for nearly twenty years. Since our first acquisition in 2011, we've been uniting leaders in the specialty pharmacy field to expand and enhance our demonstrated, proven our model of care. Today, our family of companies has grown to include 11 pharmacy locations nationwide. Our commitment has and will continue to be the same: providing outstanding pharmacy and support services to the patients we are privileged to serve. Our current family of companies include: Matrix Health, Factor Support Network, Medex Biocare, BiologicTx and Elwyn Pharmacy Group. This year, we are excited to announce formal unification of under one name: BioMatrix SpRx.

BioMatrix SpRx will continue to expand the Matrix Health Group legacy. As we move into this new chapter, know that our dedication and commitment to the bleeding disorders community remains the same. Over the coming months we'll be communicating more details of this exciting transition. Stay tuned for more news!

Matrix Health · FACTOR Rx SUPPORT NETWORK · MEDEX BIOCARE · BiologicTx · Elwyn PHARMACY GROUP

#GIVINGTUESDAY

For this year's Giving Tuesday, BioMatrix proudly presented the Hemophilia Federation of America with $10,000 to support the Helping Hands program. Annually, Helping Hands provides emergency financial assistance for hundreds of families in the bleeding disorder community.

CONGRATULATIONS TO OUR 2017

In 2017, Matrix Health Group offered nine $1,000 scholarships for bleeding disorders community members seeking higher education. These scholarships honor the memory of several individuals who impacted the bleeding disorder community in unique ways. Given the growth of our scholarship opportunity, in 2017 we partnered with Hemophilia Federation of America to administer the program, including independent third-party evaluation of applicants.

It is with great pleasure we announce the 2017 recipients of our Memorial Scholarship Program. Thank you to everyone who applied and we wish you great success in each of your bright futures!

AHMED ALBADRI – Joe Holibaugh Memorial Scholarship

Born in Iraq, Ahmed Albadri faced significant challenges growing up with severe hemophilia. Despite great adversity, Ahmed was determined not to let his bleeding disorder control his life. One outlet for Ahmed was focusing on education. Earning high marks through his academic career, Ahmed studied Chemical Engineering before relocating to the U.S. as a refugee in 2013. Ahmed will be taking English courses at the Central Piedmont Community College Charlotte, North Carolina. He shares, "I want to continue my education, stay strong and never give up. My bleeding disorder will not beat me."

RYAN BALOG - Ron Neiderman Memorial Scholarship

Growing up with vWD, Ryan dealt with restrictions and precautions that come with managing a bleeding disorder. Getting involved with the community provided Ryan with mentorship and support, influencing his decision to become a teacher. "I received so much assistance from the community, it inspired me to pursue a degree in teaching. Even though vWD has caused many challenges for me personally, it has enabled me to meet people that have guided me in a positive way, and inspired me to believe that I can be successful." Ryan will graduate in 2019 with a degree in Middle Level Education Mathematics from LaRoche College in Pittsburgh, PA.

DAVID CHEUNG – Tim Kennedy Memorial Scholarship

As a young child, David Cheung was diagnosed with factor IX deficiency. He recalls, "Within the first year of my diagnosis, I felt crushed...alone and stigmatized. I felt as if no other individual my age struggled with the limitations I faced." These perceptions began to change as David got active with his local bleeding disorder camp program. Returning year after year, David became a counselor. "My experiences with hemophilia and camp provoked my ambition to attend medical school...I hope to find a future in hematology to give back to the community." David will complete his Doctoral degree at St. Louis University in 2021.

ANGELA KESSLER – Millie Gonzalez Memorial Scholarship

"Having a bleeding disorder is helping me to become a better person. Someone who is more compassionate, grateful, and strong." Angela studies at University of Wisconsin Stevens Point, pursuing degrees in Clinical Laboratory Science and Spanish with a minor in Chemistry. She cites her experiences with vWD as a primary influence in her career path and educational goals, "I hope to one day contribute to a medical advancement that will benefit the bleeding disorder community." Angela actively volunteers with several community organizations and enjoys raising awareness and funds for the bleeding disorder community.

MEMORIAL SCHOLARSHIP RECIPIENTS!

TREVOR MARTIN – Mike Hylton Memorial Scholarship

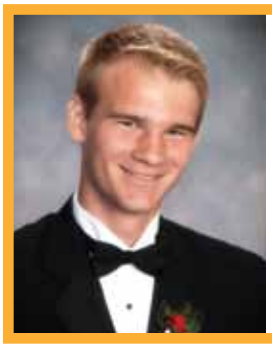
Trevor is studying Commercial Music / Music Business at Belmont University in Nashville, Tennessee. In addition to his studies, Trevor volunteers as a counselor at a camp for kids with bleeding disorders. Witnessing the positive effects of maintaining his prophylactic regimen (no bleeds for the past four years!), Trevor feels compelled to serve the community to "Help these young men learn to live a normal life with hemophilia and be able to be open about their disorder." Trevor shares, "I know that I will face more challenges with hemophilia, but with a positive attitude and a will to succeed, I know I can overcome anything!"

SARA QUILLEN – Millie Gonzalez Memorial Scholarship

Sara Quillen will begin her collegiate career in 2018. Sara is pursuing a Bachelor of Science in Nursing at East Tennessee State University in Johnson City. Even as a freshmen, Sara's primary career objective is crystal clear, "My career goal is to be a pediatric family nurse practitioner. " Leveraging her experience living with vWD to affect positive change for others, Sara shares, "I strongly desire to serve the medical community that helped me. I have the desire, the determination and the insight to help people fight and to find a cure for rare diseases. I want to be that type of a medical professional that people seek and trust for their medical care."

JOHN RHEA – Joe Holibaugh Memorial Scholarship

John will complete a Master's Degree in Health Administration at University of Kentucky in Lexington in 2019. He currently works in healthcare as a physical therapy technician, helping patients achieve improved health. He has also dealt with his own challenges having hemophilia. "My life has been influenced by hemophilia tremendously. I have had to learn to do things differently from activities to sports. I had to embrace what I could do." John got creative when it came to enjoying Lacrosse. He helped his school team as a manager. He shares, "I got to be as close to the sport as I could without actually putting myself in harm's way. It was very rewarding."

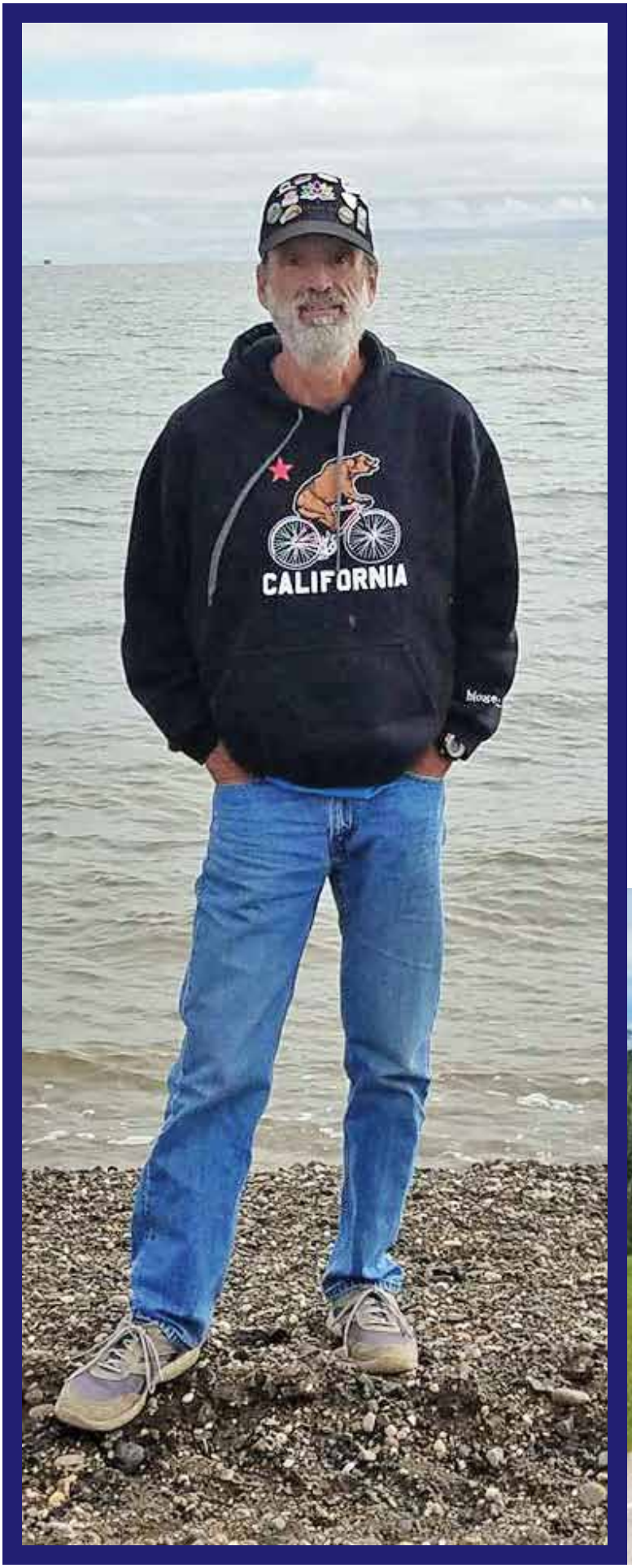


ANDREW SNYDER – Joe Holibaugh Memorial Scholarship

Andrew does not view his hemophilia diagnosis as a burden, even with the additional challenges of an inhibitor, Andrew shares, "Hemophilia is not a burden, it is a gift...you come to appreciate every aspect of life at a very early age, which makes you more mature and knowledgeable." Despite his hardships, Andrew has excelled in soccer, mentored kids with chronic health conditions, participated in the drama club and started a Star Wars group at his high school. In 2018, Andrew will begin his college career pursuing a Bachelor of Science in Nursing at Villanova University in Villanova, Pennsylvania.

DANIEL WARREN - Tim Kennedy Memorial Scholarship

Daniel is pursuing a Master's of Music Education at James Madison University in Harrisonburg, Virginia. He has extensive experience leading as both a music and band director. He cites his bleeding disorder as providing him unique perspective. He notes, "Growing up and living with hemophilia, while a challenge at times, has given me self-discipline and fantastic insight on looking at the big picture, the macro perspective of life rather than constantly concentrating on minute matters." Daniel is active in the community, currently serving on the board of directors for the Virginia Hemophilia Foundation.



Barry Haarde doesn't let hemophilia get in the way of his ambitions. The advocate, fundraiser and cyclist has completed five cross-country trips by bicycle. In 2017, Barry completed the sixth and final installment of his "Wheels for the World" initiative along the Alaskan highway. The objective: to raise awareness about hemophilia and HIV while fundraising for Laurie Kelley's charity, *Save One Life*. All proceeds directly support *Save One Life's* vision of providing all people with bleeding disorders in the developing world medical and economic resources necessary to live independent and productive lives.

RIDING THE GREAT ALASKAN HIGHWAY

AN INTERVIEW BY JUSTIN LINDHORST

Matrix Health Group has been a proud supporter of Barry and his cross-country rides. He recently shared some thoughts regarding his unforgettable trip along the Alaskan Highway:

Tell us about the route you chose and why.

The first five installments of "Wheels for the World" began on the west coast, traversed the country, and concluded on the east coast. For 2017, we chose to do something a little different and decided on the Alaskan Highway and beyond for our route.

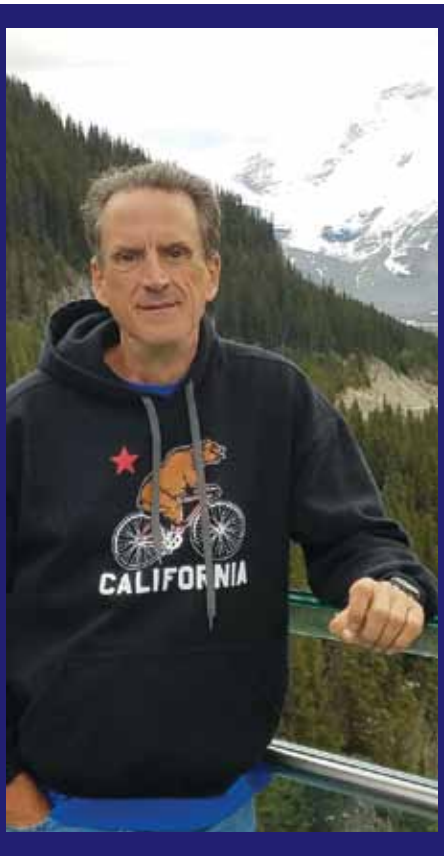
The ride began in Dawson Creek, British Columbia and headed northwest through the Yukon, entered Alaska, and concluded near Fairbanks. After completing the Alaskan Highway, I continued on around Alaska circling back to Fairbanks. I continued by plane and van to the northernmost point in the U.S., which is Barrow, Alaska. It was a nice complement to last year's tour from Seattle, Washington to Key West, Florida, which is the southernmost point in the 48 contiguous states.

Were there unique challenges associated with this ride in comparison to rides through the lower 48? If so, how did you handle them?

Yes! The biggest challenge I confronted on the Alaskan Highway tour was when I suddenly found myself sprawled out in the oncoming traffic lane after a high-speed collision with another rider. We crashed pretty badly and I had to take a week off the bike settling for the relative comfort of

the tour's support van while my lower back healed from the effects of the crash. All things considered, I was fortunate to even continue the tour given the extent of injuries and overall pain levels, which lingered for several months after the incident. Sadly, the other rider with whom I collided was not able to continue after being diagnosed with a concussion and fractured pelvis.

The weather was a bit of a challenge as well. Quite a few days were defined by rain and wet riding conditions as well as temperatures as low as the 40s. Local residents encountered along the way consistently commented on the fact this particular summer was the coldest and wettest many had experienced in years.



What was your most memorable moment?

There were so many! The scenery on this ride was truly beyond spectacular. Mountain ranges, glaciers and boundless wildlife defined virtually every day of the ride. I shot over 2,500 photos during the seven weeks of this tour. I suppose the aforementioned crash was also quite memorable as it was the first time in all the tours that I collided with another rider. The value of prophy dosing came into play in a big way, as well as the educational experience of trying to obtain factor in a remote portion of a foreign country.

How much was raised for SOL?

This year, we lost our primary sponsor who had been our biggest funder for the first five tours. Donations were also a bit off this time, but in spite of those challenges, we were still able to raise over $35,000 thanks to our sponsors, including Matrix Health Group.

We achieved a 20,000+ total mileage benchmark, and our combined fundraising efforts for all six tours broke the $250,000 mark this year!

What's next?

In view of diminishing fundraising totals, the Alaskan Highway tour will most likely be my last ride for *Save One Life*. I may focus on shorter rides, such as the many local fundraising rides in my area and of course, the Hemophilia Federation of America bike ride fundraisers as well as the California Coastal ride, which benefits the California Council of Hemophilia chapters. I hope to someday have the chance to complete another cross-country tour, of course.

In 2012, I set out to become the first person with hemophilia to ever ride across our nation and having now completed five trips across America, I know I will always consider these rides and the funds raised from them to be my greatest accomplishment. As always, I express my eternal thanks to *Save One Life*, all our sponsors and people who made donations. Without each of you, "Wheels For the World" would not have been possible.

Interested in how you can combine your cycling interest with advocating and fundraising for the community? Check out these great rides occurring in 2018!

Gears for Good:
www.hemophiliafed.org/programs/gears-for-good/

California Coastal Ride:
www.hemophiliaca.org/programs/2017-california-coastal-ride/

BOOK REVIEW

BLOOD ON THEIR HANDS:
HOW GREEDY COMPANIES, INEPT BUREAUCRACY, AND BAD SCIENCE KILLED THOUSANDS OF HEMOPHILIACS

Authors: Eric Weinburg and Donna Shaw
Rutgers University Press 285 Pages ISBN: 9780813576220

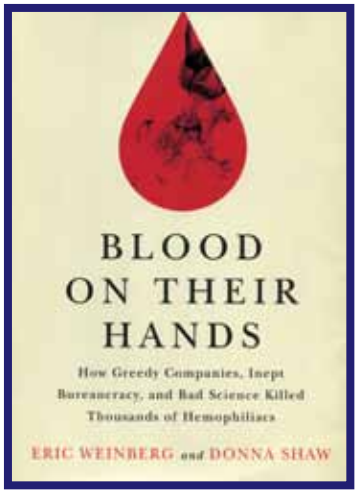
BY SHELBY SMOAK

Faulkner was likely right when he wrote, "The past is never dead," for *Blood on Their Hands: How Greedy Companies, Inept Bureaucracy, and Bad Science Killed Thousands of Hemophiliacs* by Eric Weinberg and Donna Shaw bears that truth, reminding the hemophilia community of its own history with HIV and AIDS. The nonfiction work—written in sparse, quickly paced prose—chronicles lawyer Weinberg's involvement with the 1994 class action negligence lawsuit against manufacturers of HIV-tainted factor products. It's a tough story to read, but the work is infused with the strength of a resilient community set on bringing to task those responsible for the tragic HIV infection that almost wiped out a generation of bleeders.

Weinberg and Shaw's account begins in June 1991 when a mother (herself infected with HIV) walks into Weinberg's law office and says of her hemophiliac husband's death from AIDS, "The more I think about it, the more I wonder how could it be? How could it happen and nobody did anything wrong?" As Weinberg begins to uncover the answer, *Blood on Their Hands* becomes a narrative of obstacles and how Weinberg, with help from others, overcomes them. One hurdle involves the case strategy; pinpointing plasma-derived HIV infection to a single dose from a single manufacturer would be impossible to show in a population that uses multiple doses, often from different manufacturers. This leads to the "viral-inactivation theory" where the suit claims manufacturers' negligence in failing to implement a cleaner plasma product. Weinberg collects data to prove that drug companies were aware of viral contaminants in the factor and ignored experts' advice to implement safety mechanisms like heat-treatment or detergent rinse in their manufacturing process.

As word gets out about Weinberg's case, it soon draws in more lawyers, more clients, and more defendants: Big Pharma, government regulators, and the National Hemophilia Foundation (NHF). The narrative is then driven by two tensions: the competing goals of the law team and Weinberg's quest for case evidence. With lawyers like Wayne Spivey, David Shrager, Leonard Ring, and others joining—the case evolves into a class action suit that falls prey to the courtroom drama of denied appeals and declined settlement offers. Critical evidence is hard to uncover and key figures, like Dr. Edward Shanbrom—the inventor of clotting factor who had been proposing a detergent-cleansing process to manufacturers since the late 1970s—are hard to get testimony from due to pressure from the defendants. Many of Weinberg's discoveries are still upsetting: plasma harvested from hepatitis-infected prisons; researchers' letters and testimony to the FDA warning about the dangers of factor products and paid plasma donor sites; NHF's testimony for drug manufacturers in other cases; and some drug manufacturers' decision to continue to sell untreated factor after the risks of HIV and hepatitis are known.

Blood on their Hands shakes off the dust of a past many would prefer to not relive. While the reader trails



Weinberg in fighting for a modicum of right in a travesty of injustice, the book champions activist figures like Michael Rosenberg, Corey Dubin, Roger Holt and Rich Vogel, and contextualizes the rise of organizations like the Hemophilia Federation of America and the Committee of Ten Thousand (COTT, named after the estimated number of hemophiliacs infected with HIV). The story ends with the litigation settled, but with a cautious sense of the future safety of the blood supply. What becomes clear through Weinberg and Shaw's account, however, is the hemophilia community's united front. Despite some lawyers' pressure to divide the cases and try those they deem more winnable and in spite of settlement offers that come in, the affected hemophilia community is undivided: all for one and one for all. While triumphantly heartwarming, the narrative especially highlights how easily the litigation could have divided, dissolved, and failed. And in all the hurt, sickness, sadness and anger—the resolve and championing spirit of the hemophilia community yet rises.

LET'S NOT OVERREACT!

BY SHELIA BILJES

My father had hemophilia and I felt I was extremely educated on the topic. So why did panic set in when the doctor told me the newborn baby boy in my arms had hemophilia too? I felt completely blindsided. Suddenly, I forgot everything I knew and was overcome with apprehension and a sense of hopelessness. Maybe my panic originated from the timing? My son Jordan was born in 1996 and the dust had not yet settled with the HIV and hep C tragedy. The community was still in turmoil. Or maybe it stemmed from the weight of responsibility knowing this little guy fully relied on me, whereas my father took care of himself. I was taking on a new role – primary caretaker of a new born with hemophilia.

Since my husband and I knew I was an obligate carrier, we had Jordan tested before leaving the hospital. When the doctor returned later that day with the results, it explained all the bruising on his precious little face and head. It was announced that Jordan was being taken to radiology for an MRI and I felt like all the life was sucked out of me. Strange, because this should not have come as a surprise. I called my parents. My mother stated that she would move in with us and hold the baby until he was school age so he wouldn't get hurt. I think she was serious. It didn't take long to realize that wasn't necessary, although her intentions were noble.

Before his birth, Jordan's nursery had been decorated ceiling to floor in everything "Mickey Mouse" and I was so proud of how it turned out. From the bedding to the wallpaper, everything matched and I couldn't wait to bring my baby boy home. Arriving home with him, I opened the door of his nursery.

To this day, I still cannot think of a word to adequately describe what I saw. If you were raised in a Baptist church, you may be familiar with the term "ladies' auxiliary." Essentially, this is a group of caring women with time on their hands who love to do good for others within the congregation. When word

spread that our newborn baby had hemophilia, they decided to spring into action.

They sewed padding into white sheets that covered every square inch of the crib. They taped Styrofoam onto every single corner of every single piece of furniture. It no longer looked like a cozy nursery, but more like a padded room for the insane; which was exactly how I was starting to feel. I remember dropping to the floor and crying. I am still not sure if it was because I knew where their hearts were as they created this overly safe, but frightening room and I was grateful; or because of the realization that life as I knew it, no longer existed.

The second day home from the hospital proved to be the true test. With my husband returning to work, I was alone with my baby and my two-year-old daughter. Staying busy was the absolute best thing for me, so when my daughter took her nap, I decided to bathe Jordan and trim his sharp, tiny newborn baby nails. The nervousness that came over me while completing this task was the beginning of my downfall that day. One snip just the slightest tad too close and there it was. Out came the drop of blood… the drop of blood that sent me into my first, honest-to-goodness nervous breakdown.

I called 9-1-1. I told the dispatcher I needed an ambulance fast because I cut my baby's fingernail too close and it was bleeding. She calmly said she didn't think the baby was in any danger, but she would stay on hold while I put a ice on his finger. Well, there was *not* a second drop of blood, but just in case we weren't in the clear, I had my husband leave work and had both of my parents en route. I was NOT going to be home alone with a baby who could bleed to death at any second.

As soon as the initial shock wore off and the fog began to clear, I removed the excessive padding from his nursery. Instead, I started to lean on the support received from the wonderful women I met through our local hemophilia chapter.

It's quite a comical story now, 21 years later. Because of my history with hemophilia, I knew he would be fine and that we would get through this; however, at the time, I couldn't see the light. I often wonder how different my thought process might have been if Jordan had been a spontaneous gene mutation and I had no family history on which to fall back on.

Somehow, we managed to raise an amazing young man. He learned to self-infuse at a very young age and manages his hemophilia wonderfully. As a small boy, and often to my irritation, he enjoyed disassembling every single toy, which now makes sense as he is currently enrolled in college studying to become an engineer.

We allowed him to grow up and do what he desired, and we kept him protected by routinely infusing clotting factor. Jordan laughs at pictures of family events where he is wearing a helmet. We did the best we could with what we knew until we learned an even better way. As his mother, I am proud of how far I have come, and am happy I didn't keep him in that insanely padded room. I am especially and overwhelmingly proud of the young man Jordan has grown in to. My heart is full. He is everything I could ever have hoped for in a son.

When I meet a mom of a newly diagnosed child, I offer this advice – if you trim your baby's nails too close, don't call 911. In other words, let's not overreact!

Sean with Landan (left) and brother Logan

CONFIDENCE COMES IN TIME

BY CINDY PICOS

When Yuba City, California couple, Jessica and Shane found out they were pregnant, they immediately contacted their physician and informed him of the family history of hemophilia. Since Jessica's maternal grandfather had hemophilia, she had her own labs drawn and based on those results, was told there was just a slight chance her children would be affected by hemophilia.

As the years continued, they had two sons, Luke, 3 1/2 years old, followed by Logan, age 2, and were celebrating the arrival of baby number three, Landon. There were no complications with the birth of either Landon or his brothers. However, chaos began when Landon's circumcision began bleeding excessively. The on-call pediatrician ran a blood test to determine the baby's PTT level, cauterized the circumcision area three times, but the oozing wouldn't stop. After they informed the doctor of their hemophilia history, more tests were taken. They waited for one very stressful week to hear the results; it was confirmed - their newborn baby boy was diagnosed with severe hemophilia A.

With two toddlers and a newborn, Jessica and Shane were already very busy parents. Even though hemophilia was in the family, Jessica truly knew nothing about the diagnosis and it wasn't long before Google became her best friend. In retrospect, she does not recommend this to anyone. She found the information online to be vague, scary and not very informative. They were so consumed with fear not knowing what was coming that they couldn't see past Landon's diagnosis.

Jessica recalled that during the first month, she was in a fog. As she was healing from childbirth, trying to help her baby heal from the circumcision and dealing with two toddlers, she found herself with no one to turn to. As she recovered, she reached out to the same hemophilia treatment center where her grandfather had been a patient. It was through the treatment center that she was introduced to Sean Hubbert, Chapter President of the Central California Hemophilia Foundation. Sean was just what Jessica needed, providing a strong and comforting presence.

"Don't worry about this, we've got it. This little guy and your family will be just fine," explained Sean, who also has children with hemophilia. It was that confidence and faith that got Jessica and Shane through those early months. They began participating in foundation functions, met other parents, took solace in social media groups, exchanged information and drank in the knowledge shared.

"Landon's little feet probably didn't touch the ground during his first year. He wore a comfy cap until 18 months old - if there had been a bubble available, we probably would have kept him in it. However, as he grew older and as we became more educated and learned to

infuse, we gained confidence in ourselves. The HTC nurse and Sean were right there by our side the whole way."

Jessica and Shane have grown to feel well informed and empowered. Landon is now 6 years-old and attends kindergarten. Prior to beginning school, they met with school personnel including the principal, teachers, playground staff and whoever else would be involved in Landon's school day. Their goal was to educate school staff and help reduce any fears of having a child with a bleeding disorder in class, and to be assured that Landon would be safe. Jessica shared, "It's a challenge when someone overreacts and calls to inform us of the slightest little incident. However, I appreciate their willingness to engage and help make Landon's life as typical as possible. Hemophilia no longer consumes our life. In fact, we rarely think about it until infusion time. He has been on prophy since 18 months-old and we've gotten into such a good routine. Landon has never missed a day of school, and although he has had some bleeds, none of them have been significant or kept him down for very long.

Jessica and Shane have words of wisdom to share with new parents of a child with hemophilia, "Don't let the diagnosis hold you or your child back. Let him enjoy and experience life. Let him be a boy. There are so many resources and people willing to help, and once you've got it down, be a resource to others."

After speaking with Jessica and other families, it occurred to me that I haven't witnessed the "helicopter mom" personality to be prevalent within our local foundation. Kids are very active at functions and families are just having a good time with lots of smiles and laughter. "That's because of Sean," explains Jessica. "She encourages families to be confident in their abilities and assures us we can handle it. My goal is to do the same with families we encounter. There has been so much progress within the hemophilia world and we are blessed, but we need to remember to help each other, share our stories, and build confidence within our hemophilia family."

THE BIRTH OF GRACE

BY SAMANTHA FRANCESCA COSTAS

To fully convey my amazing birth experience with my third child, Grace, I should first explain my personal hemophilia diagnosis. Now 34 years-old, I was not diagnosed with mild hemophilia A and Ehlers Danlos Syndrome until age 32. Being female made it more of a challenge to be properly diagnosed. At 20 percent, my factor levels are low. Throughout my life I have endured many bumps and bruises from playing sports and being in a car accident, and I have major joint damage in my right hip and knee.

Factor infusions have helped tremendously with reoccurring micro-bleeds within my target joints. My everyday life is usually accompanied with physical pain, even with low activity. Access to treatment has been a life-changer for me. Living with less pain after I infuse has allowed me to fulfill many of the physical demands of motherhood. One of these more recent was the pregnancy and birth of my third child. With a proper treatment plan, I was able to endure the process and recovery so much better than with the births of my two older children.

After the exciting news of being pregnant, I was immediately overcome with the daunting task of having to put together a proactive care team for my hemophilia. However, with the collaborative efforts of my Ob/Gyn, midwife, and private hematologist, I could have a healthy pregnancy and a peaceful water birth delivery.

> **“Access to treatment has been a life-changer for me.”**

Throughout my pregnancy, my factor 8 levels were evaluated - monthly in the beginning, then weekly toward the end. I wanted a closer look at my levels and thankfully my hematologist agreed with a more proactive approach. My doctor also believed it was necessary to continue prophylaxis treatment if my levels were under 50 percent. My factor 8 levels fluctuated throughout my pregnancy and at one point, hit a low of 15 percent. Consequently, I

continued my weekly infusions. During my first two pregnancies, I experienced extreme pain in my hip. I did not have this pain during my third pregnancy and I give all the credit to maintaining a prophylaxis schedule. My treatment protocol helped protect my already vulnerable joints and the health of my baby girl in the womb.

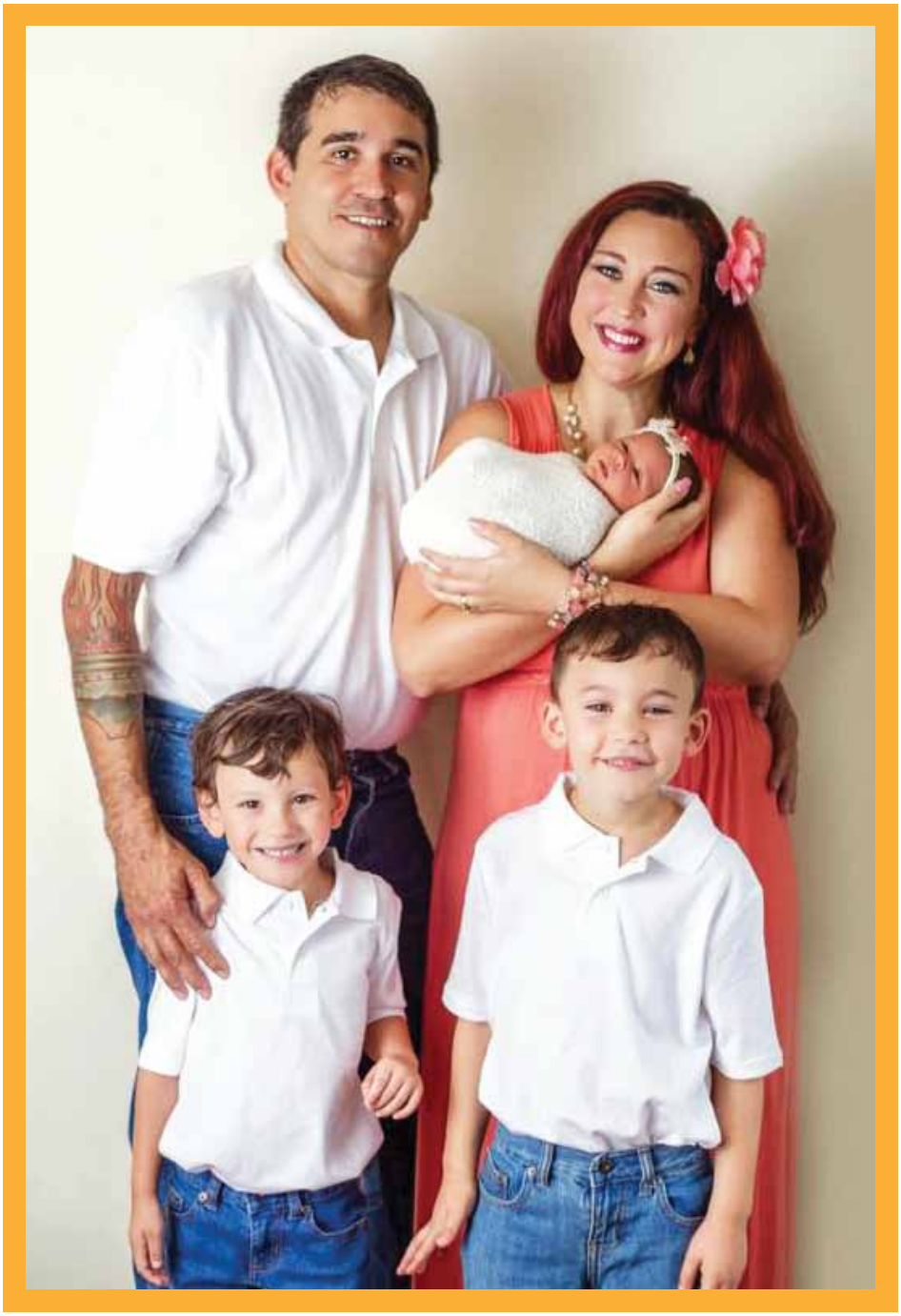
Of course, I give the glory to God for my baby being born healthy without any complications, but it is important to note that increased miscarriage rates in women with a bleeding disorder is of concern. Staying on prophy to control any joint or internal bleeding helped me feel secure and calmed my fears while carrying my daughter.

As a childbirth educator, my birthplace of choice is a birthing center, in a non-hospital setting and in relaxing water. I wanted to experience a peaceful, tranquil water birth filled with prayer and worship music. With the amazing collaboration and cooperation of my hematologist, obstetrician, and midwife, I was able to achieve the birth of my dreams.

Braxton Hicks contractions had been felt for a whole week, but when they became more regular and intense, I knew it was time. I infused at home and my husband and I headed to the birth center.

We arrived at 1:00 am and were instructed by my midwife to walk around outside to help the process go faster. As the contractions drew closer together, we headed back in for the birth. Shortly after getting into the birthing tub and meditating on scriptures of how God gives me strength, I gave birth to our beautiful and sweet baby girl at 4:00 am September 27, 2017.

An hour after having our daughter, I infused another factor dose, and then again 24 hours later. After two weeks of periodic infusions, my postpartum bleeding subsided. I never could have imagined it was possible to heal so quickly! With my previous births, the bleeding lasted at least 6 weeks. Prior to my diagnosis, I thought this was normal.



When baby Grace was only 8 weeks old, I flew to Chicago for the NHF annual conference, still in disbelief at how quickly I was able to resume normal activity.

I do believe my quick recovery was due to the assertive and effective treatment I received. My hematologist told me his plan was to treat me as he would a male with mild hemophilia undergoing surgery. My hemophilia was treated equally despite my gender! Unfortunately, this still seems to be remarkable in the bleeding disorders community today.

I hope my story of proactive, unbiased treatment from the onset of pregnancy through birth to postpartum recovery will inspire other moms who are carriers or are diagnosed with hemophilia to seek excellent care...
YOU deserve it!

TESTING FATE

By Jennifer Valdes

My father was a huge advocate in the hemophilia community. I think he felt so strongly about advocacy because his parents were told he would not live past two or three years old. Born in 1948 with severe hemophilia A, doctors predicted if he did somehow live longer, he would never walk. He did live, and he did walk. He became an advocate because he never wanted anyone to feel the way he and his parents felt, when on many occasions they were told of his impending death and/or permanent loss of mobility.

Some of the very first memories I have of my dad are of his dealing with his hemophilia. After my three older brothers were born, my dad was unsure of having more children. He feared passing the hemophilia gene onto daughters, of which he eventually had two (glad my mom won that argument!) and of course, we are both obligate carriers.

I remember my dad sitting me on his knee to sing and play the guitar. He did this a lot because he couldn't get down on the floor to play. I remember sitting at a blood bank waiting for my dad to get a whole blood transfusion; and again, when I was a little older, waiting to get his factor.

Early on, he made sure I was aware of what lay ahead. While I would watch him infuse, he would tell me that my babies would have to do the same thing; he read books about hemophilia to me and shared the basics of how I got my gene from him, and how I would give it to my children. My mom was a nurse and she often explained a child with hemophilia was no different than a child with asthma or an allergy to strawberries. Being a logical kid, that made sense. After my dad's passing when I was nine, I still had that book and I still knew hemophilia would be part of my future. I was ok with that.

Life went on knowing I would one day have to tell my future husband we could possibly have babies with hemophilia. I don't think it affected me negatively – emotionally or mentally, but it did make me behave differently. I was a lot more cautious about the men I dated. He would have to be strong, compassionate and not afraid of needles, which is hilarious because

my husband is very afraid of them, but didn't share that with me until AFTER we were married!

Talking about hemophilia was always a hard conversation to start, but what conversation is easy in the early stages of any relationship? Telling my husband about hemophilia wasn't as hard as I thought it would be. I was very lucky to find a "keeper." I had known Mike since high school and he was totally up for the challenge.

In 2006, our first baby Emily was a carrier. We dodged the bullet with our second child in 2012; Jacob was unaffected. We tempted fate a third time in 2014 when Esmé was born - she was not a carrier. By baby number four, we knew we could no longer keep sticking our tongues out at Mother Nature. This baby was *going* to be a boy and he was *going* to have hemophilia. At 16 weeks, we had an ultrasound to determine the baby's gender. If we had a boy, we wanted an amniocentesis to determine if he had hemophilia. If a girl, her cord blood would be tested at birth to determine carrier status.

As we stared at our fourth child on the ultrasound screen, I just knew he would have hemophilia, and I was sad. Not because he was affected, but because such a little guy would experience pain so early and I could not stop it or prevent it. I knew the first few years would be the hardest because babies and toddlers can't understand what is happening. Once

he was older, it would be easier. Most everyone with hemophilia has physical struggles and he would be no different, but I was ready. I was born to raise a son with hemophilia. Mike had a lot to learn, but he had me to show him the ropes and answer his questions. We were aware and prepared.

Once I found out that my baby was indeed a boy, I scheduled an amniocentesis with a prenatal doctor. Going in, I just wanted the amnio to confirm what I already knew. Nothing else. Not another ultrasound confirming he had ten fingers and toes. Not a genetic counselor who knew less about hemophilia than I did. "Tell me about hemophilia," I asked. None of what he told me was accurate and he had the audacity to ask if I wanted to abort my baby! I just wanted an amnio. Finally, two hours later I got it. I could only imagine what a nightmare the process would have been for someone who was NOT prepared for the diagnosis.

I wanted to deliver my baby naturally, in my birthing center, at my own pace and with my midwife. Birthing comes easy to me. I don't say this to boast, it's just the way God made me. From first contraction to holding baby, I do it mostly on my own and in less than two hours. However, there were a few hurdles to overcome. First, I was over 40 and overweight, adding to the risk. Our third issue was a stubborn, high-risk mom carrying a high-risk baby, refusing to deliver in a hospital. I wanted my birthing center. The doctors and hospital administrators vehemently protested my choice. We had meetings and conferences; obstetricians met with hematologists and after many "are you sure?!" and with the complete support of my midwives, I finally got the greenlight to deliver at the birthing center!

Emmett was due the second week of June. On the 8th, my family went to run errands and get dinner. The moment our food arrived at 7:30 p.m., I felt what I thought was a contraction and set a timer. Sure enough, five minutes and two bites of dinner later, another contraction. Another came after just four minutes. We gathered the kids, got our dinners to go and headed home to get my bag.

Without time to find a sitter, we hit the freeway with the kids and their overnight bags in tow. *Of course*, the stretch of interstate was under construction with barriers and a posted speed limit of 50 miles an hour. Mike flew through the construction zone. He was determined NOT to deliver a baby with hemophilia on the side of the road. I still think he just didn't want to deliver a baby by himself and, to this day, we still razz him about this. For the first 20 minutes, the contractions were every two minutes; then back-to-back with just 10-20 seconds in between.

Making the 50-minute drive in just 30, we pulled up to the birthing center at 8:45 p.m. I was immediately wheeled in and was barely in the delivery room before I experienced another big contraction. With no time to change, I was given a blanket - not even a hospital gown.

A 9:00 p.m. on the dot, Emmett made his appearance. It was a completely uneventful, un-medicated labor and delivery. Five pushes was all it took. He was perfect - no trauma, no respiratory issues, no bleeds; his Apgar score was eight, then nine. Despite all the naysayers, Emmett arrived safe and sound. I delivered a perfect baby with hemophilia, naturally, with no complications, no factor, no emergency surgery, no specialists - just my hubby, my kids and me. My experience was happy and content and I sincerely wish this for all hemophilia parents.

SPOKES MEN FOR BLEEDERS

The Spokes Men ride 100 miles to support the West Virginia Chapter of NHF's Hemophilia Walk

BY STEVE NICKS

Baseball....

Life is like a game of baseball. It can throw you fastballs and curves, but nothing knocks you off balance more than when it throws a changeup. All throughout our 20's, my wife and I felt alone when it came to raising a child with hemophilia. We knew nothing about hemophilia other than what we researched ourselves or what we learned during our son's appointments at the Hemophilia Treatment Center at West Virginia University.

This stage of our life was trial by error. Looking back with our first affected child, there were mistakes, but we always did our best. In our late 20's, we decided to have our third child. As it turned out, he too has severe hemophilia. However, this time we were prepared. My wife and I knew how to "play the game" of hemophilia now. We were drafted, blew through the minor leagues and went straight to the majors. Even though we could handle our son's factor infusions, emergency room visits and day-to-day life with hemophilia, we were still missing something. That something is called the West Virginia National Hemophilia Foundation Chapter (WVNHF).

In 2015, we were invited to an event called "Men's Day." This was one of the first events held by the WVNHF chapter. At the event, we met a lot of people from different parts of the state. It was great to meet families that deal with the same things that we deal with. This support network was what we were missing. We now consider these community members an extension of our family.

After the fun-filled weekend, my father and I were adding up the cost of what the chapter had spent for us to attend the event. The total came to around four hundred dollars. I told my father that I was going to ask for donations to give back to the chapter, and this is how *Spokes Men for Bleeders* was born.

A few weeks later, I had an idea. I wanted to ride my bike 100 miles from Harpers Ferry to Washington D.C. and back all in one day, and have folks sponsor me to ride and raise money for the chapter. That's when I contacted Amber Tichnell, WVNHF Executive Director, and she thought this could really be something!

Five months later in 2015, the first *Spokes Men for Bleeders* ride took place. I rode a total of 109 miles and raised $2900. Not bad for doing the ride alone, but we needed to brainstorm to make it better and bigger for the next year. In 2016, *Spokes Men for Bleeders* grew by six more riders, and my wife held a painting party and silent auction to help with our fundraising goal. That year, we raised just shy of $6000, a decent increase. This year, on October 7, 2017 we set a goal to reach $6000. What a way to play the game, because we hit that goal out of the park! It proved to be another great ride and another great fundraising event.

Our family's goal is to continue to work hard to raise funds for the chapter so they can, in turn, continue to help the bleeding disorders individuals and families in West Virginia with educational programs and support. We are so thankful for all the help we've received from our sponsors, family and friends who have assisted in making *Spokes Men for Bleeders* a grand slam!

Interested in learning more? Please contact:
Ryan Wallace, 681-212-9255 or by email:
rwallace@hemophilia.org

To donate, please visit: https://hemophiliawalk.donordrive.com/index.cfm?fuseaction=donorDrive.participant&participantID=39733

LEVELING UP:

LEARNING SELF-INFUSION AT A YOUNG AGE

BY JUSTIN LINDHORST

Zach is an energetic 9-year-old who loves guessing games. Favorite color? Orange. Favorite ice cream? Chocolate chip cookie dough. Favorite song? "Thunder" by Imagine Dragons. During our conversation, I learned a lot about Zach and his love for soccer, fidget spinners and video games, but what impressed me most was his ability to take control and manage his bleeding disorder at such a young age.

Zach started participating with his infusions when he was about 7 years-old. "First, I learned how to set it up and mix it, then I practiced finding my vein, then I practiced by sticking my doctor," Zach explained.

The following year when summer rolled around, Zach was motivated to take it a step further. He shared, "I wanted to learn so when I'm a little older if I want to go on a trip with my friends I'll be able to stick myself."

He continued practicing and through ongoing support from family and medical staff, Zach completed his first solo infusion at age 8. Though it took a few times to hit the vein, Zach did not get discouraged. He shrugged, "When I missed a vein, I would just find another spot."

Now Zach performs many of his infusions all on his own. He explained, "Now I can stick myself instead of someone else sticking me! I'm even helping other kids learn how to infuse at camp."

Though it took time and effort, learning how to self-infuse has paid off for Zach. I asked if he had any advice for other kids learning to infuse on their own. He grinned, "If you are scared, before you stick yourself it's good to practice on someone else."

Of course, his parents and the medical team at his hemophilia treatment center are happy with his progress. Zach's mom explains, "We always tried to make infusion time part of our regular routine. Engaging him in that process helped to normalize hemophilia and teach him he has some level of control over the condition."

Zach loves guessing games, but there is no question about what he wants to do with his future. With a wide grin and firm, child-like certainty, he asserted, "When I grow up, I'm going to be a scientist and I am going to find a cure for hemophilia!"

DR. ROLAND HERZOG

AWARDED RESEARCHER OF THE YEAR

NATIONAL HEMOPHILIA FOUNDATION ANNUAL MEETING IN CHICAGO, 2017

BY DIANE HORBACZ
BIOMATRIX RESEARCH AND EDUCATION DEVELOPMENT SPECIALIST

In the Summer 2017 edition of Matrix Health News, our Spotlight on Research focused on promising therapies being developed in the Roland Herzog Lab at University of Florida. Years of Roland's adult life have been dedicated to assuring immune tolerance and gene therapy protocol becomes a reality. His distinguished research on gene therapy and immunogenicity to ensure tolerance to future therapies brings us closer to a cure for hemophilia. For the full article, please visit: https://www.matrixhealthgroup.com/wp-content/uploads/newsletter/Summer-2017-MHG-News.pdf

In a recent visit to the Roland Herzog Lab, I had the honor and privilege of touring the lab and meeting his team of talented researchers. As Roland discussed the various projects currently being focused upon, it is apparent his sympathetic concern for individuals with hemophilia and his compassionate determination inspire the impelling force behind his work.

We congratulate Roland Herzog on his award and thank him for his sincere and profound determination to improve the lives of individuals with hemophilia.

BIOGRAPHY:
Dr. Herzog received a Ph.D. in Microbiology from Auburn University in 1996. He subsequently performed postdoctoral research in gene therapy at the Children's Hospital of Philadelphia and became Assistant Professor of Pediatrics at the University of Pennsylvania in 2000. In 2005, he joined the University of Florida (UF) as an Associate Professor. Dr. Herzog's research has received multiple awards, including a career development award from the National Hemophilia Foundation (2000), an outstanding new investigator award from the American Society of Gene and Cell Therapy (ASGCT, 2003), a Bayer Hemophilia Award (2007), and a Faculty Research Award (UF College of Medicine, 2012). He published >160 articles and chapters, edited two textbooks, and served as treasurer for ASGCT. Dr. Herzog was promoted to Professor in 2011. He is currently Editor-in-Chief of the journal Molecular Therapy Methods & Clinical Development and became UF Research Foundation Professor in 2015. Multiple grants from the NIH and other funding agencies support his research on the development of immune tolerance and gene therapies for hemophilia.

SPOTLIGHT ON RESEARCH

BY DIANE HORBACZ
BIOMATRIX RESEARCH AND EDUCATION DEVELOPMENT SPECIALIST

Exposing Benefits and Barriers: mHealth Use in Managing Hemophilia

The Journal of mHealth
The Global Voice of Digital Health

Published January 15, 2018

Hemophilia and the Potential of mHealth to Improve Adherence

Considerable clinical evidence has shown prophylaxis treatment prevents bleeding from an early age, allowing those living with hemophilia to lead a fuller life with minimal restrictions. Yet, despite medical recommendations, many patients do not consistently remain adherent to their prophylactic schedule.

Lack of adherence isn't limited to maintaining a prophylaxis regimen, but also extends to appropriate treatment recording keeping. As stated in Managing Hemophilia: The Role of Mobile Technology, "Good record keeping is an essential component of home-based hemophilia care. Well-kept treatment diaries can help healthcare professionals to ensure optimal factor use, adherence with treatment regimens and timely infusion practices."[1]

The advent of mobile health apps provides a new alternative to managing bleeding disorders. Individuals can set reminders and track their treatment, record information related to bleeds, generate logs, access additional resources, and even locate a hemophilia treatment center (HTC), while traveling, all from the palm of their hand. Despite the potential benefits mHealth offers, many people have not embraced this new technology.

BioMatrix SpRx, the parent company for a family of industry leading specialty pharmacies, conducted a study investigating the use of hemophilia mobile apps. The purpose of the study was to provide insight into the current use of hemophilia mHealth, to increase awareness of potential benefits, and to provide recommendations to increase usage with the goal of improving health outcomes for people living with bleeding disorders.

A cross-sectional survey was conducted with severe hemophilia patients. This was followed by a systematic evaluation of current hemophilia mobile apps within focus group meetings. Results of the study were organized into a white paper, *Exposing Benefits and Barriers: mHealth Use in Managing Hemophilia* (November 2017).

A full copy of the white paper is available at *The Journal of mHealth:*

http://bit.ly/2EzBkIa

SURVEY RESULTS

High Access to Mobile Technology and Moderate Experience with mHealth

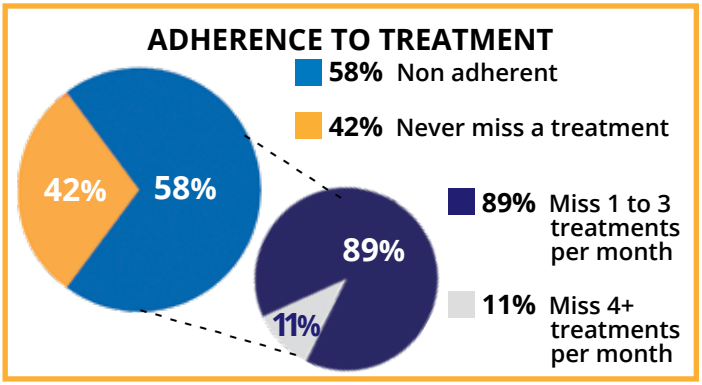
Most survey respondents had access to mobile technology and were quite familiar with mobile apps. Ninety-three percent use a smart phone and 65% use a tablet or other portable personal computing device with a touchscreen interface. Only 5% were non-app users. Furthermore, 90% use mobile apps daily, with a majority using between 1 and 5 apps per day with social media, photo/video, and music/games/entertainment being the most frequently used apps. A little over half (56%) had experience with mHealth, but only 14.5% regularly use hemophilia mobile apps.

Narrow Awareness and Limited Use of Hemophilia Mobile Apps

- Majority of survey respondents (68%) were not aware of the scope of hemophilia mobile apps currently available
- While there was a wide spread of opinions regarding the benefits of using hemophilia mHealth, 32% saw no benefit
- 66% indicated use of an app was never recommended by their doctor or HTC
- 45% had downloaded a hemophilia mobile app. From this group:
  - Approximately 1/3 discontinued using the app
  - Approximately 1/3 use the app on a regular basis (a few times a week)
  - Approximately 1/3 are limited users (once a month or only for the alert feature)

Hemophilia Mobile Apps Improve Adherence to Treatment

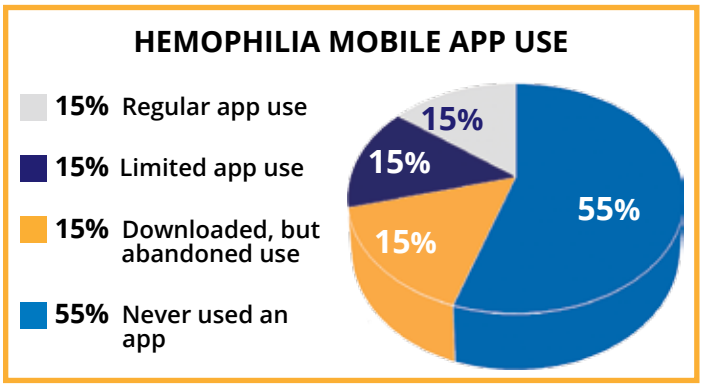
Fifty-eight percent of individuals reported some degree of nonadherence to treatment, defined as missing a regular scheduled infusion over a period of one month. Within this group, 89% missed between 1 and 3 infusions per month and 11% missed 4 or more infusions per month.

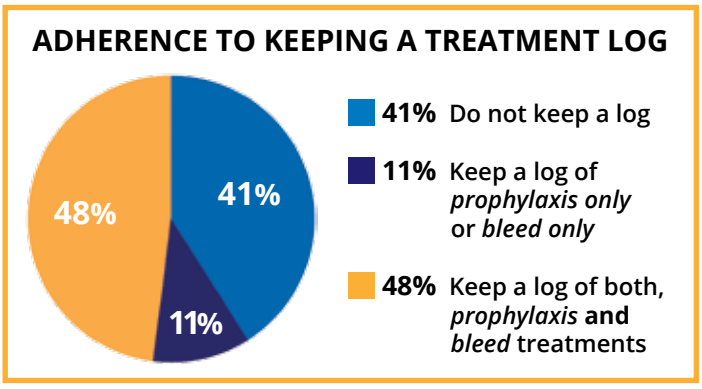


Regarding adherence to record keeping, our survey responses were more positive than expected given research findings indicate "compliance with record keeping is notoriously poor."[2] Survey data within this group revealed:

- 41% do not keep any treatment records
- 11% keep "prophylaxis only" or "bleed only" records
- 48% keep a record of both regular prophylaxis treatment and bleeds

Adherence to record keeping was lowest in the age 18-24 category and highest in the age 60+ category.





While we were unable to draw statistically significant conclusions from this study regarding the relationship between adherence to a treatment regimen and good record keeping, it appeared those who kept some sort of a log were less likely to miss scheduled treatments. Additionally, those who use a hemophilia mobile app appeared more likely to remain adherent to treatment.

Open-ended responses to survey questions highlighted the value of an "alert feature," serving as a reminder to infuse and thus supporting adherence to a treatment regimen. One parent commented, "When my first son went to college, he did not use a hemophilia mobile app or keep a log. As a result, he experienced many bleeds (including 2 kidney bleeds) due to missing treatment. When my second son went to college, he used a hemophilia mobile app just for the alert feature (he did not log treatments). However, he remained 100% adherent to his treatment and didn't experience a single bleed during his first year of college."

Consumers Provide Insight into Valuable Features

Seventy-four percent of survey respondents indicated bar scanning technology to automate the logging of dosage information was the most wished-for feature that would encourage use of a hemophilia mobile app.

Other noteworthy desired features include the following: the ability to locate an HTC when traveling (45%), the ability to share information with a personal HTC or doctor (44%), and the ability to use voice command to enter data (42%).

Other recommended features included sending alerts for treatment, reordering factor and supplies from a pharmacy, recalling product information, printing graphs from logs, tracking inventory, and customizing and capturing data to accommodate inhibitor patients.

Non-use and Discontinued Use of a Hemophilia Mobile App

For those who had never downloaded a hemophilia mobile app, the most common reason for not using an app included, "I don't keep a log," "I'm not familiar with hemophilia apps," "They are too complicated or too much of a hassle to use," and, "I prefer to use paper logs or a spread sheet." A lack of interest in an app and a lack of trust in the protection of personal data were also noted concerns.

Common reasons for discontinuing the use of a hemophilia mobile app included failure of an app to do the following: to allow for multiple patient profiles, to accommodate a respondent's current factor product, to meet the needs of patients with inhibitors, to provide an easy-to-use interface, and to work without malfunction.

Implications to Consider Voice-activated Technology and Other Devices in Managing Hemophilia

- Voice-activated Technology—While only 10% of those surveyed reported using voice-activated technology in the home, such as an Alexa or Google-Home device, 55% reported having interest in voice-activated technology. Those who had downloaded a hemophilia mobile app tended to be universally interested in using voice-activated technology, whereas those who had never downloaded an app were equally divided in their interest.
- Fitness Tracker—Approximately 1/3 of respondents expressed interest in linking a fitness tracker, such as a Fitbit or Garmin, to a hemophilia mobile app.

Experience with Hemophilia mHealth Influences Perceived Impact

Perceived impact varied based upon previous experience with hemophilia mHealth. The vast majority of respondents (90%) who had downloaded a hemophilia mobile app (not necessarily current users) believed the use of a hemophilia mobile app would improve their healthcare. Opinions were equally divided among those with no previous experience with hemophilia mHealth.

Survey Conclusions

- Although the sample size was too small to determine a statistically significant relationship, the study is consistent with earlier research findings, which have found that hemophilia mHealth improves adherence to a treatment regimen.
- Access to mobile technology (smart phones and tablets) is high.
- Respondents generally embraced technology and were quite supportive of technological solutions to improve healthcare. Many respondents were

also receptive to solutions beyond hemophilia mHealth, including the use of voice-activated technology.

- Respondents were generally aware of the benefits of hemophilia mHealth and its likelihood of improving adherence.
- Despite access to technology, willingness to employ the technology towards managing their healthcare, and an understanding of the benefits of using hemophilia mHealth to improve adherence, adoption rates of hemophilia mHealth remain quite low.
- Several factors seem to be driving low adoption rates of mHealth: a lack of awareness of hemophilia mHealth options, app complexity, burdensome data entry, concerns with the protection of health information, and inflexible app features (e.g. unable to use with an individual's factor product, cannot be customized to accommodate inhibitor patients, etc.).

Focus Group Summary

Several hemophilia mobile apps were reviewed and evaluated by focus groups.

1. Problems exist in identifying a hemophilia mobile app that best meets consumer needs.
2. Many focus group participants expressed little interest in using hemophilia mHealth due to a lack of interest in record keeping and lack of time.
3. Protection of health information within a hemophilia mobile app and the transmission of treatment logs through a non-secure method were expressed as major concerns.
4. While several hemophilia mobile apps required users to create a username and password for exploration, focus group participants favored an app that allowed users to investigate the product without the prerequisite of registering.
5. Hemophilia mobile apps that had too many menus or features prevented clear navigation and were perceived as complex and frustrating.
6. Opinions varied between digital natives and non-natives regarding hemophilia mobile app layout, graphics and visual appeal.
7. Most focus group participants were frustrated by a hemophilia mobile app's inability to submit a bleed or infusion record without providing 100% of the requested data.
8. The most valued features included treatment alerts through a mobile device along with the ability to log an infusion by responding to a hemophilia mobile app alert.
9. Evaluation process served as a beneficial educational opportunity for all group participants. Many participants who didn't use a hemophilia mobile app are now using one to manage their bleeding disorder.

CONCLUSION

Research studies have concluded there is great potential for mobile healthcare apps to facilitate improved adherence to chronic disease management. Although the obvious feature of treatment reminders through SMS is "most widely, frequently and successfully used to facilitate adherence to chronic disease management,"[3] hemophilia mHealth can potentially improve overall medical adherence by cultivating other motivational factors. These include improved patient-provider communication and relations, better monitoring and awareness of bleed warning signs, increase in adolescent independence, confidence in managing care, and self-empowerment.

Nonadherence to treatment within the hemophilia community is high and remains a primary concern. Hemophilia mHealth can improve the level of adherence, which can lead to improved health outcomes.

The hemophilia community (drug manufacturers, app developers, HTCs, physicians, and consumers) should focus time and resources to develop an action plan to overcome the barriers that have resulted in limited adoption of hemophilia mHealth.

Recommendations to Increase Hemophilia mHealth:

- App developers should address the key barriers to wider implementation and usage.
- mHealth informational resources and databases should be made available to the hemophilia industry to help educate and to highlight the significant benefits that result from using mHealth to manage a bleeding disorder.
- The hemophilia industry should increase awareness among consumers by providing educational opportunities to highlight these benefits and should make specific hemophilia mHealth recommendations.
- Further assurance that personal health information is protected and that HIPAA compliance is met needs to be addressed within the bleeding disorders community.
- Educational materials, such as user guides and comparison charts, need to be made available to aid physicians and patients in the selection of an app that satisfies specific consumer needs.

Recommendations for Future Hemophilia App Development:

- Create a single hemophilia mobile app with the flexibility to handle multiple products.
- Include a detailed privacy statement on the home screen. According to Future Privacy Forum, "even though a privacy policy is not the be all and end all for building consumer trust, there is no excuse for failing to provide one – doing so is the baseline standard."[4]
- Safeguard security of shared data. Data should only be shared through a secure website; as well a user should be provided a print option within the app.
- Enable users to determine the data they chose to document when recording a bleed. Include a "pop-up" reminder to provide users with the option to include additional information later.
- Enable users to investigate the app without the prerequisite of creating an account. Include a brief tutorial at the opening of each app allowing users to freely explore.
- Develop an app with the flexibility to provide multiple interfaces, depending upon user needs.

AVAILABLE PRESENTATION

APP CLOSE AND PERSONAL:

INVESTIGATING THE USE OF MOBILE APPS IN MANAGING HEMOPHILIA

Program Description:
Mobile phone health apps (mHealth) are changing the landscape of healthcare and are showing promise to improve the lives of individuals with hemophilia. The influx of mobile apps within the bleeding disorders community provides an alternative to manual record keeping and can help patients better manage their bleeding disorder.

This presentation provides an overview of research investigating the use of these apps, explores the future potential of digital technology in managing hemophilia, and includes hands-on exploration and evaluation of hemophilia mobile apps. Handouts include: Hemophilia Mobile App Feature Summary Charts and articles related to managing hemophilia through digital technology.

For information on how to bring this presentation to your community, please contact:
Diane Horbacz, 732-678-7779 diane.horbacz@biomatrixsprx.com
or call BioMatrix SpRx Corporate Office, toll free: 1-877-337-3002

REFERENCES

1. Khair, H. (2014, May 6). Managing hemophilia: the role of mobile technology. Dovepress. Retrieved from https://www.dovepress.com/managing-hemophilia-the-role-of-mobile-technology-peer-reviewed-article-SHTT
2. Arnold, E., Heddle, N., Lane, Sek, J., Almonte, T., and Walker, I. (2005, May 5). Handheld computers and paper diaries for documenting the use of factor concentrates used in haemophilia home therapy: a qualitative study. Haemophilia, 11(3). 216-226. Retrieved from http://onlinelibrary.wiley.com/wol1/doi/10.1111/j.1365-2516.2005.01095.x/full
3. Hamine, S., Gerth-Guyette, E., Faulx, D., Green, B.B., and Ginsburg, A. S. (2015, Feb. 24). Impact of mHealth Chronic Disease Management on Treatment Adherence and Patient Outcomes: A Systematic Review. Journal of Medical Internet Research, 17 (2). 52. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4376208/
4. Bates, M. (2016, Aug. 17). Best Practices for Consumer Wearables and Wellness Apps and Devices. Future of Privacy Forum. Retrieved from https://fpf.org/2016/08/17/future-privacy-forum-releases-best-practices-consumer-wearables-wellness-apps-devices

ADVOCACY TEAM

PRESERVING INSURANCE COVERAGE PROTECTION

BY SHELBY SMOAK, Ph.D.
ADVOCATE|EDUCATION SPECIALIST

The MHG Advocacy Team has been working hard to preserve insurance coverage protections for persons with a chronic illness. The team recently submitted comment to CMS (Centers for Medicare and Medicaid Services) and HHS (Health and Human Services) regarding a proposed change to the essential health benefits (EHBs) included in current state insurance plans. Currently, all plans must provide 11 essential health benefits—including prescription drug coverage, physical therapy, and emergency room coverage—and the EHB design is overseen by the federal government. The CMS 9930 rule, however, proposes increasing state flexibility in designing and assigning EHBs in insurance plans. While some may favor a state's increased control in EHB benefits, the MHG Advocacy Team had concerns that persons with chronic illness would be negatively impacted as states slimmed benefit offerings and increased patient costs for services and prescription drugs.

The MHG Advocacy Team recommended that CMS not change the current EHB design and not provide states with increased flexibility. We argued that states could potentially redesign prescription benefits to cover a single drug and rely more heavily on a formulary system, thus limiting options to available treatments or increasing the cost of access to non-formulary drugs. We also argued that without federal oversight, as states individualize EHB coverage, a patient in State A could no longer expect or receive the same coverage as a patient in State B, resulting in uneven and inequitable coverage across America. We further argued that as states trimmed coverage in redesigned, cost-savings plans, the cost burden would fall to patients, making care especially unaffordable and inaccessible for persons with a lifelong chronic illness. Ultimately, we argued that the CMS proposal would allow an extreme inequity and wide variance in state EHB plan offerings which would, in turn, fail to provide affordable and accessible care to chronically ill patients.

You can read the MHG Advocacy Team's comment here: https://www.regulations.gov/document?D=CMS-2017-0141-0280.

Our Team is awaiting a response from CMS and is hoping our voice will be heard.

All marketplace plans must cover the same set of essential health benefits:*

1. Ambulatory patient services (outpatient care you get without being admitted to a hospital)
2. Emergency services
3. Hospitalization (like surgery and overnight stays)
4. Pregnancy, maternity, and newborn care (both before and after birth)
5. Mental health and substance use disorder services, including behavioral health treatment (this includes counseling and psychotherapy)
6. Prescription drugs
7. Rehabilitative and habilitative services and devices (services and devices to help people with injuries, disabilities, or chronic conditions gain or recover mental and physical skills)
8. Laboratory services
9. Preventive and wellness services and chronic disease management
10. Pediatric services, including oral and vision care (but adult dental and vision coverage aren't essential health benefits)

11. Birth control and breastfeeding coverage

For more information, visit:

Healthcare.gov "What Marketplace health insurance plans cover"

* https://www.healthcare.gov/coverage/what-marketplace-plans-cover/

Paul R. Brayshaw, M.P.H.

Director of
Healthcare Advocacy and Programs
Matrix Health Group

THE HEALTH ADVOCATE

SECOND AND THIRD OPINIONS: THE VALUE AND UNCERTAINTY OF COMPARING MEDICAL ADVICE

As a person with severe hemophilia B, I have sought the opinions of multiple clinicians and healthcare providers throughout my life. I have followed good, bad, incorrect, and perhaps reckless medical advice as long ago as my memory allows.

Earlier this year, I sought medical advice from an Orthopedist/ Sports Medicine specialist to assess my ankles for hemophilic arthropathy, and receive relief from complications including pain, mobility constraints, and suffering. Following a prior referral from my local hemophilia treatment center, I had already seen a specialist at that clinic for another procedure and had confidence in the practitioner's familiarity with hemophilia. I was prepared for guidance on either joint fusion of the ankle or ankle replacement within the next two or three years.

Upon review of my x-rays and a visual assessment, the orthopedist discussed the risks and benefits of both procedures. While the doctor thought both options were likely in my future, he also thought he could help me be functional with my current ankles for another ten years with steroid injections two or three times each year in both ankles. The doctor was confident we could get started right away, so at that same visit I proceeded with injections for my left ankle. Approximately one month later, I returned for injections in my right ankle. While there was stiffness in both ankles for a couple days following each procedure, thereafter I felt significant relief from pain and had an improved range of motion for almost six months.

> **"I left my appointment deeply confused and without any immediate plan to proceed."**

Based on past experience, I believed steroid injections would solve the complications associated with my target joints for another ten years, allowing time for ankle replacement technology to advance. Also, I would benefit by avoiding added risks for infections, muscle atrophy, and challenges of rehabilitation associated with these types of invasive procedures. Without the therapeutic advice of this orthopedist, it is quite possible I would have progressed to an ankle fusion, or replacement within two to three years, if not sooner.

However, after a visit to my local hemophilia treatment center the promise of steroid injections into the ankles was quickly dispelled. I described my experience to my local care team and was advised to strictly avoid steroid injections due to bone softening and bone loss. Moreover, they explained steroid-related bone degradation could be exacerbated over time and possibly harm my chances of a successful ankle replacement in the future.

During the same visit, I was advised a joint replacement would be a better option, as new technology was already available at the same hospital by a renowned surgeon who designed and developed a total ankle replacement technology. I left my appointment deeply confused and without any immediate plan to proceed.

The variation in medical advice provided by both clinical specialties, orthopedics and hematology, has left me in pain, and in limbo. After choosing an orthopedic group recommended by the treatment center because they understood hemophilia and related arthropathy, my hematologist recommended against the use of steroids, and alternatively recommended a replacement procedure that carries its own significant risk, with possible benefits limited to ten years.

Because of my lifelong experience with hemophilia, I was not completely discouraged, nor was I convinced about one recommendation over another. While I am favorable to the steroid injections for the short-term benefits and relief from pain and improved the ankle function, I also maintained a certain respect for the clinical care provided by my local hemophilia treatment center.

Confused by the conflicting medical advice, I searched for another perspective from a different hematologist. I hoped he would offer insight into the risks and benefits between immediate steroid injection versus replacement now or later, and I discovered that doctor supported steroid injections. Buoyed by his opinion, I feel this consultation has provided me the assurance I needed to commit to additional steroid injections.

It has been nearly a year since my initial appointment with the ankle specialist. Throughout the entire process, I have attempted to understand the varied risks and benefits of viable interventions. While I continue to be challenged by reduced capacity and severe pain in both ankles, my efforts have helped empower me with some assurance of my next steps. Meanwhile, I am reminded that the exhaustive determination to ease the physical burdens of hemophilic arthropathy is just part of enduring life with a chronic illness.

ADVOCACY TEAM

THE BLAME GAME
INSURANCE AND THE ACA

When Ben Franklin founded the United States' first insurance program in 1752 for fire, this established the tenets of our modern insurance industry: setting rates based on risk assessment and establishing a financial reserve from which to pay claims. However, in contrast to Franklin's era of fire insurance, the stakes are enormously higher for today's healthcare; risks are greater and more expensive, and the financial pools for companies involved reach into the billions. Have we strayed too far from Franklin's "an ounce of prevention is worth a pound of cure"?

> **"Republicans blame Democrats; Democrats blame Republicans. Trump blames Congress; Congress blames Trump. Nobody wins; everybody loses."**

According to financial site Axios, the top 5 insurers alone (Cigna, Aetna, Anthem, Humana, United) collectively earned $4.5 billion in the first three quarters of 2017, with the largest insurer, United, netting $2.1 billion of that. Naturally, these figures cause ire amongst the sick. But insurers blame high drug costs for their rising premiums, deductibles, and out-of-pocket costs. Maybe there's truth here; according to Forbes, the top two pharmaceutical manufacturers (Johnson & Johnson, Pfizer) reported revenues totaling $119.1 billion in 2016. PBMs aren't immune to the blame game either. In a recent Senate HELP Committee hearing, Congress pressed pharmaceutical manufacturing about costs while also aiming a finger at PBMs whose top earner, Express Scripts, posted 2017 second quarter revenue of $841.7 million, according to PR Newswire. In that same hearing, the generics' industry pointed fingers at Big Pharma; distributors claimed it's them, not us; and pharmacists blamed rising cost on "upstream" decisions. Everybody got blamed.

The Congressional tug-of-war has equally impacted healthcare, sparking uncertainty and putting affordable coverage at risk. The Republican repeal-and-replace push with the Graham-Cassidy bill proposed state block grants whose funding amount was based upon a complex population formula. It may have solved an immediate cost issue, but it also removed essential health benefit protections that the ACA provides such as high risk pools and pre-existing condition clauses. Moreover, the CBO (Congressional Budget Office) estimated millions would lose coverage, and in lieu of that and other questions, the bill did not pass, but still left uncertainty in its wake.

That uncertainty amplified when Senator Sanders then proposed his single-payer, "Medicare-for-all" bill. Analysts agree that with a Republican-held Congress the bill will not pass, but it will upset the discussion and distract from a bipartisan solution.

The confusion continued with cost-sharing reduction payments, or CSRs. Always a contentious issue, CSRs lower the amount qualifying members within

100%-250% of poverty level must pay for deductibles, copayments and coinsurance in ACA plans. CSR payments to insurers, however, were introduced to offset the cost of offering these savings to poor Americans. The legality of this has been called into question since the payments are authorized by the executive branch instead of Congress, but the payments kept high premiums at bay—until at least Trump's executive order in October 2017 unsettled things immediately, requiring a cessation of all payments at the end of that month.

States filed lawsuits against the Trump administration, but that failed to overturn the executive order and the payments were halted, upsetting state marketplaces and causing an estimated 20% rise in 2018 premiums; however, in December 2017, Congress and the White House came to a settlement regarding ACA subsidies, and CSR payments are a promised negotiation in that settlement, though the continuation of payments is still up in the air at the time of this writing.

The cost-burden, however, to consumers and their ability to access healthcare was even more up in the air than before. And then, blaming Congress for its inability to repeal the ACA—"They aren't getting the job done," he said and "should be ashamed of themselves" —Trump issued another executive order allowing association health plans to operate, a move that would loosen restrictions and allow plans to be guided by federal and not state laws; it was attempted before and its "darker side" then showed, according to The New York Times, "a long history of fraud and abuse." It further puts marketplace plans at risk as analysts predict these plans will only appeal to the healthy and will draw their needed support away from state plans.

Ultimately, it is unhealthy to divide the healthy and the sick, the burning house and the fire-free home from each other. The support must be mutual. That is the quintessential principle of insurance: "the equitable transfer of risk of loss from one entity to another, in exchange for a payment." But with these movements, the spiral of insurance uncertainty continues. Republicans blame Democrats; Democrats blame Republicans. Trump blames Congress; Congress blames Trump. Nobody wins; everybody loses.

What is missing today from Ben Franklin's insurance vision? Well, Franklin's driving force in creating insurance was his vision of preventing tragedy through a collective investment. The goal was simple and not tainted by earnings or ideology. It is also important to remember that insurance as Franklin envisioned it offered coverage in cases of catastrophic loss—a loss of such a magnitude from which it is difficult to financially recover. Understanding this informs our view of insurers as they play with payment burdens to discover an acceptable financial responsibility for plan members. But is this fair? Acceptable? What is the way forward?

For starters, industry within the supply chain (manufacturing, insurer, PBM, distributor, and pharmacy) must be open to scrutiny and to change, and in Washington the effort must be bipartisan. Ultimately, parties are going to have to stop playing the blame game and accept responsibility for rising costs and insurance instability. Again, Ben Franklin: "Any fool can criticize, condemn, and complain—and most fools do." So let's stop being foolish. And when the deal is struck, we can only know it was good by again considering Franklin: "Necessity never made a good bargain."

RESOURCES:

1 Herman, Bob. "Profits are Booming with Health Insurance Companies." Axios. 24 May 2017. www.axios.com.

2 Jurney, Corinne. "2016 Global 2000: The World's Largest Drug and Biotech Companies." Forbes. 27 May 2017. www.forbes.com.

3 "Express Scripts Announces 2017 Third Quarter Results." PR Newswire. 24 Oct. 2017. www.seekingalpha.com.

4 Congressional Budget Office. "Preliminary Analysis of Legislation That Would Replace Subsidies for Health Care with Block Grants." Sept. 2017. www.cbo.gov. PDF.

5 Amatulli, Jenna. "Trump Refuses to Blame Himself for GOP 'Not Getting the Job Done." Huffpost. 16 Oct. 2017. www.huffingtonpost.com

6 McLaughlin, Seth. "House Democrats: Republicans should be 'Ashamed' of Health Care Bill." The Washington Times. 24 Mar 2017. www.washingtontimes.com.

7 Pear, Robert. "Cheaper Health Plans Promoted by Trump Have a History of Fraud." New York Times. 21 Oct. 2017. www.nytimes.com.

8 "Insurance." Wikiquotes. www.wikiquote.org.

MATRIX ON THE MOVE!

NEW MEXICO

Dan Hicks

The Sangre de Oro, Inc. (SDO) presented a collaborative event for the ***Breaking Blood Men's Group*** September 7th at Flix Brewhouse in Albuquerque. Men gathered from all over the region to join in a sensational speech presented by Aptevo's spectacular guest speaker, Felix Garcia.

This unique and uplifting men's group event was coordinated by Gary Pennington with SDO, Steve Calderon with Aptevo, and Lynn Barker, Chris Ingram and Elizabeth Pulley, all with Octapharma. Felix presented a speech titled, A Spartan Life, an amazing analogy comparing the courageous conquest of the Spartans in the 480 BC Battle of Thermopylae to the everyday adversity in the lives of those living with hemophilia. Whether you're forced to comply with insurance companies dictating your choices or forced to comply with the Persian King Xerxes, the message is all the same: Be brave and stand strong in your convictions even in times of agonizing adversity.

Although it may be easy for many to stand their ground, for some, it isn't always that simple! That's why it is so important to stay involved and to stand united within our community. Together, we can conquer adversity just as the 300 Spartans triumphed over 150,000 Persians.

OHIO

Shelia Biljes

Over 340 walkers gathered at the beautiful Akron Zoo September 9th as the Northern Ohio Hemophilia Foundation (NOHF) held its annual ***Walk and Superhero Run***. Previously hosted at Sunny Lake in Aurora, the venue change was welcomed and seemed to attract even more walkers this year! Manufacturer and specialty pharmacy representatives greeted walkers as they visited the

Carter and Jordan show off their muscles!

exhibit booths and began the morning with bagels, granola bars, bananas, coffee and plenty of bottled water.

Everyone joined in the one-mile, uphill hike to visit the bears and then down a trail to see the wolves and lions. The children stayed very involved as they kept track of animal exhibits encountered on scavenger hunt cards. Later, the cards were collected, shuffled and winners drawn for awesome prizes such as a LeapPad tablet and a remote control mini-drone.

The Ed Kennedy Memorial Team hosted a picnic lunch where the various walk teams mingled and visited with each other. Homemade cakes, pastas and of course, hot dogs complete with chili and slaw were featured on the buffet spread for the hungry walkers.

Chris and Samantha enjoy the day!

NOHF exceeded its goal of $40,000 the day before the walk and brought in even more donations at the event. With such roaring enthusiasm and eagerness from participants and supporters alike, the Chapter looks forward to next year's event!

NEW YORK

Richard Vogel

As many of us know, school can be difficult to navigate for a child with a bleeding disorder. It's important to know the various resources available to you. Do you need an Individual Education Plan (IEP) or a 504 plan? Or both? And what's the difference between the two?

When I was going to school in the 1960s, these resources were not available to me. My mother would go to the school and advocate on my behalf. She would talk with the school nurse and teachers and explain hemophilia and what to expect. She would let them know I would sometimes need extra time to get to class, that my participation in physical education was limited, and that I would need a tutor if I was absent for extended periods of time.

Well on Sunday, September 10th, the New York City Hemophilia Chapter addressed these issues with their second ***Bilingual Back to School Education Event***. The event was held at the downtown Marriott hotel, close to the new World Trade Center.

Best to be prepared - Miquel attends with his son, Miquel, Jr. to learn about IEPs, with Brenda Montgomery King

The first gathering consisted of four breakout sessions: *504s and Other Education Plans* was presented by Ben Shuldiner and was for patients/caregivers. Ben discussed how to set up a 504 or IEP and the difference between the two. An IEP addresses educational services provided such as requesting two sets of books, one for school and one for home tutoring if your child is out for a length of time due to a bleed. A 504 focuses on mobility issues, removing the barriers in the way of their education such as wheelchair access or requesting additional time to walk to class if your child's disability prevents them from getting there in the time allotted. Claudio Sandoval, MD presented similar information in Spanish.

Directed toward teens, *Getting Ready for What's Next*, presented by Aliana Soto discussed transitioning to young adults. Meanwhile, kids 12 and under were kept busy at *Mural Making* facilitated by Kerry Cox.

The second group of sessions included *Esperando lo Inesperado: Las Emergencias Ocurren* by Karla Zevallos in Español, which covered what to do in emergencies and *Communicating with Providers: It's Your Responsibility* by Milybet Montijo Cepeda. While adults attended the sessions, teens were off on a field trip and the younger set was treated to an ice cream party.

The event was well attended because there was something for everyone, from patients to caregivers, to teens and children and to those whose first language is Spanish.

PENNSYLVANIA

Tina McMullen and Eric Lambing

Karen, Steven and Tina drink in the sunshine!

What a gorgeous day it was for 92 golfers who attended The Eastern Pennsylvania Chapter of NHF ***Annual Golf Classic***! September 12th began with a nourishing lunch followed by a shotgun start at the beautiful RiverCrest Golf Club and Preserve in Phoenixville.

Many great prizes were awarded for contests such as *Closest to the Pin* for men and women, *Longest Drive* for men and women, and a *Putting Challenge*. The day concluded with a delicious buffet dinner and prizes being awarded including TaylorMade golf clubs, a RiverCrest Golf Shop gift card, sterling cut wine glasses etched with the RiverCrest logo, just to name a few. Executive Director Curt Krouse and his amazing staff and volunteers provided everyone with a picture-perfect, fabulous day of good cheer while raising funds to benefit the valuable chapter programs.

CALIFORNIA

Gabriela Griffin, Marina Vera and Hector Heer

A three-day event designed to change, educate and empower the lives of the Spanish speaking bleeding disorders community of California took place September 15th–17th in Anaheim at the Marriott Hotel. Families from all over California - from the sunny south to the northern parts of the state - to kick off the spectacular ***Familia De Sangr***e hosted by Hemophilia Foundation of Northern California (HFNC), Hemophilia Foundation of Southern California (HFSC) and the Hemophilia Association of San Diego County (HASDC). Well over 565 community members were in attendance for this long awaited, first-time event!

Gaby Griffin and Marina Vera lead the maraca making

The action began Friday with the opening of the exhibit hall. Community members were given a "passport" game card to fill with a sticker from each booth visited, which were entered into a prize drawing. During dinner, guest speaker Carlos Safadi Marques of the World Federation of Hemophilia (WFH) shared what living with a bleeding disorder is like for those in countries where there is a lack of access to healthcare, support groups and educational events. He illustrated the challenges in an emotional video featuring family interviews, leaving attendees teary eyed. Carlos also spoke about the work WFH is doing to combat their circumstances.

Saturday began with a hearty breakfast and more time to visit industry booths and learn about new products and services from company representatives.

The kids were also enjoying themselves! Some attended a *My Amazing Blood* session where things got 'slimy' as they learned about blood. Kids also lined up at the Factor Support booth to make colorful maracas out of spoons, rice and plastic eggs.

Throughout the day, a wide selection of educational sessions were led by captivating speakers who imparted their expertise and wisdom. Sessions included, *My Life Story* with speakers Mickey Price and LA Aguayo, who shared uplifting stories about their personal experiences living with hemophilia and how they try to inspire and encourage others affected by a bleeding disorder.

Vanessa Salinas, MD of City of Hope spoke on *Gene Therapy for Hemophilia A and B*. She explained gene therapy and gave an update on finding a cure for hemophilia. The *Female Connection* speaker, Maria C. Velez, MD discussed how hemophilia is inherited, and about the unique needs of women with hemophilia. Other topics included *How to be Prepared for Changes in Immigration Law and Policy* by Sarina Rivera, Esq.; *Understanding von Willebrand Disease* by Susana Escojido, RN; *Kinesiology Tape* by Michael Zolonitsky, PT; and Chef Doreen Colondres who discussed *Healthy Cooking*. These speakers and more shared their expertise in their specific areas and made themselves available for questions and answers.

Thank you chapter executive directors, Patrick Dunlap HFNC, Michelle Kim HFSC and Nooshin Kosar HASDC for developing this spectacular program!

CALIFORNIA

Heather Messerly

Trevor with instructor pro-surfer Austin Keen

The 3rd annual Mauli Ola and Hemophilia Alliance of ***Orange County's Shaka Surf Fest and Beach Day*** event took place Saturday, September 16th at beautiful Huntington Beach, surf capital of California!

Mauli Ola is a non-profit organization that pairs surfers with children who have complex medical conditions. This was the third year that Hemophilia Alliance of Orange County paired with Mauli Ola to provide their program to children affected with a bleeding disorder.

The perfect weather day was spent with one-on-one lessons teaching the kids to surf and enjoy the ocean. Paired with their instructor, the children donned wetsuits, chose surfboards, and went off with their instructor for dry land training first. When ready for the real thing, they headed excitedly into the ocean. Some learned to float on boards while others actually caught a wave. Regardless, all had a wonderful time enjoying the sandy beach, ocean waves and salty air.

I think it's great that a group of passionate athletes share their skills with children who may not otherwise ever get to surf. Their motto is "May the wave heal us all" and I truly believe there is strength and healing powers in the water.

Heather with Hans Hagen, Mauli Ola Executive Director

Dry land instruction

ILLINOIS

Eva Kraemer, Lisa Miller and Susan Moore

Illinois Team Matrix - Keepin' in Clottin'!

Lincoln Park is a scenic 1,208–acre park - Chicago's largest, located along a 7–mile stretch facing Lake Michigan. Named for Abraham Lincoln, the park has everything; beaches, nature reserves, recreational areas and even a zoo. It is not hard to figure out why Lincoln Park is bustling with people enjoying all it has to offer. Saturday, September 16th was no exception as the Bleeding Disorder Alliance Illinois (BDAI) held their ***8th Annual Hemophilia Walk.*** The day was beautiful - sunny, blue skies and warm temperatures made it perfect for a walk in the park!

BDAI brought the community together – folks with bleeding disorders, friends, family, industry – we were all there with enthusiasm! Matrix Health Group was proud to have an eager walk team ready to help further the support our chapter offers in the way of advocacy, education and research. The walk to the finish was fast, with everyone talking and catching up since our last encounter.

MAINE

Cheryl Ashmore

More than 100 Mainers of all ages gathered to celebrate and fundraise for Hemophilia Alliance of Maine September 16th. ***Hike 4 HAM***, Maine's version of the NHF Walk, was held at Mt. Battie in Camden. With the opening ceremony being broadcast via Facebook Live, HAM Treasurer Terry Rice shared a new walk tradition - both the oldest and the youngest members with bleeding disorders were invited to ring a bell to mark the start of the trek up the mountain.

Mt. Battie has approximately 700 feet of elevation over 1½ miles, which can be challenging at times! Arrival at the summit brought cheers, quickly

Terry Rice takes the stage!

distributed water bottles and another tradition – handing out of the coveted annual patch, designed by Matrix's Justin Levesque.

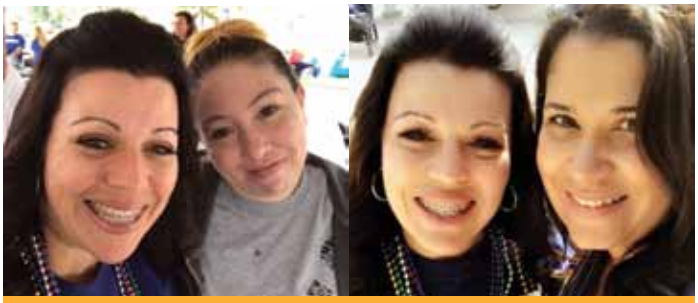
With option of a paved road to walk for the return trip, the families made their way to the park at the base of the mountain as the aroma of savory barbeque quickened their steps. Several kids took advantage of the nearby meadow to throw a football or Frisbee, while adults socialized and new families were welcomed into the fold. It was a beautiful day to share with the hemophilia community and everyone eagerly looks forward to next year's hike!

NEVADA

Kelly Gonzalez

A brisk morning in Reno did not discourage over 125 community members from heading to Bartley Rancho Park September 16th where they hung out with super heroes, visited with friends, celebrated birthdays of the HTC providers and of course, walked to raise money for the Nevada Chapter of NHF.

Cindy Picos, Sean Hubbert and Kelly Gonzalez ready to welcome visitors to the booth!


Kelly Gonzalez takes selfies, first with Lisa and then with Maureen

Walk Reno was filled with friendship and laughter from a group of people who know how to put the "fun" in fundraising! Thank you to the amazing community members, industry sponsors and dedicated chapter personnel for making this event such a pleasant success!

MISSOURI

Danny Hicks and Cyndy Coors

Midwest Hemophilia Association (MHA) hosted its ***24th Annual Family Fun Fair*** September 16th–17th at the Hilton Garden Inn of Independence. Familiar faces gathered from all over Missouri and Kansas for a wonderful weekend full of great fun, good food and plenty of useful education information to take home.

This year featured an array of breakout sessions with something of interest for everyone! Topics included *Health Insurance Considerations for Persons with Bleeding Disorders – Getting Insured, Staying Insured* presented by Lynn Szott and Roy Pura; *Exploring Emotional Well-Being* by Joe Schuch with Pfizer; *Journey of Factor* by April Littrell; *Hope* presented by Jessica Hurtig of Novo Nordisk and Chef Dana Herbert, TLC's "Cake Boss" Winner; *Pain in Hemophilia* by Bayer's Jessica Walker; and *Oh, the Places We'll Go! Novel Therapies for Hemophilia and Other Bleeding Disorders* presented by Shannon Carpenter, MD.

In addition to the many interesting sessions, kids in kindergarten through 5th grade took an exciting trip to visit the remarkable animals at the Kansas City Zoo while those in grades 6–12 went to Kansas City's Worlds of Fun amusement park for a cool afternoon of thrilling rollercoaster rides. With eye-opening educational sessions and the awesome opportunities to connect with the constituents made this year's Family Fun Fair a definite triumph. It's not surprising this is one of MHA's most heavily attended events of the year!

NEW JERSEY

Richard Vogel

Oscar Wilde said, "The English have a miraculous power of turning wine into water." Well, not the French. On the evening of September 18th, Hemophilia Association of New Jersey (HANJ) held its 25th annual ***Gourmet Dinner and Wine Tasting*** event themed, "The Other Red Wine of Burgundy: Cru Beaujolais."

Hosted by HANJ board member Mark Scudiery, who donated the wines from his foundation of the same name, the event was held at il Tulipano, a posh Italian restaurant in Cedar Grove.

Amid hors d'oeuvres, pizza bar and antipasto table, community members, manufacturers and specialty pharmacies representatives mingled, networked and, of course, imbibed in Beaujolais wines, full bodied and delicious.

The evening was a great success for HANJ! The $40,000 raised will assist the chapter in providing patient programs and care. Matrix Health Group was proud to sponsor this event, and happy to support HANJ and the fantastic work they do for the bleeding disorders community!

SEPT. 22-24 SOUTH CAROLINA

Peggy Klingmann and Brenda Montgomery King

Keeping It Coastal was the theme for Hemophilia of South Carolina Chapter's ***Family Educational Camp and Adult Retreat Weekend***. Over 220 arrived at the Ocean Creek Resort and Conference Center in Myrtle Beach for this annual event September 22nd–24th. Friday evening began with the opening welcome remarks, acknowledgements and chapter announcements. The rest of the evening gave way to carnival games, photo opportunities and family board game tables.

Ward and Marilyn dine with Brenda Montgomery King

Saturday brought an array of breakout sessions with amazing speakers presenting helpful information on bleeding disorders issues. *How to Tell Your Story With Impact* was the topic presented during dinner, followed with more family-fun entertainment including a deejay for dancing and karaoke competition with an ice cream social!

Sunday dawned with a peaceful, relaxing sunrise beach walk. Breakfast was served and the final session offered was *Real Talk: Hot Topics*. The *Walk Kick-Off* and boxed lunches wrapped up the weekend of fun. See you all next year!

NEVADA

Kelly Gonzalez

A little chill and wind in the air didn't stop over 300 supporters of the Nevada bleeding disorder community from arriving at Floyd Lamb Park September 23rd in Las Vegas for an amazing ***Hemophilia Walk and 5K***! Led by energetic young runners and walkers, the boisterous crowd made the adventure even more exciting as we raised over $50k for our Nevada Chapter of NHF! Thank you to all the sponsors - big and small - as well as the motivated volunteers and incredible participants, who rallied to put the "fun" in fundraising!

Maddy Lynn and Nevada Blood Drop looking good!

VIRGINIA

Michelle Stielper and Terry Stone

It was a wild and wolfy ***Family Weekend Retreat*** at Great Wolf Lodge in Williamsburg with the Virginia Hemophilia Foundation September 23rd–24th! Families were dressed up in wolf ears as they experienced all sorts of nature-themed events within the enchanted lodge hotel. From the indoor waterpark, bowling alley and arcade, to the nature show, magic quest and attending story time in pajamas, there was fun to be had all!

Terry Stone, Dr. Emily Druzgal and Michelle Stielper

Young cubs enjoyed playing games together while older pups did science experiments including an erupting diet cola volcano, and played trivia to test their bleeding disorders knowledge. Teen wolves assembled to play Jeopardy – bleeding disorders style, and had a howling good time. Meanwhile the leaders of the pack were treated to an informative session titled, *After the Campfire*, where they were given pointers and creative ideas to help support their children and enable them to live their best life.

The weekend concluded with an educational breakfast where John Vieke, a police officer with hemophilia B, discussed overcoming obstacles, self-care and finding a healthy way to achieve your dreams while managing your bleeding disorder. Following the program, little wolf cubs were invited to try on Officer Vieke's S.W.A.T. gear. Their awe and excitement was electric! It was a weekend to remember with heartfelt family time and strengthening of friendships that will keep this pack together for years to come.

DELAWARE

Tina McMullen and Rich Vogel

The Brandywine Valley Hemophilia Chapter hosted its ***Family Picnic*** Sunday, September 24th at beautiful Lum's Pond State Park in Bear. This September day was extremely warm and families arrived ready to participate in all sorts of activities. The exciting day of family fun included canoeing, paddleboats, basketball games, face and tattoo painting, and arts and crafts.

The families were also treated to an array of mouth-watering foods provided by Mission BBQ. Foundation board member and chairman of this event, Gerry Reed, and his wife Becky, did an absolutely amazing job in organizing this fantastic day filled with entertaining activities and great food for the families of the Brandywine Valley Foundation!

Rich Vogel gets a fancy design painted on his arm

ARKANSAS

LeAnn Wilson

Big Dam Bridge in Little Rock October 7th was the place to be as the Hemophilia Foundation of Arkansas held their 4th Annual Hemophilia Awareness Walk/Fundraiser. "Halloween Fun" was the theme of this event and walkers of all ages were encouraged to wear costumes. Imaginative costumes crossed our path from an assortment of scary zombies, a cute little Superman, and even a whoopee cushion (didn't stand near that one!).

McConnell, Patsy and DeWayne visit LeAnn Wilson

Taking place along the Arkansas River, it proved to be a gorgeous outdoor event. The walk started with everyone visiting industry reps and grabbing a bite from the continental breakfast bar. With fans and walk personnel cheering them on, over 100 walkers took to the starting line. Some walked to the bridge while others walked across the bridge and back the 4226-foot structure. Spanning the Arkansas River, it is the longest pedestrian and bicycle bridge in North America, connecting over 15 miles of scenic riverside trails between Little Rock and North Little Rock.

Fun continued after everyone returned with announcements of the winners of the largest team and the most funds raised by a team. The day was made even more fun with face painting, music and a costume contest!

One step at a time, this event is growing and we look forward to participating again!

MICHIGAN

Enrique Morey

October 7th marked Hemophilia Foundation of Michigan's ***3rd Annual Walkin' on the Westside*** fundraiser. Rain or shine was the attitude for those in attendance at Fifth Third Ballpark in Grand Rapids. The day started out slightly damp, yet cleared up just in time for the day's activity. Kick off and opening ceremony began just after 10 am with

walkers beginning their course around the stadium and finishing on the baseball field. After times were tallied, attendees joined for an awards ceremony and special program to thank sponsors and attendees. Funds raised at this event support chapter programs such as Camp Bold Eagle, HFM's Financial Assistance Program, medical ID tags, and many more important and vital services to assist those with bleeding disorders. Matrix Health Group was happy to attend this event and look forward to it in 2018!

NEVADA

Kelly Gonzalez

A warm welcome was extended to families of a diagnosed child under 7 years-old during the New Family Group Event in Las Vegas October 7th. Here, families were offered support and community resources. The group of 20 families (50+ people) gathered at John's Incredible Pizza Company to enjoy an interesting and fun-filled day while learning about the ins and outs of our bleeding disorder community. Thank you to the Nevada Chapter of NHF for supporting these wonderful events!

Andrés and Sofía take a moment to smile for a picture!

PENNSYLVANIA

Tina McMullen

A glorious day greeted walkers and runners at the Eastern Pennsylvania Chapter's Annual Trick or Trot 5K Run/Walk in Collegeville October 7th. With 20 teams and over 300 runners, it was by far the largest attendance for this popular event.

With the sun shining brightly in a beautiful fall sky, our day started with participants visiting a variety of industry vendors under the exhibit tent. Children enjoyed the bouncy house and games including basketball shooting, batting, and kicking a soccer ball into a huge inflatable target.

Smiles from two little buddies - Brooklyn and Bella

Team Tommy's Trailblazers!

After the run/walk, awards were given to the top runners in various male and female categories. Participants outdid themselves dressing in creative costumes; even four–legged friends arrived decked out! Awards were given to children and adults for scariest, funniest and most creative outfits. A special prize was given for the best group costume. The day ended with Curt Krouse, Executive Director of the Pennsylvania Chapter, presenting a $30,000 grant check to The Children's Hospital of Philadelphia, surpassing last year's amount! Kudos to Curt and his staff Lindsay Frei, Charlotte Conmy and Kat Kocsi for a job well done!

FLORIDA

Marcy Foertsch and Peggy Klingmann

Matrix Health Group and Octapharma partnered to host a most delicious ***Gathering*** at Farris and Foster's Chocolate Factory in Orlando October 10th.

Sara Cesera, Marcy Foertsch, Peggy Klingmann, Sherri Rojhani, and chocolate tasters, Peyton and Cody

Sara Cesera, a community advocate for Octapharma, whose husband and two daughters have von Willebrand Disease, spoke on the topic of *Taking Care of Yourself*. Her presentation focused on the importance of caring for oneself as a caregiver, who is often neglected while caring for a family member with a chronic condition.

Following the sharing of such important information, everyone was treated to a lesson in the finer points of making candy - specifically chocolate! Thank you to our wonderful partner at Octapharma, Sherri Rojhani, for an evening where we became the chocolatiers. We will remember this unique opportunity for quite some time!

UTAH

Kelly Gonzalez

The ***vWD Conference***, hosted by Octapharma in support of the Utah Hemophilia Foundation, was a roaring success! This amazing, informative and helpful event, held October 13th–14th, allowed participants to cozy up in the scenic Homestead Resort located in Midway, about an hour southeast of Salt Lake City.

Friday night began with vWD bleeding disorder panelists fielding questions from inquiring attendees. Conversations the next day kicked off with round-table discussions for women, men and parents, and continued with presentations from speakers Amber Federizo, Hemostasis and Thrombosis Center of Nevada; and Danielle Nance, Arizona Bleeding Disorder Clinic. As BioMatrix Educational Development Specialist, I also presented on a wide variety of subjects surrounding vWD.

The weekend was interesting, enlightening and community driven! We are so grateful to the Utah Hemophilia Foundation for inviting us to be part of this educational event!

CALIFORNIA

Gaby Griffin and Marina Vera

The 5k walking course at Liberty Station in San Diego took participants on a scenic trip with breathtaking views of the San Diego Bay. Hemophilia Association of San Diego County welcomed over 100 participants October 14th to the ***Hemophilia Walk*** and to enjoy a gorgeous, sunny Southern California morning.

With opportunities to visit vendor booths, face painting for kids, a bounce house, Jamba Juice and ice cream for all made this all a grand day! This event

Having fun at the Walk!

was a fantastic opportunity to catch up with friends and take part in a worthy cause. A big thank you to the San Diego chapter, especially Executive Director Nooshin Kosar, Programs Director Lisa Heffernan and their amazing board!

FLORIDA

Peggy Gay

In the spirit of Halloween, the ***Jacksonville Creepy Crawl 5K and Vampire Walk*** attracted a crowd of nearly 200! The Hemophilia Foundation of Greater Florida (HFGF) welcomed everyone to Nocatee for an early 8:00 am walk October 14th. With many dressed in Halloween attire, everyone visited company representatives at the booths, enjoyed coffee and other refreshments, and munched on snack bars, bagels and yummy doughnuts!

In addition to being a blast, this annual fundraiser proved to be very successful for HFGF as they exceeded their goal and raised well over $45,000!

Congratulations to the chapter and to all the volunteers, sponsors and participants for their part in making this event great!

Bioverativ Rep. Lily Gomez with Isabella, Adam and Rachel

NORTH CAROLINA

Xaviette Pointer-Kincy

A whopping 650 excited community members arrived for Hemophilia of North Carolina's ***10th Annual Family Festival and 5K Walk*** October 14th at Lake Crabtree County Park in Morrisville. This very popular event is the chapter's largest fundraiser of the year and resulted in raising over $123,000, which was 112% of the total goal. This event continues to grow yearly and so does the fun! In addition to all sorts of treats such as cotton candy and a sundae bar, breakfast, lunch and beverages were offered. Kids enjoyed having their face painted and slipping down the inflatable slide. A photo booth, caricature artist, music, dancing, arts and crafts, and more added to the day's excitement!

Morgan enjoys her day

The event was made even more special in that it was a celebration of its 10th anniversary! In honor of this momentous occasion, community leaders presented a decade of milestones and accomplishments by Hemophilia of NC. Congratulations to Executive Director Charlene Cowell and her dedicated team for this spectacular and successful gathering!

VIRGINIA

Terry Stone, Michelle Stielper and Paul Brayshaw

Records are meant to be broken, right? That's exactly what Hemophilia Association of the Capital Area did!

Team Harley Heroes - Matrix Health walking & talking!

Thanks to sponsorships and many generous donations HACA exceeded all previous walks and raised over $90,000 this year at their ***Annual Walk and Fall Picnic*** Saturday, October 14th at Lake Accotink in Springfield. This year's event brought two changes. First, it was moved from the grounds of the National Mall in DC to a local park with a lovely lake where many of us visited as children. Secondly, the board decided to break away from the national walk effort and host their own chapter walk. Both changes were big, and they certainly paid off as participation and support were impressive and so were the funds raised. Go big or go home!

James is honored for donating to HACA almost $3000 saved from his dog walking business by Brenda Bordelon, ED.

Matrix Health Group was pleased to sponsor this event and participate with a walk team. Congratulations to Executive Director Brenda Bordelon for her leadership and hard work to make this event successful. Although there were many generous donors, one young man was recognized for his large donation of almost $3000. James has a dog walking business and his services are highly sought after. He saved all of his proceeds for the year and donated them to HACA via his family's walk team, *Non-Clotter Trotters*. What a kid! Matrix Health Group honors your efforts and everyone who made this event great and a tough one to beat for next year!

CONNECTICUT

Justin Levesque

Held at the Marriott Downtown in Hartford October 14th–15th, New England Hemophilia Association's ***2017 FallFest*** was very well attended by community members from across the entire New England region. Some traveled from as far as Calais, Maine – that's a seven-hour drive of dedication!

Sessions included *Powering Through* by Patrick James Lynch of *Stop the Bleeding!* fame and a teen program that tied into their educational initiatives. The most moving of sessions featured Jeanne White-Ginder delivering a keynote speech on the inspiring story of Ryan White and how he became a symbol of hope for the hemophilia and HIV/AIDS communities in the 1980s, and how his legacy continues to live on today. There wasn't a dry eye in the house. As we've come to expect from NEHA, this event was top notch!

CALIFORNIA

Heather Messerly

Mondays may not always be everyone's favorite day of the week, but October 16th was an exception! Hemophilia Foundation of Southern California held its ***34th Annual Memorial Golf and Tennis Tournament*** at La Cañada Flintridge Country Club, a beautiful location with fantastic mountain views. This year, the event was held in memory of Gerry Green, a much beloved member of the Southern California bleeding disorders community who passed away in April 2017.

Heather Messerly and Jenna work the wine pull table

Golfers teed up, tennis players took to the courts... and the day began. Following the enjoyable round of play, a reception took place in the clubhouse. A silent auction and cocktail hour was followed by a prime rib dinner, presentation of awards and guest speakers. Dr. Luck, a much-admired hematologist for 49 years, welcomed the assembly, and a group of campers told stories of their most memorable times at camp and what camp meant to them. The stories these young men shared encouraged everyone to be even more generous. All funds raised at this event are dedicated to sending children with bleeding disorders to camp at Painted Turtle, a most worthy cause!

Dr. Luck

ILLINOIS

Eva Kraemer

Set on Lake Michigan at the Columbia Yacht Club, the Bleeding Disorder Alliance Illinois (BDAI) hosted their ***Annual Autumnal Wine Dinner and Auction*** October 20th. Jim Hurster of CSL Behring, the Champagne Sponsor, superbly selected red and white wines to sample for nearly 100 guests. Many generous and talented people donated their time and genius to making baskets for auction in support of BDAI to continue providing education to the Illinois bleeding disorder community.

Allison, Eva Kraemer, Sergio, Gina and Kirk enjoy the elegant evening

The breeze off the lake was invigorating as well as unseasonably warm, enhancing the dazzling backdrop of the evening Chicago skyline. Everyone indulged on delectable food, superb company, complete with exquisite wine parings. Many thanks to BDAI, CSL Behring and all those who came out to make the evening a success!

PENNSYLVANIA

Tina McMullen

An evening of music, silent auction items, award winning wines, Yards beer and fabulous hors d' oeuvres set the scene at picturesque Crossing Vineyards and Winery in Newton October 20th as the Eastern Pennsylvania Chapter of NHF held their ***Annual Evening of Wine and Beer Tasting***.

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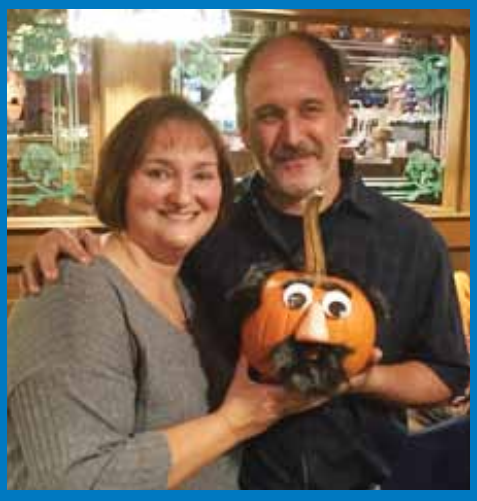
OHIO

Shelia Biljes

Laughter was flowing along with creative juices as Matrix Health Group sponsored another fun ***Couples Night*** in Brooklyn October 17th. As women decorated pumpkins resembling their husbands, men had an agenda of their own decorating and painting jewelry boxes for their wives. They wrote beautiful love letters to put inside, all in honor of Sweetest Day.

After the crafting, a wonderful meal was served by TGIF including steak, ribs and amazing salads. While the couples dined together, Brenda Montgomery King, Matrix Health Group Social Worker, spoke about the three C's essential for a good relationship - *Connection*, *Communication* and *Concentration*.

Following dinner and amidst frequent outbursts of hilarity, the men were directed to pick out the pumpkin they believed to be created in their image by their wife. Amazingly, each man picked the correct pumpkin, proving the ladies were spot on with their works of art. Laughing together is one of the essential keys for a good marriage and as a group we experienced plenty of that!



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Gorgeous smiles from Jess, Kat, Kocsi and Brittney

Silent auction pieces included a variety of fabulous coveted items such as a weekend in the Poconos, a basket full of gift cards, a wine tasting for 12, a fitness basket and a set of tickets to an NFL Philadelphia Eagles football game just to name a few! Proceeds from this event benefit the chapter's patient support and program services. Thank you to Executive Director Curt Krouse and his entire staff for making this event so spectacular!

WEST VIRGINIA

Michelle Stielper

October 21st was a brisk and beautiful morning for a walk at the Waterfront Place Hotel in Morgantown and this one was wildly successful. For the ***WV Hemophilia Walk,*** the West Virginia Chapter of NHF set a goal of $35,000 and surpassed it by raising over $36,000! It was the first time the chapter met, let alone beat their goal! I was proud to help kick off the walk by sponsoring the kid's Monster Dash and setting the adorable ghouls and goblins off to run like zombies were chasing them to the finish.

Following the walk, family fun was around every corner. There was a bouncy castle, face painting, yummy food and great conversation. It was a wonderful and memorable event to raise money for the chapter and we cannot wait to see them raise even more next year!

KANSAS

Dan Hicks

Matrix Health Group, the Midwest Hemophilia Association and Bayer teamed up for the ***1st Annual Pumpkin Patch Event*** at the KC Pumpkin Patch October 22nd in Olathe. There were fun activities to choose from including the gourd gun, the epic pumpkin slide, tug-of-war, hayrides and way too many more to list!

Hunter and Rex

Bayer's Patient Advocate Speaker, Dakota Rosenfelt, presented *Game On*, a special program to help one better understand eating right, staying fit, maintaining insurance coverage, and planning for college and a career. The session turned into more of a discussion with everyone involved, sharing stories, opinions, past experiences and ways they've stood up against adversity!

We look forward to collaborating with The Midwest Hemophilia Association and Bayer next year for the 2nd Annual Pumpkin Patch Event!

VIRGINIA

Terry Stone and Michelle Stielper

The morning came early,
The weather was grand,
Some ready to run,
Others just lent a hand,
The Trick or Trot event was finally here,
So they came one and all, As their mission was clear,
The members wore costumes,
But we knew who they were,
Generous supporters who love VHF
And for that there's no cure!

Trick or Trotters!

The Virginia Hemophilia Foundation held its annual ***Trick or Trot 5K Monster Dash*** fundraiser on a lovely fall day, October 28th at the Robious Landing Park in Midlothian. This has become a very popular event for the serious runner as well as the Halloween loving family who needs one more reason to dress up in their favorite costumes. Filled with music, games, a fun run for the little spirits, tasty treats and time for visiting, Trick or Trot has grown to be a favorite event. Matrix Health Group was a sponsor and we loved dressing up as Waldo (RCC Michelle Stielper), and Puss in Boots (RCC Terry Stone), who won third place in the adult category! There were lots of winners, especially VHF for another successful fundraising event!

PENNSYLVANIA

Tina McMullen

The Warehouse Hotel and Spooky Nook Sports Complex in Manheim was the place to be Sunday, October 29th. That's where the Eastern Pennsylvania Chapter of NHF held an ***Educational Event***, *Adventures in Learning*. Honored guest speaker of the day, Patrick James Lynch captured the audience's attention with his charm and humor! Patrick, who has hemophilia, possesses a long list of talents from being an award-winning actor, director to producer and host. His work focuses on creating entertainment and engagement to educate and empower people affected by bleeding disorders. After a tasty buffet lunch, an educational session titled *Powering Through* began.

Patrick James Lynch listens intently to Bella as she imparts her wisdom.

A fun scavenger hunt followed giving everyone a chance to mingle and collect information about various bleeding disorder products. While all this was going on with adults, children were having fun of their own with arts and crafts. Once things wrapped up, families had full run of the activities at Spooky Nook Sports - backyard games, basketball, kickball, Wiffle ball, Clip 'n Climb and more!

It was a great day for the members of the Eastern Pennsylvania Chapter. Thank you to Curt Krouse and his staff along with the Consumer Advisory Board of the Central PA Hemophilia Treatment Center for hosting such a wonderful event!

OHIO

Shelia Biljes

Hosted by the Northern Ohio Hemophilia Foundation, ***Fall Family Fun Fest*** is an event no one wants to miss! It's the time of year before holidays kick off to spend a weekend with our extended family – members of the bleeding disorders community. Taking place November 3rd–4th at the Holiday Inn of Independence, industry sponsors were on hand to share information Friday

Using a Matrix Health Group fidget spinner, Kelly showed off her talents and tricks, including nose spinning!

Assuming the position of official photographer, Steven snapped pictures of everyone having fun!

evening as everyone gathered in the ballroom. After dinner and a warm welcome by Chapter President Tanya Ricchi, it was off to the hotel pool for family time!

Saturday morning opened with an early breakfast and time to visit industry representatives who discussed their services and products. When it was time for adults to get down to the business of learning, kid's said goodbye and headed off on a field trip to an Escape Room adventure.

Hemophilia Treatment Center physicians, Dr. Ahujah of University Hospital and Dr. Fargo of Akron Children's, led a question and answer session. The adults asked many excellent questions on topics such as gene therapy, women bleeders and inhibitors. The doctors were impressed with the depth of knowledge possessed by parents of a child with a bleeding disorder. Another session covered *Disclosure in the Workplace*.

Soon the kids returned, lunch was served, and it was time to head home. Thank you to Tanya and her team for the great weekend!

CALIFORNIA

Gaby Griffin and Marina Vera

What a way to start the day on an exciting adventure - ***Walk the Realm***, Hemophilia Foundation of South California's ***9th Annual Bleeding Disorders Walk*** took place November 4th at Griffith Park in Los Angeles. Kicking off the walk and welcoming families was Senator Anthony Portantino. Member Mickey Price then paid tribute to those we have lost in the bleeding disorders community and gave honor to those who continue to fight every day.

Following the walk, contests were in full swing for the best t-shirt and the best costume! Children had many opportunities to have their face painted and participate in Nerf archery, shield and crown making, and balloon twisting. A character photo booth was also in place for everyone to take home a long-lasting memory of this spectacular event. Families enjoyed pizza and ice cream and enjoyed a performance of entertaining medieval sword fighting! Once again, HFSC hosted a fantastic event!

MARYLAND

Michelle, Stielper, Terry Stone and Paul Brayshaw

The Hemophilia Foundation of Maryland's ***Family Weekend*** was surely an event to remember! Every minute was full of activity and excitement with over 300 people in attendance at the Hyatt Chesapeake Bay in Cambridge November 3rd–5th. The program kicked off with an educational dinner Friday following a speech from Board President William Hoffman to welcome all the new families.

The men enjoyed a poker game Friday evening as everyone was settling into their rooms. Saturday was an activity filled day for all, from the tall to the small. While most stayed snug in their beds, some early risers chose to watch the sunrise over the Chesapeake while fishing from the pier. Following breakfast, adults could sit in on multiple educational sessions, enjoy a pampering appointment, participate in cooking classes, or get creative with craft projects.

Michelle Stielper and Paul Brayshaw ready with warm and welcoming smiles!

Teens enjoyed a paintball excursion and programming while hanging out with their friends. Little tykes enjoyed events all weekend from paint projects to making stuffed animals and playing with all of their best buds. Saturday night's *Carnival* was a flurry of activity from games and prizes to a talent show, opportunities to hit the dance floor, or partake in all the delicious snacks that were sure to cater to everyone's taste buds. The weekend wrapped up with an educational breakfast Sunday morning, and a slide show of the years' events highlighting the wonderful memories made at numerous events that have taken place. HFM's Family weekend 2017 will be hard to top, but we cannot wait to see what's in the works for next year!

MISSOURI

Dan Hicks and Eva Kraemer

Matrix Health Group had the great opportunity to sponsor a table at the Gateway Hemophilia's annual ***Who's Who Trivia Night*** at The Pavilion at Lemay in St. Louis. Many gathered November 4th to put their knowledge to the ultimate test for 1st, 2nd, and 3rd place prizes. Other activities included a silent auction,

Eva Kraemer and Dan Hicks (front row) with Tim, Nancy and Debbie (center)

50/50 raffle, and heads & tails game. What an absolutely great way to connect with members of the hemophilia community and raise money! Matrix Health Group looks forward to joining everyone at Gateway Hemophilia Association's Trivia Night next year!

NEW YORK

Richard Vogel and Tina McMullen

On the gorgeous, crisp fall day of November 4th, the Bleeding Disorders Association of Northeastern New York held their ***Annual Meeting*** at the Great Escape Indoor Lodge and Water Park in Queensbury. With leaves changing colors and weather cooling, community members arrived for a day of enjoyment and information.

Lily and Logan

Dennise, Jake, Lilyann and Dorothy

Following a buffet lunch and a session on general association business, community members paid attention to a presentation by keynote speaker Dr. Joanne Porter of the Albany Hemophilia Treatment Center. She spoke on new products available to the hemophilia community. Afterward, families enjoyed the rest of the day splashing their way through the indoor waterpark!

NEW MEXICO

Felix L. Garcia

Fall is a beautiful time of year in New Mexico as leaves change color and the sunsets show off magnificent hues of red, yellow and orange. Nightfall greets us earlier and earlier, while we look forward to Sangre de Oro hosting their ***Annual Family Education***

Weekend. This year's event was held November 10th–12th at the Albuquerque Crown Plaza Hotel. Over 300 community members came together for education, networking, and even a little tai chi.

Former board president and active volunteer Lori Long put together a diverse program for everyone. The children's agenda included a field trip to the museum and teens had the opportunity to work with Gut Monkey for experiential learning and life skills development. Women with bleeding disorders are not forgotten in our community as they learned of treatment options and advocacy tools for everything from getting a diagnosis to working with payers.

Teens interact

Felix Garcia

As a committed volunteer with New Mexico's Breaking Blood group, I had the opportunity to facilitate their meeting. We discussed things the group felt worked well for them this year and began planning for 2018.

This year, Sangre de Oro had a session for spouses, attended by both men and women. It was wonderful to see this level of participation - everyone in attendance expressed appreciation for this first of its kind meeting in New Mexico.

To say the least, it was a wonderful weekend event. Filled with education, but more importantly with community, laughter, love, and even a few tears. Hooray, to Sangre de Oro for such a great event and to community members who traveled from all over the state, as well as from El Paso, Texas.

TENNESSEE

Stephen Lawrence

Tennessee Hemophilia and Bleeding Disorder Foundation's ***Royal Gala*** was held again at the Loveless Barn in Franklin November 10th. It is evident the Gala committee worked hard planning, coordinating, and decorating this wonderful evening! Upon arrival, guests mingled and said hellos as they admired the fantastic silent auction items. When seated for dinner, Tim Diffenderfer, Executive Director, and committee chair members gave introductions and a warm greeting. Guests then enjoyed a video of camp and teen summit illustrating the importance of chapter sponsored programs.

Guest speakers of the evening were Matrix Health

The Cassada Family

Group's very own Shannon Cassada and her husband, Chris. They were asked to share their personal journey raising children with hemophilia. Their story was heartfelt with true emotions, tears, laughter and encouragement all along the way. After dinner, their 12 year-old son Teigan was invited to be the very first Junior Camp Freedom Auctioneer. With his wit and talent, he kept the audience engaged, laughing and bidding the whole time, raising nearly $5500 with just 6 items! Some partygoers were having so much fun they failed to realize they were bidding against themselves! The evening was hugely successful with proceeds benefiting the great programs of THBDF!

LOUISIANA

LeAnn Wilson

LeAnn Wilson and Kelly Gonzalez ready for HOPE!

Over 250 bleeding disorder community members from far and wide came for the November 10th–11th event at the Hilton Hotel in Kenner for the ***HOPE 2017 Annual Meeting***. President and CEO of HOPE Jonathan James kicked off the empowering event with a sincere welcome and introductions. Attendees were then encouraged to visit the exhibit area to discuss and learn about products and services with the informative industry representatives.

During a tasty Cajun style dinner, several speakers kept the audience engaged with motivating presentations. One who always seems to stand out is Dr. Tammuella "Tami" Chrisentery-Singleton,

Pediatrics Hematology/Oncology at Tulane University School of Medicine and Associate Director of the LA Center for Bleeding and Clotting Disorders ,who gave great clarity and understanding to the subject of inhibitors.

Benjamin visits with LeAnn and Kelly at the Matrix Health Group booth

Kelly presents *It's OK Not To Be OK*

The next morning began with Jonathan James covering the topic *The Case for Crisis: Understanding the Needs of the Community*. Breakout sessions began with Matrix' Health Group's very own Kelly Gonzalez, Educational Development Specialist, up to bat. She hit a home run with a very impactful and emotional topic, *It's OK Not to Be Okay*, expressing the importance of talking and helping each other during difficult times. She emphasized how we are all in this together. With the education imparted, everyone came away feeling stronger in knowledge and empowered. HOPE for Hemophilia brings true hope to our community.

ILLINOIS

Eva Kraemer

Bleeding Disorders Alliance Illinois (BDAI) and Shire recognized *"Celebrando el Mes de la Hispanidad"* or ***Celebrating Hispanic Heritage Month*** as a tribute to Hispanic/Latinos throughout the United States.

Along with dancers who delivered a marvelous display of traditional Mexican dances from all regions of Mexico, an educational program was also provided for the Latino bleeding disorder community Saturday, November 11th at the National Museum of Mexican Art. In Pilsen, a well-known Mexican neighborhood within Chicago, around 75 community members listened to a presentation from community youth about their experience with a bleeding disorder. Good conversation, authentic Mexican food and colorful festivities were enjoyed by all.

Rose and Jonathan ham it up with Eva Kraemer (center)

FLORIDA

Hector Heer

With many years of continued success, Florida Hemophilia Association celebrated its ***28th Annual Swing for the Kids Golf Tournament***! This wonderful event teed off November 13th at noon with a full course of players at Lago Mar Country Club in Plantation. Following friendly rounds full of competition and contests along the way, players and volunteers gathered for a meal and an Awards Ceremony presented by Debbi Adamkin, Executive Director. With the popularity of this event, we're sure to see a full roster and happy faces again next year!

TENNESSEE

David Tignor and LeAnn Wilson

Together, Pfizer and Matrix Health Group hosted an ***Educational Dinner*** in Memphis November 14th highlighting a presentation by Linda Pollhammer, BSN, RN, on *Overcoming Challenges*. Linda led an open discussion on managing stress, staying physically active and healthy, and communicating with health care providers. Discussions ranged from how to identify stress, its effect on your body, utilizing support systems and talking about your stress with healthcare providers. In addition to physical activity, something as simple as sitting down as a family and having a meal together can improve self-esteem and relieve stress.

Gabrielle, Victor and Keiflyn visit with LeAnn Wilson

As the evening's conversation continued, Linda and the group talked about *Taking Care* by staying physically active, eating a balanced diet, maintaining a support network and appropriate medical care. This led to conversation about the importance of routine hemophilia treatment center checkups and

how to prepare for your appointment. Suggestions included bringing your treatment log, any new prescriptions, making a list of questions or concerns, and letting your medical team know in advance of scheduled surgery, invasive tests or dental work. Also discussed was how best communicate with the staff in order to receive the most beneficial and timely care, and what conditions warrant an immediate call to your treatment center such as injuries to the head, eyes, throat, neck, groin and stomach.

The program wrapped up with talk about school in-services and teachers, temporary caregivers, and the tribulations of finances and medical insurance. Individuals and families shared how they overcame challenges and what worked for them personally. This was a wonderful opportunity for community members to share and learn from one another.

NEW JERSEY

Richard Vogel

In the last few years we have seen many new clotting products introduced to the hemophilia community. What's the difference? Is it an extended half-life product? How does it work in my body? And what exactly does all that mean? These questions and many others were answered at an ***Educational Dinner*** at Don Pepe Restaurant in Newark Wednesday, November 15th.

The evening started with an overview of Idelvion, CSL Behring's extended life product for Factor IX. Dezarae Tate, RN is a Hemophilia Nurse Coordinator at the South Texas Hemophilia Treatment Center in San Antonio. She was very engaging and explained the product in an easy to understand manner while still explaining the clinical aspects. As appetizers and dinners were served, we continued our conversation with the patient advocate portion presented by Gina Wiberg, a mother of a young son with hemophilia. Open and engaging, she explained how life has changed for her and her son with using the extended half-life product.

Gina, Bob, Janet and Christopher

Good friends, Mili, Rich Vogel and Gina

Participants enjoyed the presenters so much we mingled after dessert until we were asked to leave the restaurant because they were closing.

WEST VIRGINIA

Michelle Stielper and Tina McMullen

The West Virginia Chapter of NHF's ***Annual Meeting*** was an educational, family-fun filled weekend that will be hard to top next year! Taking place at the Stonewall Resort in Roanoke, the weekend of November 17th–18th kicked off with BioMatrix's own Kelly Gonzalez, Education Development Specialist, who presented *It's OK to Not Be OK* at the opening dinner Friday night. Later, caregivers took the kids to the pool so parents could freely discuss their feelings and share concerns and daily struggles of managing life with a bleeding disorder. It was an emotional thought-provoking evening and many hugs and connections were shared due to common challenges and triumphs.

Saturday, while kids enjoyed activities, a myriad of educational topics were presented to the adults, from *Pain Management*, to *Advocacy* and *Parenting Tips*, to *Information on Advanced Directives* and a discussion on *Planning for the New Year*.

This annual meeting saw new attendees and has grown into a great family weekend providing much needed topics and resources for the community. We are so happy to have been a part of this meeting and are already looking forward to it next year!

Jasper and Gaige smile for the camera with Michelle Stielper and Tina McMullen

NEW YORK

Richard Vogel

The holiday season in New York City is a special time – ask anyone who has been there! Walking on Fifth Avenue, the holiday lights, the store fronts decorated and the New York City Hemophilia Chapter (NYCHC) hosts their 2017 ***Education Day and Holiday Party.*** A sold-out crowd celebrated community and friends at JW Marriott Essex House New York on Central Park South November 18th to raise money in support the programs of NYCHC.

The evening began with cocktails followed by a sit-down dinner. Executive Director Jeremy Griffin emceed the event and was very entertaining, making everyone comfortable, relaxed and feeling like family.

My friend, Aliana Soto, was honored as the *2017 Susan Galligan Volunteer of the Year*. She became involved in the community in 2009 when her nephew was born with hemophilia. She jumped right in, becoming team captain of Jaylen's Walkers, establishing the Volunteer Engagement Outreach and became a very active member of the NYCHC Latino Outreach.

The ***2017 Award of Distinction*** was given to Bradley Schoenfeld. Having twin boys with hemophilia, Bradley became involved with NYCHC and is now Vice President. The awards were followed by a raffle, which included sports memorabilia, event tickets and restaurant dinners, and then the crowd danced the night away.

The following day, NYCHC held their educational program and holiday celebration at the Marriott Marquis in Times Square. The day began with a timely advocacy update presented by Tricia Brooks from Georgetown University Health Policy Institute, and Bob Graham from the NYS Bleeding Disorders Coalition who spoke on *What's Going on with Healthcare*. There was plenty of time to visit and talk with industry and specialty pharmacies before the educational seminars began. A workshop for everyone was available whether you were a family new to the bleeding disorders community or an old timer like myself. No matter how old you are, there is always something to learn from this community.

Morning sessions included *vWD Now What?*, *Welcome to the Jungle-How to Master ER Visits*, *Journey of Factor*, *Changing Landscape of Therapies*, and *Carriers - Finding Your Voice*. A lunch session on *Advances in Treatment and Clinical Trials* was led by four well know doctors in the bleeding disorder community, Drs. Walsh, McGuinn, Acharya and Mitchell, and included another friend and patient advocate, Christopher Templin. The session was very informative and stressed the need for participation in clinical trials in advancing therapies for the bleeding disorders community. If it were not for those of us in the past who participated, we would not be seeing all the new therapies we have today.

Volunteer of the Year Aliana Soto with Rich Vogel

Afternoon sessions included topics regarding pain, addiction and management, getting older with a bleeding disorder, along with sessions in Spanish. Teen and children programs were presented throughout the day.

The electricity and excitement in the air came to a head with the arrival of Santa Claus and his elves! There were gifts for all children under 18 years old, a fun photo booth, and limbo challenges added to the festivities. This was another successful weekend for NYCHC and a great way to start the holiday season!

Dr. Walsh, Chris Templin and Dr. McQuinn

NYC family having fun! Tim, Egypt, Jacqueline, Chance, Jordyn and Londyn

SOUTH CAROLINA

Peggy Klingmann

Charleston Harbor Resort in Mount Pleasant was the location for an ***Educational Luncheon*** November 18th hosted by Hemophilia of South Carolina and sponsored by Matrix Health Group and Novo Nordisk. Guest speakers included Vaughn Ripley, who spoke about *My Life with Hemophilia*, and Patricia Amerson, RN, CPNP, who presented *HERO: Strength in Numbers.*

Following the education portion of the event, the group visited Patriot's Point Naval and Maritime Museum, an impressive historical marina home to several World War II vessels. We had the opportunity to board the USS Yorktown (an aircraft carrier) and the USS Laffey (a destroyer). Also on display was the USS Clamagore (a submarine). Other interesting sights included exhibits highlighting the Vietnam War, Medal of Honor museum, and the Cold War Submarine Memorial. We wrapped up the event by posing for a group photo!

LOUISIANA

LeAnn Wilson

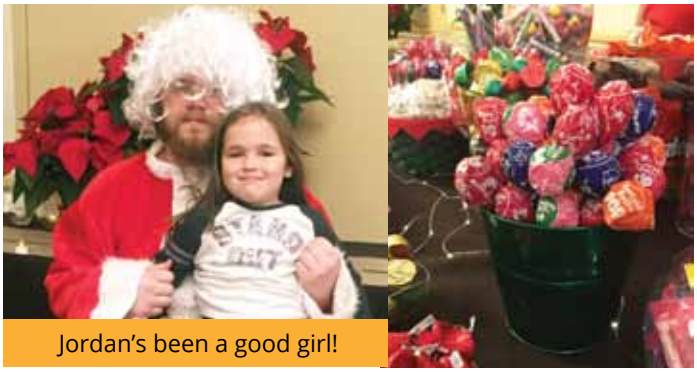
Proving to be a very popular and well-attended event, the Louisiana Hemophilia Foundation's ***41st Annual Meeting and Educational Symposium*** was hosted at Embassy Suites in Baton Rouge December 1st–2nd. Upon arrival and registration, families and individuals browsed the exhibit booths and spoke with industry representatives about their products and services. Kicking off the event and welcoming the crowd were Foundation Board President Edgar Guedry and Executive Director Erica Simpson. Dinner and quality time to visit with one another followed.

After a hearty breakfast Saturday morning, it was time for a session by Brendan Hayes with NHF on *The Evolution of Advocacy in the Bleeding Disorders Community*. She gave us a historical look at our bleeding disorders community and showed how far we have come. Remembering members of our community whom we have lost too soon, a special ceremony called *Lighting the Future* was led by Erica Simpson. This observation was not only very emotional, but a beautiful one as we came together to celebrate these extraordinary individuals. Memorializing those we have lost, candles were lit for, and kept burning throughout the remainder of the event.

Memorial observance candles

Kelly Gonzales, BioMatrix Educational Development Specialist, presented *Putting on the Mask First*, which addressed how we deal with stress. Donald "Donnie" Akers, Jr., JD, General Counsel, a professional advisor to HFA, presented another helpful session titled *Emergency Room Standards of Care*, which focused on how to get appropriate emergency treatment and discussed the importance of documenting all conversations with your insurance company.

The day wrapped up with the ***Annual Holiday Party*** complete with sweets and dancing, where much to their delight, children were paid a surprise visit by Jolly ol' Santa! Many thanks to Louisiana Hemophilia Foundation and their dedicated staff for this regaling gathering!



Jordan's been a good girl!

NORTH CAROLINA

Xaviette Pointer-Kincy

An excited group of 109 Hemophilia of North Carolina (HNC) community members attended the chapter's ***Holiday Party*** at the contemporary Hilton Hotel in Greenville December 2nd.

The event featured a presentation by Lora Joyner, Physical Therapist of East Carolina University Hemophilia Treatment Center. Her special topic of discussion enhanced member's understanding of resiliency when managing their bleeding disorder and influencing positive healthcare outcomes.

Xaviette Pointer-Kincy pauses for a photo with Virginia

Everyone enjoyed a special visit from Santa who presented them with gifts! In addition to the most evident giving spirit, HNC also collected items to benefit *Save One Life*, an organization that helps people with bleeding disorders in other countries. Happy Holidays to HNC and all its members!

PENNSYLVANIA

Tina McMullen

What a wonderful holiday celebration it was for the more than 30 families who attended the Eastern Pennsylvania Chapter of NHF's ***Annual Holiday Party***. Held at Cannstatter Volksfest Verein in Philadelphia December 2nd, the day began with a wonderful buffet lunch, giving families time to get acquainted.

Also in store was plenty of fun activities in which to participate, including holiday cookie decorating at the Factor Support booth. It seems the adults were having just as much fun as the kids! Once lunch was over, kids were treated to the astounding talent of magician Francis Menotti. None too soon, it was time for the star of the day to arrive, Santa Claus! Santa patiently listened to gift wishes and lists, and all the children went home with a gift card. It was truly an amazing holiday celebration for the families of the Eastern Pennsylvania Chapter.

By their smiles, these two friends know they were good!

SOUTH CAROLINA

Peggy Klingmann and Brenda Montgomery-King

We were thrilled to attend the South Carolina Hemophilia Chapter (HSC) ***Year-End Meeting and Holiday Gathering*** at Embassy Suites Hotel in Columbia December 2nd. More than 150 community members arrived to have a good time and celebrate the spirit of the season together. Continuing to be a highly anticipated chapter tradition, children excitedly search for HSC's Jingles Elf on the Shelf and were kept very engaged with craft projects and activity books.

The evening included a dinner buffet, an informational program and time to visit with industry representatives at the exhibit area. Mr. Seth Rojhani, keynote speaker for the evening, presented *Rising to Life's Challenges*. Determined to play sports from a young age despite physical challenges, Seth shares his story on how he turned "you can't" into "you can".

Justin, Angie, Carson and Lacie, Bethany, Adam, Greg and Sonia with Brenda Montgomery-King

Another chapter tradition continued after dinner when children were treated to a special storybook time with *The Night Before Christmas*. With anticipation high in the air, Santa Claus arrived with gifts for all the children ages 0–18 years old. A few lucky adults also received gifts when they won a raffle prize! As in the past, this event is a wonderful way to wrap up the year and look forward to the New Year!

MAINE

Justin Levesque and Cheryl Ashmore

The Hemophilia Alliance of Maine's ***Annual Winterfest*** was held December 2nd–3rd at the beautiful Samoset Resort in Rockland; a tradition that honors the legacy of the hemophilia community's history in Maine and provides spectacular ocean views. To kick off the weekend, chapter volunteers were honored with an awards ceremony Friday evening. Saturday was filled with educational sessions, self-infusion classes by the Maine Hemophilia and Thrombosis Center, an update from the New England Bleeding Disorders Advocacy Coalition and family swim time at the indoor pool.

Of course, no Winterfest in Maine is complete without a visit from our jolly friend to the north. Mr. Claus himself appeared with gifts in hand for every child and teen in attendance! Every year Winterfest gets better and better and it's a warm, welcome reminder of what makes the Maine bleeding disorders strong, connected and empowered!

Syrus likes his gift!

Tricia and Azaylia!

OHIO

Shelia Biljes

Holiday excitement filled the air as Matrix Health Group and CSL Behring welcomed more than 140 guests to their ***Annual Holiday Event*** for the Northern Ohio Chapter December 9th. Dinner and dancing with the monkeys was the perfect agenda for an event happening in the Cleveland Zoo's Primate Building. The big gorilla was a source of entertainment, making it clear that he would not be found on Santa's naughty list while the habitat of small monkeys danced along with the children mimicking the YMCA motions.

A sit-down dinner was provided by Aramark Catering as families enjoyed delicious crusted chicken and pesto pasta along with salad and a pastry bar. A special holiday cake was served to end the meal. Each established family was paired with a new family for dinner, encouraging many new friendships forged that night! Blake the Balloon Bender strolled among the tables doing street magic for dinner entertainment.

Designing T-shirt's was a big hit for kids and teens alike! Using special fabric markers, each child drew a picture depicting a moment in their spectacular life.

Santa made a surprise appearance, posing for photos with the kids and listening intently as they eagerly shared their wish list!

Intended for the children, a dance contest grew into a full dance floor of kids, teens, adults and even monkeys joining in the fun! YMCA, Cupid Shuffle, the Locomotion and, of course, the Chicken Dance were just a few of the fancy dance moves leading to many winners of mini fun monkey toys.

As we were saying our goodbyes snow began to fall, giving us a perfect ending for a perfect night!

Raffle prize winner baby Quinton and his mom Gabrielle with Shelia Biljes

Lee Family

Hunger Family

Jacob and Destiny. "Nice" of course!

Griffin showing off his dance moves!

Santa visits a gorilla

CONNECTICUT

Richard Vogel

Hemophilia and northeast weather have something in common, you must be prepared and you must be tough because change can happen hour to hour. On December 9th, an early winter storm could not deter the strong Connecticut Hemophilia Society community from attending their ***Annual Meeting***. This year the meeting was held at the Wyndham Southbury. The morning started with a breakfast buffet where members could gather information from sponsoring exhibitors. We were informed in the opening remarks by President Dennis Mackey and Executive Director Maryann May that beginning in 2018, CHS will be a NHF chapter.

The first session was a presentation by Jeff Kallberg, PT, who discussed joint health, what happens inside the joint when you have a bleed and how to prevent or minimize damage. As a community member, Jeff can certainly relate. After lunch, afternoon sessions centered on preparedness and bullying. Standing out during the bullying session was that sometimes we, as a community, unknowingly may become 'clickish' or 'snobbish.' Let's all make a concerted effort to be inclusive of all bleeding disorders and especially of severities of bleeding disorders. Whether you are severe, moderate, mild, A, B or vWD, we all want to be informed, educated, and want to feel like we belong. A bleeding disorder can make one feel alone and isolated so as a group, let's not perpetuate condescending attitudes by ignoring those who are newly diagnosed or 'less severe' than others.

With snow falling all around, we couldn't hear Santa's sleigh approach, but we did feel the anticipation! Festivities continued as Santa and his elves handed out gifts to all the good boys and girls!

Daniela and Madeline display their brand new Matrix Health Group fun lunchbags!

Little Isabella seems a bit unsure...

ILLINOIS

Eva Kraemer

The Bleeding Disorder Alliance Illinois (BDAI) celebrated its ***Annual Holiday Party*** on Saturday, December 9th at the William Tell Holiday Inn in Countryside. About 75 bleeding disorder community members, family and friends feasted on a delightful buffet, while a fire burned at the hearth and in our hearts.

We all felt jolly while creating homemade ornaments and decorating cookies. Santa Claus arrived to surprise children of all ages and to spread cheer and presents, sitting for keep-sake photos to be cherished. I was jubilant to have been able to spend time with Illinois families, sharing stories from the year gone by while looking forward to a very happy and healthy 2018.

Sparkling smiles from Rocky W. and Eva Kraemer!

UPCOMING EVENTS

FEB. 10, 2018 CALIFORNIA
Central CA Hemophilia Foundation
916-549-3125, cchfsac.org
Surf & Turf Crab Feed
Sacramento Elks; Sacramento

FEB. 13, 2018 CALIFORNIA
Hemophilia Found. of Southern CA
626-765-6656, hemosocal.org
Hispanic Women's Dinner
Maggiano's Little Italy; Costa Mesa

FEB. 16-19, 2018
MAINE | NEW ENGLAND
Hemophilia Alliance of Maine
207-631-7550
mainehemophilia.org
New England Hemophilia Assoc.
781-326-7645
newenglandhemophilia.org
Winter Camp
Camp Mechuwana; Winthrop

FEB. 17, 2018 ARKANSAS
Hemophilia Found. of Arkansas
501-48-5754; arkhemofoundation.org
Dads in Action and Infusing Love's Valentine Event
Hilton Garden Inn; Little Rock

FEB. 17, 2017 PENNSYLVANIA
Western Pennsylvania of NHF
724-741-6160, wpcnhf.org
Iced Tee's Winter Golf Outing and Chili Cookoff
Diamond Run Golf Club; Sewickley

FEB. 23, 2018 NEVADA
NHF Nevada Chapter
702-564-4368, hfnv.org
Winter Wine Fest & Silent Auction
Tivoli Village; Las Vegas

FEB. 24, 2018 CALIFORNIA
Hemophilia Found. of Southern CA
626-765-6656, hemosocal.org
3rd EmPOWERment Forum
Bloody Hot Salsa Challenge
Picwick Gardens; Burbank

FEB. 24, 2018 KENTUCKY
Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org
Vegasville Gala
Olmsted Building; Louisville

FEB. 24, 2018 PENNSYLVANIA
Eastern Pennsylvania Chapter NHF
215-393-3611
hemophiliasupport.org
Bowling for Fun
Thunderbird Lanes; Philadelphia

FEB. 25, 2018 OHIO
Central Ohio Chapter of NHF
614-985-3752
nhfcentralohio.org
Chapter Open House
Star Bowling; Columbus

MARCH 1, 2018 NEW YORK
The Coalition For Hemophilia B
212-520-8272; www.hemob.org
11th Annual Eternal Spirit Award Dinner
Terrace On The Park; NYC

MARCH 3, 2018 VIRGINIA
Virginia Hemophilia Foundation
804-740-8643; vahemophilia.org
Winter Fundraiser Bowling for Bleeding Disorders
(Two Locations!)
AMF Sunset Lanes; Richmond
AMF Sunset Lanes; Chesapeake

MARCH 4, 2018 NEW YORK
New York City Hemophilia Chapter
212-382-2974, nyhemophilia.org
United for Bleeding Disorders Walk Kickoff
NY Marriott Downtown; NYC

MARCH 4, 2018 FLORIDA
Foundation Hope & Life
786-374-6143
fhlusa.org
Annual Family Educational Rally
Tropical Park; Miami

NATIONAL EVENT!

MARCH 7-9, 2018
WASHINGTON D.C.
National Hemophilia Foundation
800-424-2634
hemophilia.org
NHF Washington Days
Hyatt Regency on Capitol Hill

MARCH 9–10, 2018
NORTH CAROLINA
Hemophilia of North Carolina
800-990-5557
hemophilia-nc.org
HNC Annual Meeting
Embassy Suites; Winston-Salem

MARCH 10, 2018 ARKANSAS
Hemophilia Found. of Arkansas
501-48-5754
arkhemofoundation.org
Bowling Bash
Bowling World; Fort Smith

MARCH 10, 2018 LOUISIANA
Louisiana Hemophilia Foundation
255-291-1675
lahemo.org
Shoot For a Cure (Skeet Shoot)
Riverside Sporting Clays;
Denham Springs

MARCH 16-18, 2018
CONNECTICUT | VERMONT
Connecticut Hemophilia Society
860-997-4525
cthemophilia.org
Alpine Walk
Mt. Snow; West Dover, VT

MARCH 17, 2018 CALIFORNIA
Hemophilia Association of San Diego County
619-325-3570; hasdc.org
HASDC Family Education Day
San Diego Zoo

MARCH 22, 2018 FLORIDA
The Coalition For Hemophilia B
212-520-8272
www.hemob.org
2nd Annual Forelife Golf Outing and Fundraiser
TPC Sawgrass; Ponte Vedra Beach

NATIONAL EVENT FOR FACTOR 9 FAMILIES

MARCH 23-25, 2018 FLORIDA
The Coalition For Hemophilia B
212-520-8272; www.hemob.org
12th Annual Symposium
Sawgrass Marriott Golf Resort & Spa; Ponte Vedra Beach

MARCH 24, 2018 CALIFORNIA
Hemophilia Foundation of Southern California
626-765-6656
hemosocal.org
Women's Retreat
Descanso Gardens; La Canada

MARCH 24, 2018 LOUISIANA
HOPE for Hemophilia
888-529-8023
hopeforhemophilia.org
Crawfish Boil
Baton Rouge Zoo

MARCH 25-26, 2017 ARIZONA
Arizona Hemophilia Association
602-955-3947
salsachallenge.com
My Nana's Best Tasting Salsa Challenge
Steele Indian School Park; Phoenix

MARCH 31, 2018 NEW JERSEY
Hemophilia Association of New Jersey
732-249-6000
hanj.org
Testimonial Dinner
Fiddlers Elbow Country Club; Bedminster

APRIL 14, 2018 ILLINOIS
Bleeding Disorders Alliance Illinois
312-427-1495, bdai.org
Spring Gala
Itasca Country Club; Itasca

APRIL 16, 2018 NEVADA
Nevada Hemophilia Foundation
702-564-4368
hfnv.org
Golf Gets in Your Blood - Golf Tournament
Red Rock Country Club; Las Vegas

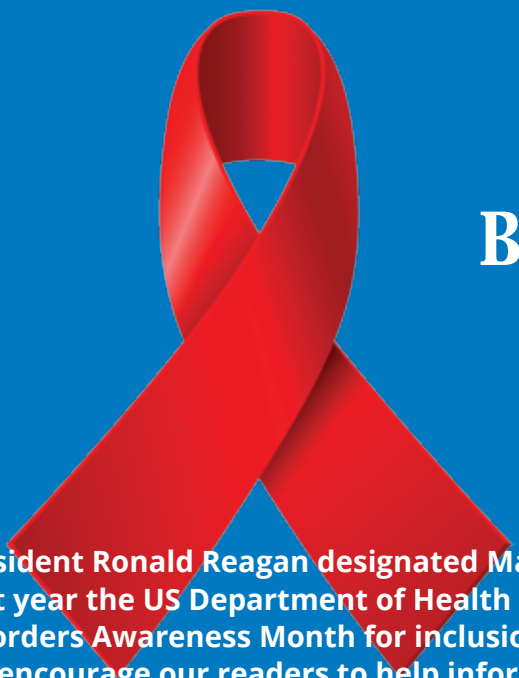
APRIL 17, 2018 CALIFORNIA
Central California Hemophilia Foundation
916-549-3125; cchfsac.org
World Hemophilia Day Celebration
California State Capitol; Sacramento

APRIL 20-22, 2018 MICHIGAN
Hemophilia Foundation of Michigan
734-544-0015; hfmich.org
SpringFest
Ann Arbor Ypsilanti Marriott at Eagle Crest; Ypsilanti

NATIONAL EVENT!

APRIL 26-29, 2018 OHIO
Hemophilia Federation of America
202-675-6984
www.hemophiliafed.org
Symposium 2018
Hilton Cleveland Downtown

MAY 11, 2018 CALIFORNIA
Central California Hemophilia Foundation
916-549-3125, cchfsac.org
CCHF Annual Golf Tournament
Sun City Lincoln Hills Golf; Lincoln



March is BLEEDING DISORDERS AWARENESS *Month!*

President Ronald Reagan designated March as hemophilia awareness month in 1986. Last year the US Department of Health and Human Services officially approved Bleeding Disorders Awareness Month for inclusion in the National Health Observances calendar. We encourage our readers to help inform, advocate and celebrate the bleeding disorders community throughout the month of March. Matrix Health Group is proud to support the community 365 days a year, but we especially appreciate the opportunity to raise awareness with the outside community during this important time of year. So let's get creative, spread the word, and shout from the rooftops together why recognizing individuals and families with bleeding disorders is so important. Be sure to check our social media pages frequently as we recognize Bleeding Disorders Awareness Month!

ANSWERS TO PUZZLES ON PAGE 63

1. SYRINGE 4. INFUSION
2. DOCTOR 5. HEMATOMA
3. NEEDLE 6. HEMOPHILIA

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

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

2018 A MOMENT IN YOUR SPECTACULAR LIFE CALENDAR NOW AVAILABLE!

Our 2018 A Moment in Your Spectacular Life calendar highlights just how amazing life can be, even with a bleeding disorder! And now it's available! Contact us to receive our special calendar free of charge!

To receive your free calendar, just do one of the following:

- Contact your Regional Care Coordinator
- Visit www.matrixhealthgroup.com and send a message
- Call our Corporate Office toll free: 877-337-3002
- Email your request to Maria Vetter: maria.vetter@matrixhealthgroup.com
- Mail your request to:
  BioMatrix Calendar, 3300 Corporate Ave., Suite 104; Weston, FL 33331

TIME FOR FUN!

HI KIDS!

Using the clues listed below, cross out each of the corresponding letters in the box. Keep in mind, each letter can only be used once!

Answers are on page 62.

A	A	A	C	D	D	E	E	E	E	E
E	F	G	H	H	H	I	I	I	I	L	L
M	M	M	N	N	N	N	O	O	O	
O	O	P	R	R	S	S	T	T	U	Y

1. An item used to hold factor after it is mixed but before it is infused. 1. _ _ _ _ _ _ _
2. A medical person who can write a prescription for clotting factor. 2. _ _ _ _ _ _
3. A sharp thin tool used to infuse factor into a vein. 3. _ _ _ _ _ _
4. The process of injecting clotting factor into a vein. 4. _ _ _ _ _ _ _ _
5. A large, sometimes lumpy bruise. 5. _ _ _ _ _ _ _ _
6. A type of bleeding disorder. 6. _ _ _ _ _ _ _ _ _ _

Sudoku!

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

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

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

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fb.com/matrixhealthgroup

DEDICATED TO MAKING A DIFFERENCE

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