

# Matrix Health Group

A BIOMATRIX<sup>SpRx</sup> Company

## NEWS



**DEDICATED TO  
MAKING A  
DIFFERENCE**

**FALL 2018  
VOLUME 13 | ISSUE 4**

**“**  
The future belongs to  
those who believe in the  
beauty of their dreams.

— Eleanor Roosevelt

**”**



## ABOUT BIOMATRIX

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

The current BioMatrix family of companies includes: Matrix Health, Factor Support Network, Medex BioCare, BiologicTx, Elwyn Pharmacy Group, and Decillion Healthcare.

The following employees of US Health Group and Atlantic Health Group appear in this publication. US and Atlantic Health Groups are independent organizations contracted by BioMatrix:

Cheryl Ashmore	Jeff Johnson	Brad Nolan
Shelia Biljes	Peggy Klingmann	Cindy Picos
Dave Burgeson	Eva Kraemer	Joe Piscitello
Shannon Cassada	Eric Laming	Xaviette Pointer-Kincy
Cyndy Coors	Stephen Lawrence	Terry Rice
Ray Dattoli	Justin Levesque	Rania Salem
Juan Bruno de la Fuente	Justin Lindhorst	Shelby Smoak
Marcy Foertsch	Cathleen Lombardo	Michelle Stielper
Felix Garcia	Carolina Luna	Terry Stone
Kelly Gonzalez	Tina McMullin	Christopher Templin
Gabriela Griffin	Lisa Miller	David Tignor
Hector Heer	Brenda Montgomery-King	Maria Santucci Vetter
Sarah Henderson	Enrique Morey	Richard Vogel
Mohammed Hoque	Carri Nease	LeAnn Wilson
Sean Hubbert		

## MISSION + VISION

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

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

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

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, or others associated with Matrix Health Group News or that of BioMatrix.

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 healthcare professionals or hemophilia treatment centers. Please consult with healthcare professionals when medical questions arise.

# TABLE OF CONTENTS

**Page 4**

**NEW ERA - SAME COMMITMENT**

**Page 5**

**THE SPLIT: DIVIDED POLICY AND THE FATE OF THE ACA**

**Page 8**

**GET YOUR FLU SHOT**

**Page 10**

**FOLLOWING THE CALL OF THE MOUNTAIN**

**Page 14**

**HEMOPHILIA and SCOLIOSIS:  
A JOURNEY OF TWISTS AND TURNS**

**Page 18**

**SIX THINGS NEWLY DIAGNOSED FAMILIES  
NEED TO KNOW**

**Page 20**

**MATRIX ON THE MOVE!**

**Page 32**

**UPCOMING EVENTS**

**Page 33**

**BOOK REVIEW: NINE PINTS**

**Page 34**

**TIME FOR FUN!**



## **CORRECTION**

In our article *A Race for a Cure* (Pages 16 -19; Summer 2018), Zinc Finger Nucleasas (ZFNs) are incorrectly referred to as “zinc finger nuclei” and “zinc finger nucleus.” A nuclease is an enzyme that can cut nucleic acids, it is not a nucleus. At Matrix Health Group News, we are committed to ensuring correct information - we sincerely apologize for our error and any confusion it may have caused.

## **A NOTE FROM THE EDITOR**

Dear Readers:

Where did summer go? One minute the conversation is all about sending kids to camp, packing bags, and putting on sunscreen and then seemingly overnight, discussions turn to back-to-school activities and falling leaves. After guiding my four children from preschool through college graduation, my calculations show I have survived a cumulative 72 back-to-school seasons! This is the first time in 26 years I don't have a student going to school. Part of me is thrilled – no more hemophilia in-services, homework, book reports, finals, or tuition. Part of me is downhearted, no more walking down school supply aisles, no more school picture days and no

more spring breaks occasionally spent with me at home.

My children, two with severe hemophilia, have made it to adulthood. Though a mother's job is never done, I can take a deep sigh of relief. With new products on the market and more on the horizon, children and adults are experiencing better, healthier lives than in past generations. As a parent, this gives me comfort.

As you settle into sweater-weather, take time to relax and read through our latest issue of our newsletter!

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

# NEW ERA – SAME COMMITMENT

**“They Thought Hemophilia Was a ‘Lifelong Thing.’ They May Be Wrong,” read the August 2018 headline in the New York Times.\***



The New York Times article outlines promising results from several gene therapy studies which could provide a cure to hemophilia. Gene therapy is not the only innovation in the bleeding disorders community grabbing media attention. Hemlibra® (emicizumab-kxwh), the first subcutaneous treatment for hemophilia, recently received approval for use in patients with severe hemophilia A without inhibitors. Drug manufacturers have robust pipelines promising a new era of treatment for people with bleeding disorders. The winds of change are blowing and bringing with them hope for a better future.

BioMatrix celebrates the innovation and promise these new therapies represent. Treatment options may be changing, but our commitment to the bleeding disorders community remains the same. Whether electing something new, or sticking with a time-tested solution, our services are designed to complement the decisions made by you and your

physician. Across the country, patients know they can depend on the individualized specialty pharmacy services, timely access to care, and focused education and support we provide.

It is unknown what the headlines of tomorrow will bring. Together, as we navigate these new and hopeful waters, our ongoing commitment to the community, access to all treatment options, and experience obtaining timely insurance authorizations makes BioMatrix a logical specialty pharmacy choice for anyone with a bleeding disorder.

Ready for a change? Contact us to submit a no-obligation referral today!  
<https://bit.ly/2Mhc9g5> or call 1-877-337-3002.

\* Kolata, Gina. (2018). They thought hemophilia was a “lifelong thing.” They may be wrong. The New York Times. <https://www.nytimes.com/2018/08/13/health/hemophilia-gene-therapy.html>

## ABOUT BIOMATRIX SPECIALTY PHARMACY

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

**Matrix Health**

**FACTOR<sub>x</sub>**  
SUPPORT NETWORK

**MEDEX BIO CARE**

**BiologicTx**

**Elwyn**  
PHARMACY GROUP

**DECILLION**

# THE SPLIT:



## DIVIDED POLICY AND THE FATE OF THE ACA

BY THE BIOMATRIX ADVOCACY GROUP

Very few government policies have had as polarizing effect as the Affordable Care Act (ACA), also referred to as Obamacare or Marketplace insurance. It divides staunch Republican from die-hard Democrat, State Attorney General from Supreme Court Justice, and, more subtly within the ACA marketplace itself, the chronically ill from the healthy. It is this latter division, however, which could prove more divisive and, in the long term, more transformative to the ACA's future.

This split—the chronically ill from the healthy—isn't as immediately obvious, but will be the result of a handful of recently passed rules and regulations. While the recent rules may seem innocuous when taken individually, viewed in their totality, a different portrait is painted. Taking a survey of the recent ACA rules and understanding the split viewpoints on the changes yields a consideration of their combined effect for both sides.

The White House shortened the ACA's open enrollment period. Previously, persons had a 90-day window from November 1–January 31 to enroll in ACA plans, but new regulation reduces that to 45 days, November 1–December 15.

**FOR:** Supporters and Centers for Medicare and Medicaid Services (CMS) claim the enrollment period better aligns with Medicare and private market.

**AGAINST:** A Health Affairs article suggests the shortened enrollment period will lead to fewer enrollees, noting almost 60% of enrollees did so during the second half of the previous 3-month enrollment period. The report adds the later enrollees “were generally younger and healthier,” a population especially vital to the ACA's economic survival.<sup>1</sup>

The White House cut the ACA advertising budget by 90%.

**FOR:** The Administration claims the ad budget cut is based on effectiveness and performance. For example, ACA



advertising spent \$100 million in 2016, resulting in 9.2 million enrollees, but spent \$51.2 million in 2015 resulting in 9.6 million enrollees. They also state the ACA witnessed a 42% decline in new enrollees in 2017, ergo past advertising has worked to make Americans aware of the ACA and it would be ineffective to continue to have a high ad budget.<sup>ii</sup>

**AGAINST:** Advocacy and patient groups claim advertising is critical to attract the necessary young and healthy consumers who help fund the ACA.

**The White House cut Navigator funding.** This program provides outreach, education and enrollment assistance for ACA plans.

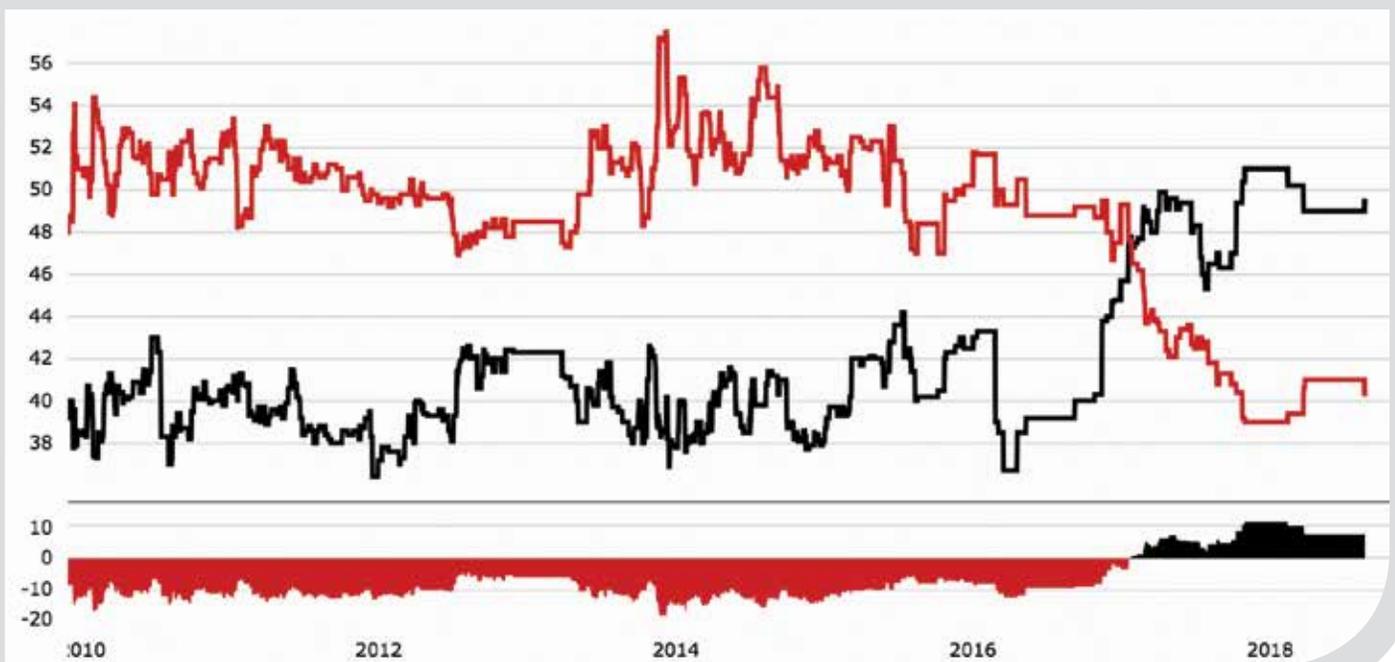
**FOR:** CMS claims consumer awareness of the Marketplace health insurance is very well known, and that face-to-face Navigators are no longer needed.

**AGAINST:** Opponents say a loss in education outreach and enrollment assistance will result in fewer ACA participants, especially the young and healthy. For example, Virginia was granted \$2,187,187 for Navigator programs in 2016, but received only \$400,000 in 2018, an 82% reduction. The severe cuts leaves the program almost unable to survive.



**RCP POLL AVERAGE**  
Public Approval of Health Care Law

**49.6** For/Favor +9.4  
**40.2** Against/Oppose



The White House waived for 9 months over whether to continue to pay insurers Cost-Share Reductions (CSR). They sought to end CSR payments in October 2017. After a see-saw of uncertainty, they resolved to keep funding CSR payments, which are made to insurers to lower deductibles, premiums, copayments and co-insurances for ACA plan members.<sup>iii</sup>

**FOR:** Supporters state Congress never appropriated CSR funds and thus they are illegal.

**AGAINST:** Without CSR payments, average ACA premiums alone would rise between 23%–37%. However even with funding restored, insurers claim such volatility has led them to factor in higher premiums as a means of protecting their business.<sup>iv</sup>

The White House expanded Association Health Plans (AHP). With the Department of Labor, they changed the criteria by which employees may join together to sponsor health plans and relaxed the definition for “commonality of interest” which determines the “association” for which a sponsor may secure a plan.

**FOR:** Employers, franchisers, trade organizations, and sole proprietors can offer insurance that no longer has to comply with the ACA insurance requirements. Plans may also provide a higher profit margin than current ACA offerings.<sup>v</sup>

**AGAINST:** The relaxed “commonality of interest” could lead to questionable association plans. An example posed by the American Occupational Therapy Association suggests “geography” as meeting the new rule’s criteria, “including multi-state metropolitan areas like Washington D.C.” AHPs also fail to have the Essential Health Benefits protections

of ACA plans and in addition to providing skimpier insurance to its purchasers, AHPs may also set premiums based on gender and age. Additionally, AHPs are to likely pull healthy people from ACA plans, leaving the ACA with a sicker risk pool.<sup>vi</sup>

The White House is extending the coverage period for “Short-Term” health plans. Meant as supportive coverage during insurance transitions, the ACA provided 3-month plans, but new rules extend this to 12-month plans, renewable for 2 years, or, put another way, they are 3 year “Short-Term” plans.

**FOR:** Consumers can have less expensive health insurance. Short-Term plans can cost as little as \$124/month compared to an average \$393/month for ACA coverage.<sup>vii</sup>

**AGAINST:** Coverage for prescription drugs, maternity care or mental health are often excluded. Insurers can also deny coverage for pre-existing conditions and charge more if a person is likely to need medical care. Many label these as “junk” and “buyer-beware” policies. The plans will splinter the market between healthy and sick consumers.

As is evidenced above, all of these rule changes have originated not from Congress, but from the White House. It remains to be seen what Congress will do to either aid or obstruct these rules. But either way, the ACA is likely to look different going into 2019, and healthier consumers may need the ACA protections less and may migrate into other health care policies with fewer protections.

So, as it was with Caesar that no single blade was his undoing, but the totality of the betrayals which led to his downfall, so it appears the ACA may become victim to 1,000 cuts. For many, it will be a time to cheer; for others, as with Caesar, a time to mourn.

## RESOURCES

- i. Shafer, Paul, and Stacie Dusetzina. “Looking Ahead to 2018: Will a Shorter Open Enrollment Period Reduce Adverse Selection in Exchange Plans.” Health Affairs. 14 April 2017. [www.healthaffairs.org](http://www.healthaffairs.org)
- ii. Luhby, Tami. “Trump Slashing Obamacare Advertising by 90%.” CNNMoney. 31 Aug. 2017. [www.money.cnn.com](http://www.money.cnn.com)
- iii. Pollitz, Karen, Jennifer Tolber, and Maria Diaz. “Data Note: Further Reductions in Navigator Funding for Federal Marketplace States.” Kaiser Health News. 17 July 2018. [www.khn.org](http://www.khn.org)
- iv. Moore, Susan. “CSR Uncertainty Could Cause 9.4M Uninsured, 37% Premium Increase, Report Says.” Healthcare Finance. 8 Sept. 2017. [www.healthcarefinancenews.com](http://www.healthcarefinancenews.com)
- v. Waxman, Jay Mark, and Morgan J. Tilleman. “Association Health Plans—The Final Rule is Issued.” Health Care Law Today. 10 July 2018. [www.healthcarelawtoday.com](http://www.healthcarelawtoday.com)
- vi. The American Occupational Therapy Association. “The Association Health Plan (AHP): What You Need to Know.” AOTA. 3 July 2018. [www.aota.org](http://www.aota.org)
- vii. Kodjak, Alison. “Under New Rules, Cheaper ‘Short Term’ Health Care Plans Now Last Up to 3 Years.” NPR. 1 Aug. 2018. [www.npr.org](http://www.npr.org)
- viii. Bagley, Nicolas, and Abbe R. Gluck. “Trump’s Sabotage of Obamacare is Illegal.” The New York Times. 14 Aug. 2018. [www.nytimes.com](http://www.nytimes.com)



BY NANETTE VAUGH, RN



It's that time of year again! Flu season is upon us – peak season is December to February. It's recommended to be vaccinated by the end of October, but immunization is beneficial if given as late as January. Most insurance carriers cover the cost 100% and vaccines are available at physician offices, drug stores, urgent care centers and health departments.

The CDC suggests everyone six months and older receive a flu shot, especially if you are in a high-risk group. The high-risk group includes those with asthma, diabetes, heart disease, HIV, cancer, history of smoking, obesity, are pregnant or are around children under the age of five.

If you or your loved one has a bleeding disorder, there are several reasons why decreasing the risk of flu is important.

Common symptoms associated with the flu can be more worrisome for persons with a severe bleeding disorder:

**COUGHING:** Frequent and forceful coughing can cause blood vessels in the throat, nose or anus to rupture and bleed. The strong pressure generated by severe coughing can strain muscles and cause small tears leading to bleeding.

**NASAL CONGESTION:** Excessive nose blowing can cause blood vessels to rupture and bleed. Children may also be more inclined to pick their nose, which can result in scratching the nasal lining and bleeding. Warm or cool mist vaporizers can help ease congestion, though a cool mist may be safer in households with children. With any vaporizer, prevent the growth of bacteria and mold by wiping the unit down daily with a solution of 9-parts water to 1-part bleach.

**VOMITING:** A tear in the lining of the stomach or esophagus could occur with forceful or prolonged vomiting. If a child with a bleeding disorder is vomiting, special consideration should be taken. Review your child's activity over last day or two — have they fallen or hit their head? Vomiting can be a symptom of an intracranial bleed. If there is any doubt, be sure to contact your medical team for advice. Take your loved one to an emergency room if he or she is throwing up blood.

**FEVER:** Temperatures above 102 should be treated immediately to decrease the risk of a febrile seizure, which is more common in children than adults. A seizure could lead to a fall causing injury or a bleed. Acetaminophen (Tylenol) in the proper dosage is safe to take, though ibuprofen (e.g. Advil, Aleve, Motrin) is more effective for fever; however, may affect platelets and blood clotting. Check with your doctor before taking ibuprofen. Persons with bleeding disorders should always avoid taking any product containing aspirin. The chemical name for aspirin is acetylsalicylic acid (ASA). Be aware — many over-the-counter medications, such as Alka Seltzer, contain aspirin. Read labels carefully!

**INJECTION SITE BLEEDING:** Flu shots are most often given as an intramuscular injection (into the muscle). There is no intradermal (just under the first layer of skin) vaccine this year, but a nasal spray is available for people age 2–49. The spray contains a live virus and should not be given to pregnant women or anyone with a weakened immune system. It should also not be given to children age 2–4 who have asthma or have had wheezing in the last 12 months.

If you have a bleeding disorder talk to your doctor about your best option for receiving a flu vaccine. Some hematologists recommend the intramuscular

shot be given subcutaneous (into the fat layer beneath the skin) to minimize risk of a muscle bleed. Unfortunately, the vaccine may not be as effective when administered this way. Another option may be to infuse clotting factor before receiving an intramuscular injection. Lastly, some clinics will use a smaller needle and inject into a large muscle group, such as the thigh, to decrease the chance of bleeding. However, if the person with a bleeding disorder is a good candidate, the best choice may be the nasal spray.



### NEW FOR 2018-2019

Each year flu vaccines are updated to better match the circulating viruses. There are two available vaccines. The **trivalent** covers three flu viruses and the **quadravalent** covers four viruses (includes an additional B flu virus). Ask your doctor what is available in your area and be aware the quadravalent vaccine may be more expensive. A higher dose vaccine is available for people 65 and older. It has an added ingredient to help create a stronger immune response. People who have egg allergies can safely receive a flu vaccine. However, if your allergy is severe, including angioedema or respiratory distress, the vaccine should be given in a medical setting with supervision.

### ADDITIONAL WAYS TO HELP AVOID THE FLU:

- Stay away from people who are sneezing or coughing
- If someone in your home is ill, be sure to wipe down common surfaces daily such as phones, light switches, door knobs, television remote controls, and cabinet and refrigerator handles
- Don't share food or drinks with someone who is sick
- Encourage those who are sick to handle and throw away their own tissues
- Most importantly, WASH YOUR HANDS often and keep them away from your face!

### REFERENCES:

- <https://www.cdc.gov/flu/index.htm>
- <https://www.hog.org/publications/detail/fall-is-for-flu-shots>
- <https://my.clevelandclinic.org/health/diseases/13464-nosebleed-epistaxis>
- <https://hemaware.org/life/when-your-kids-bleeding-disorders-get-sick>

# FOLLOWING THE CALL OF THE MOUNTAIN

AN INTERVIEW BY JUSTIN LINDHORST

The Appalachian National Scenic trail is the longest footpath in the world. Also known as the *A.T.*, the trail spans 14 states and 2,200 miles along the Appalachian Mountains. Millions of visitors take to portions of the trail annually. Every year, roughly 3,000 ambitious hikers attempt to “thru-hike” the entire trail in one pass, though only 1 in 4 can complete the months-long challenge.

Jacob is a young professional, an Eagle Scout, and an avid runner. He also happens to have severe hemophilia. Jacob counts himself among the few “2,000 milers,” completing an A.T. thru-hike in 2017. Averaging 17.5 miles a day and carrying up to 40 pounds of gear at any given time, Jacob accomplished his trek beginning at Springer Mountain, Georgia, in April and ending at Mount Katahdin, Maine, in September.





### **When did you first take an interest in hiking?**

Hiking is something I've always been interested in. I've been an outdoor kind of guy since I was just a young kid. It's where I feel the most natural, the most at home. It's always just been a part of who I am. I grew up in the scouts – my dad was also very involved, and as a family we did many outdoor activities together.

### **When did you become interested in taking on the Appalachian Trail?**

In high school I started getting competitive with cross country, track and field, and eventually, triathlons. I'm

the kind of guy that always likes to pursue things to the next level. As a hiking enthusiast, the Appalachian Trail was the "next level" in the back of my mind for years. Nearing the end of college, I began to realize it could actually happen.

### **How did you prepare?**

Planning the whole thing took around a month. Physically, I had been preparing for years with all the running, hiking and other physical activities. Logistically, preparation for the Appalachian Trail was not too difficult. Half the US population lives within a single-day's drive of the trail. There are many small cities along the way to pick up food and other



supplies. I worked with my specialty pharmacy and together we planned where I would pick up my factor along the way.

I had no severe bleeding episodes while on the trail. I knew one bleed could end my trip, so I strictly adhered to my treatment regimen. Also, when you are literally carrying your medication on your back, you're not going to miss a dose because it means less to carry!

### What was your greatest challenge during this trip?

I did not anticipate the difficulties in mentally preparing for a trip like this. Being away from friends and family coupled with the repetition of the trail day-after-day, month-after-month became more mentally taxing than I ever anticipated. The biggest challenge occurred when I was in northern Pennsylvania during a hot, humid day on a rocky part of the trail. Sadly, I learned a good friend and cross country teammate from college had passed away in a car accident. I wanted to pack up and head straight to the airport. It was a very difficult decision, but

ultimately, I knew my friend would want me to press on and finish.

### What was the most impactful moment of the trip?

Finishing! After months, it felt great to achieve such an accomplishment. I'll never forget when I first laid eyes on the mountains of Mount Katahdin where the trail ends. I learned so much along the way. The trail gave me an appreciation for the simplicity of life and the understanding that you don't need much to be happy. I lived out of a 50-liter backpack for 5 months. It brought me new friendships and memories to last a lifetime. I'd do it again in a heartbeat.

### What advice would you offer to other bleeding disorder community members?

Learning to stay disciplined no matter what life throws at you is one of the most important skills you can develop. Staying disciplined to your treatment regimen will help you stay healthy. Staying disciplined to your goals will help you accomplish nearly everything you put your mind to. There is not much in your way if you approach your goals with discipline and a resolve to succeed.

### What are your future hiking aspirations?

I've got my eyes on the Triple Crown. The Triple Crown consists of the three major US hiking trails – the Appalachian Trail, the Pacific Crest Trail and the Continental Divide Trail. I've got 2,000 miles down and 5,000 more to go!



# HEMOPHILIA AND SCOLIOSIS: A JOURNEY OF TWISTS AND TURNS

A young man with hemophilia and his mother share perspectives, recounting their journey with scoliosis, surgery and challenges related to severe hemophilia.

**Justin:** Severe scoliosis was detected during my sophomore year of high school after my pediatrician recognized a curve in my spine and recommended I see a specialist. I wasn't having any problems with my back and didn't think much of it, but went ahead and met with a local orthopedic doctor. The first set of x-rays showed I had an upper spine curve of almost 50 degrees and a lower curve of 27.

**Diane:** My heart dropped as I stared at the x-ray of my son's spine in the shape of the letter S. We were completely surprised as the doctor began providing information about a scoliosis brace to help prevent further bending of the spine. My son was to wear the brace during all waking hours. My mother's instinct wanted to discover the cause (or find blame), but I learned this was genetic and, like hemophilia, nothing caused nor could have prevented this.

**Justin:** When I was told I'd have to wear a brace for 18 hours a day, I immediately thought, "No way." As a swimmer, I didn't want scoliosis to interfere with my ability to practice and compete. When I went for the brace fitting, all I can say is that it was terrible and how much I hated the idea of having to wear it.

**Diane:** I sat there looking at this full-of-life, athletic, high school kid, imagining him strapped in a brace. While Justin's focus was on the inconvenience, I wondered how this was going to work with his hemophilia. And more importantly, of the social/emotional impact it was going to have. That night, I researched facts about the brace and realized we needed a second opinion. I identified another orthopedic doctor at a nearby hospital, but unfortunately he was not covered under our insurance. I reasoned it was worth the out-of-pocket expense for a single appointment.

**Justin:** Met with the new doctor and had more x-rays. After the exam and films, the doctor explained that since my bones were almost done growing, a brace was not necessary. He said the only thing a brace would do is make my life miserable and that the spine can continue to curve regardless of what I do. I was relieved about not needing the brace.



**Diane:** While the thought of having to endure a brace was put to ease, I soon became concerned over the prospect of what happens if Justin's spine continues to curve. The spine can typically curve 1½ degrees per year and at this point all we could do is monitor. The doctor expressed confidently, if surgery was needed, it could be done despite the challenges of Justin's severe hemophilia and a poor response to factor with only a 6 hour half-life. We scheduled another appointment in 6 months.

Realizing this was not a "one-time appointment," we

needed to address our insurance concerns. Our policy provided excellent hemophilia coverage, but did not cover the spine specialist. We discovered switching plans would provide coverage for spine management, but would compromise coverage for hemophilia care. Either direction we turned would leave us short of adequate medical coverage.

**Justin:** The summer following sophomore year, I started having some back problems and experienced my first bout of significant pain. After going for a run with my dad, I spent the rest of the day lying flat on the floor. The pain was severe, but pain medication and rest helped get it under control.

**Diane:** Realizing Justin was no longer able to run, I wondered what other activities might cause such episodes. As he lay on the floor in pain, my thoughts turned towards the possibility of surgery.

## A SLIGHT CURVE...

**Justin:** Halfway through junior year, I was heading toward a 4<sup>th</sup> state championship with my school swim team and was invited to Nationals. Luckily I was only experiencing mild discomfort. However, during my second visit with the specialist, I couldn't get over what my spine looked like on the x-rays. It had curved to over 50 degrees. The doctor discussed surgery but indicated it could wait since I wasn't having major pain. He also informed me I could be up to 1½ inches taller after the spine correction procedure, which I thought was awesome.

**Diane:** I knew 50 degrees was not what we wanted to see. While Justin was eager to have surgery over with, I was not in favor. Surgery prior to his senior year meant missing out on the great things the year would bring: the amazing experience of swimming for a #1 team, earning accolades, relishing in triumph and creating lifelong memories.

**Justin:** Despite my eagerness to be 1½ inches taller, I agreed it would have been difficult to give up the fun of senior year. At my third appointment in June, my curve measured 51 degrees, but with no complaints of pain, the doctor recommended a return visit in one year.

**Diane:** The hump in Justin's back caused by spine deformity was becoming more pronounced and his right shoulder was noticeably higher. Fortunately, his "swimmer's muscles" disguised the hump. Standing to wash dishes or fold laundry caused his back to ache. Despite some teasing from his sibling, we knew it was not just an excuse to get out of chores. Simple, every day activities had started causing discomfort.

**Justin:** That summer I began to understand my limitations. Fortunately, swimming was never a



problem and I was able to work as a lifeguard. One overcast afternoon when the beach was empty, a couple coworkers and I were doing handstands to see who could walk the farthest. Over the following few days, I wasn't able to walk and had to miss work. I quickly learned that handstands were on my "things-not-to-do" list. Rather than waiting until the end of the school year, we visited the spine specialist in February. Surprisingly, my upper curve was now 54 degrees.

**Diane:** The doctor pointed out surgery was now just a matter of "when." Though the curve was progressing, the doctor expected surgery could wait a couple of years.

## A SMOOTH RIDE TO COLLEGE...

**Justin:** I began my freshman year at the University of Florida (UF) and started swimming with the UF Club swim team. Increasing dryland training and building muscle mass helped diminish my back pain. Over winter break I saw the specialist again. The curve in my spine seemed to have stabilized at 54 degrees.

**Diane:** In preparation for the imminent surgery, we made changes to my husband's insurance enabling medical coverage for Justin's spine doctor and I returned to work full time to obtain secondary insurance. We now had coverage to tackle both, scoliosis and hemophilia. We also began our approach to surgery by addressing the challenges related to hemophilia.



with the pain of insurance challenges. Obstacles in obtaining authorizations for MRIs and other unexpected changes resulted in appointments being scheduled, canceled and rescheduled many times. More pressure and tension.

**Justin:** We met with the hematologist assigned to oversee my bleeding disorder during surgery. He told me he knew very little about hemophilia and couldn't help me. I never realized a hematologist could know so little about hemophilia. I was further shocked when he told me the surgery was serious and that I could die.

## HITTING A DEAD END...

**Justin:** A few years ago, I completed a trial with a long-acting factor concentrate, but the results weren't satisfactory. With surgery planned for next year, we decided to try a different product to see if I could obtain better half-life results. With so many trips back and forth for blood tests, I felt like a human pincushion. One visit, I was stuck 6 separate times and left the lab wrapped in Coban. I took a picture and sent it to my mom.

**Diane:** Justin sent a photo with the caption, "Love blood draws..." showing colorful bands of Coban wrapped around his left arm. Through it all, Justin had such a great spirit and sense of humor. Unfortunately, the second round of blood tests showed no improvement in factor half-life. It was concluded Justin simply metabolizes factor at a higher rate. We had to accept the need to approach surgery with that challenge.

## AN UNEXPECTED MAJOR CURVE...

**Justin:** In 7 months since the last appointment, my spine curved 6 additional degrees – it was now 60 degrees. All I could think was, "Holy smoke!" We met with the surgery coordinator who scheduled a series of appointments and a May 15<sup>th</sup> surgery date.

## BUMPY RIDE AND DETOUR AHEAD...

**Justin:** I can't wait to have this surgery over with and to live without pain. My spring break was a week of medical appointments and MRIs. Not the kind of spring break a college student wants to have.

**Diane:** While Justin struggled with more pain, I wrestled

**Diane:** I was stunned over what transpired during this appointment. Initial shock quickly switched to anger as I saw my son sitting on the exam table with his head hung low. I reassured Justin to disregard everything the doctor said.

As soon as we got home, I called the surgeon and explained what happened and asked for the surgery to be moved from the orthopedic hospital to the main hospital to ensure better hemophilia management with a hematologist that actually understood bleeding disorders.

## A ROAD BLOCK AND CHANGE IN ROUTE...

**Diane:** Just 8 weeks before surgery, the surgeon called to say it would be best if Justin had his surgery at Mount Sinai Hospital in New York City with access to all the resources available through their comprehensive hemophilia treatment center with a highly recommended surgeon. Initially shattered by the news, I knew it was the right decision given the first facility's lack of hemophilia experience.

**Justin:** Learning of the hospital and surgeon change, I did feel more confident about everything. My mom sent me information about the Mount Sinai surgeon, which also put my mind at ease.

**Diane:** Keeping surgery on "schedule" proved to be difficult as we were dealing with an unfamiliar facility and medical team. Postponing surgery was not an option as Justin's spine continued to curve. New concerns arose about the curvature potentially causing cardiopulmonary function interference.

## THE HOME STRETCH...

**Justin:** Three weeks before surgery I took my final exams and flew home. I met with the new doctors and obtained all necessary surgery clearances. There were a few more challenges related to coordinating specialists and concerns raised over my short factor half-life. At one point, recommendation was made to postpone surgery until August. I felt a wave of panic. No way can I do this in August.

**Diane:** Despite final challenges, we were able to proceed with plans for a May 16<sup>th</sup> surgery. After extensive blood testing, it was determined we can get Justin's factor level over 100% with extra doses of factor. He maintains a decent level for the first 3 hours and plummets at hour 4. Justin was instructed to infuse the night before surgery, infuse again an hour prior to surgery, another dose 4 hours during surgery, and then continue boosting his factor level with lower doses every four hours. Levels would be continually monitored and adjustments made to maintain a 100% level. The hematologist was confident Justin would be fine with this treatment plan. We were assured by his confidence and grateful for the amazing team in place. It was a long journey, but we were finally ready!

## THE FINISH LINE...

**Diane:** May 16<sup>th</sup> arrived. After meeting the surgeon, the team of specialists and the hematologist, Justin was prepped and wheeled into surgery.

## POST SURGERY...

**Diane:** After a nerve racking 5-hour posterior scoliosis surgery, my husband and I met with the surgeon. Justin did great! He received an additional round of factor during surgery and blood loss was normal for a scoliosis surgery. The surgeon explained Justin's spine was very stiff - to straighten it further would have required additional instrumentation. Due to Justin's hemophilia, he decided not to push things further and settled for a 17 degree correction.

Justin remained in ICU, where factor levels were monitored every 4 hours prior to each infusion. First day after surgery, the occupational therapist had Justin standing. Day 2, he walked down the hall. Day 3, he climbed a set of stairs and infusions were reduced to every 6 hours. On the 4<sup>th</sup> day, spinal drains were removed and Justin was cleared for release. An aggressive factor replacement plan was set: first week home—every 8 hours, 2<sup>nd</sup> week—every 12 hours, 3<sup>rd</sup> week—every 24 hours, and 4<sup>th</sup> week—back to normal prophylaxis schedule of every 48 hours. Despite knowing the recovery challenges ahead, we were eager to return home.



Home infusions proved to be difficult given his pain levels and side effects of medication, so we decided to have a nurse insert an intravenous catheter. During the first week, pain was most difficult to manage, but Justin was still up and walking a few times a day. Activities were very restricted, but with each day came a new milestone.

Justin now has two rods and multiple screws in the upper portion of his spine, which fused within 3 months allowing him to begin physical therapy. Surgical upper correction should also allow the bottom curve of 32 degrees to begin to straighten on its own. By fall, Justin was back on campus and within 4 months of surgery, was in the pool practicing with his swim mates, without limitations. Before surgery, Justin could no longer run – now he is running “stadiums” at the University of Florida football stadium, an extreme workout where he runs up and down stadium steps. He is thrilled to be standing straight and loves that he can walk across campus pain free and without his backpack falling off slanted shoulders.

**Justin:** With surgery behind me, life is back to normal, and I'm loving being 1½ inches taller!

# SIX THINGS NEWLY DIAGNOSED FAMILIES NEED TO KNOW

BY SARAH COTTRELL



In the wee small hours of a cold November morning in 2009, I sat in an overwhelmed ball of tears after learning my firstborn, who lay down the hall in the neonatal intensive care unit, had been diagnosed with hemophilia. I had no idea what that was at the time, but I was keenly aware of the fear and confusion that smothers any sense of reason when a doctor sits you down and says, “it’s incurable.”

Nine years have passed and in that time, my hemo kid has turned out to be whip-smart, wild and bold. My family often jokes that of all the kids in the world, the universe had to give our child, who dreams of being a pro-skateboarder, a bleeding disorder. And yet here we are, living life unafraid and refusing to let a defective gene hold our son back. For families who are grappling with the unforgiving rawness of a new diagnosis, I see you. I know where you are in this. If I could, I would tell you a few important things that no one told me in the beginning.



## YOUR KID WILL RUN WITH SCISSORS

And you will *probably* not freak out about it. Kids with bleeding disorders are no less energetic and unpredictable than any other kid. You can pad your house and the seat of your kid’s pants (I sure did!), but it won’t stop them from leaping off the couch, falling off a bike or chasing the family dog while screaming in pirate-ese. Let it happen.



## PEOPLE WILL SAY THE DUMBEST THINGS

Believe it or not, you will get to a point when it no longer irritates you because you will either develop a sense of humor (yup, we’re Russian czars) or you’ll have perfected canned responses to quickly explain your child’s bleeding disorder in a 10-second elevator speech.

You will get stares when your child has gnarly bruises. You will get unsolicited parenting advice and unhelpful comments like, “Gosh, I can’t even imagine how hard that must be!” Just smile and brush them off. You’ve got this.



### YOUR SPELLING WILL DEFINITELY IMPROVE

Along with bleeding disorders comes a whole new language of big medical words that are sometimes hard to say. Before you know it, you'll be impressing your friends with fancy words like *phlebotomy* and *prophylaxis*. It's one of the perks of being a bleeding disorder parent — you sound like the smartest person in the room!



### YOU WILL BECOME A FIERCE ADVOCATE

The most shocking part of hemophilia for me has been how medical staff at hospitals are so woefully undereducated about bleeding disorders. I cannot tell you how many times I have had to boot a nurse out of a room, explain basic hemophilia 101 to an emergency room doctor or, while insisting that my child be treated, get someone from our hemophilia treatment center on the phone to back me up. It took a while to figure out the balance between advocating in a clear way and being a scary mama bear, but I got there, and you will too.

### YOU WILL SUDDENLY HAVE 103 NEW BEST FRIENDS FOREVER



Hands down, the best part of being a family in the world of bleeding disorders is that you are inducted into a special club made up of others who all know what you're going through. We get it. The struggles with insurance, the frustrations with medical staff, the milestone moments of infusing kids and the delicate and heartwarming relationships between siblings.

Sure, it's a club no one asks to be in, but we are loving, welcoming, resourceful and we have the best snacks. With groups and organizations all over the country, it's easier than ever to find families close to you. Don't be afraid to reach out.

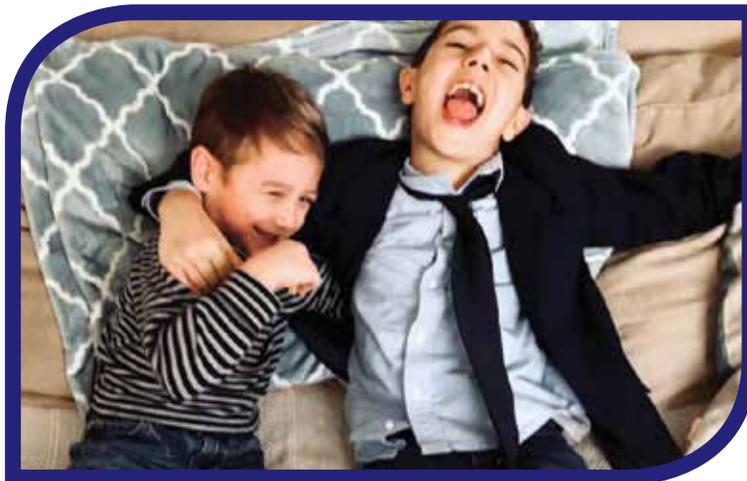


### DENIAL DAYS ARE OKAY AND SO IS RAGE-EATING



There are days when I want to scream about how unfair hemophilia is. Oh, let me count the ways! That's when self-care comes into sharp focus and I have to settle my mom hackles down and remember it's absolutely okay to take a break and indulge in me for a hot minute. Self-care can look like a million different things so just find what works for you. Be a yogi-sipping-green-tea and getting your Zen or eat an entire pizza and flip through 57 different channels.

Having a bleeding disorder is not the end of the world, although it can definitely feel like it in the beginning. The good news is you don't have to go through your bleeding disorders journey alone. You're in this amazing new club and we're glad you're here.



My children, Max and Finn

# MATRIX ON THE MOVE



## TENNESSEE

### David Tignor

Trinity Baptist Church in Jonesborough was the place to be June 16<sup>th</sup> for the **11<sup>th</sup> Annual Race for Ian**. More than 60 people participated in this consumer fundraiser race hosted by Tennessee Hemophilia and Bleeding Disorder Foundation (THBDF) and organized by Michael and Sarah Bates in honor of their son, Ian, and the bleeding disorders community. An awards ceremony and drawing for door prizes followed the race. Funds raised during this event benefit THBDF and help support hemophilia research at St. Jude. *Race for Ian* continues to grow every year, and we are proud to be a supporter of this wonderful cause.



Looking good, Clarissa!



Ian visits the Matrix Health Group booth.

## ILLINOIS

### Eva Kraemer

Bleeding Disorder Alliance Illinois (BDAl) hosted **Driving fore Hemophilia** – its 21<sup>st</sup> annual golf fundraiser June 18<sup>th</sup>. This year, we found ourselves exploring a different course at Silver Lake Country Club in Orland Park, a family owned and operated course since 1939.

It was nothing less of an inferno for a not-quite-summer day, but BDAl's Executive Director Bob Robinson, staff and volunteers still brought energetic smiles as they hosted 18 challenging holes of golf.



Zachary, Gina, Jon and Bob have a spectacular day!

Hydration was the key to enjoying the afternoon on the links. Afterward, we all made our way back to the clubhouse for food and raffled sports paraphernalia. Happily, the heat did not derail everyone's generosity as donations were made benefiting Illinois children and adults with inherited bleeding disorders! The Matrix Health Group-sponsored foursome had a blast contributing to the day and its success!

## OHIO

### Rania Salem

Family and friends of the Southwestern Ohio Hemophilia Foundation (SWOHF) gathered for the **"Fired Up" Family Fest** June 22<sup>nd</sup>-24<sup>th</sup>. After checking into Higher Ground Retreat Center just across the Ohio border in West Harrison, Indiana, groups made their way to the main hall to visit industry representatives. While adults discussed products and services, little ones enjoyed making arts and crafts. Everyone then gathered for a delicious barbecue dinner, which is looked forward to every year. During the fantastic weekend, SWOHF brings attention to its annual *Bouncing for Bucks* campaign where by bouncing balls throughout the year, children raise thousands of dollars to benefit the chapter and the services they provide.



This is a much sought out getaway for families in Dayton and surrounding areas, and is always a special time spent with family and friends. Many thanks to Kay Clark, Executive Director, and all those who worked so hard to organize this event filled to the brim with fun and essential education for bleeding disorders families.



Jalin and Talmasha share a smile.

## TENNESSEE

### LeAnn Wilson

The Tennessee Hemophilia & Bleeding Disorder Foundation (THBDF) held their **48<sup>th</sup> Annual Meeting** at Memphis' Hilton Lake Boulevard June 22<sup>nd</sup>-24<sup>th</sup>. Friday night was

laid back with a few rap sessions for *Blood Brotherhood, Women, Dads*, and one specifically for *Teens*. Tammy Jones and LeAnn Wilson hosted a special painting session for the women. The ladies were asked to think about some of their hardest experiences and find something about it that proved to be positive. By painting on a canvas, they were directed to share good things they had taken away or learned from the community. The paint party was a hit and the wonderful work was displayed in the hall for everyone to admire!

Saturday was packed full of information and inspirational speakers. Mayor Jim Strickland began the day by welcoming everyone to Memphis. *Soaring to New Heights, Reach Your Peak and Elevate Your Community* was a fitting theme with Chris Bombardier as the event's keynote speaker. Being the first person with hemophilia to scale the summits of Mount Everest, Chris shared his story in a session titled *What's your GutMonkey?* He explained the urban dictionary term as, "A deep-seated desire, or passion that at gut-level, inspires you to act." Chris helped us find ways to answer the question, "What inspires you?" He noted that personal passion is a positive motivator and a great way to engage what challenges us to get out and "Be Brave." He also had everyone get up and participate in a few new ways to play thumb war. Laughter filled the room as he walked us through the steps, "1, 2, 3, 4... I declare thumb war!" Funny how a child's game can still bring us all smiles and laughter.

Educational Specialist Kelly Gonzalez presented *Putting the Mask on First*. She opened by sharing the heartfelt story of her daughter surviving cancer and the struggles she faced as her caregiver. She spoke on how we as caregivers must take care of ourselves to properly care for our loved ones. This was a very emotional session, but one that must be addressed throughout our community.



Saturday night's entertainment showcased songs written and performed by community members – we have many talented people in our close-knit group! It was a great way to bring the event to a close. THBDF's annual meeting is always filled with great sessions and education, which is key for the continued progress of our community. Thank you to everyone who worked so hard to bring Tennessee another great meeting. We look forward to what this next year brings!

## MARYLAND

### Terry Stone

READY, SET, GO! Hundreds of supporters arrived to raise money for the Hemophilia Foundation of Maryland's (HFM) **Annual Race to Stop the Bleeding** event at Quiet Waters Park, Annapolis June 23<sup>rd</sup>. They came with their best running shoes on, they came with their strollers and wagons, and they came with their tutu's and toddlers. No one does it better than HFM to set the stage for a successful event!



Impressive bling!

What makes this event extra special besides those who run and walk to raise money? Volunteers! Yes, one word sums up the spirit of day. From the volunteers who carried in water and ice, to those who

set up tables, and especially to the lunch bunch who cooked all morning and made hundreds of hamburgers BY HAND! No, that's not a typo, runners were treated to homemade burgers fresh off the grill. Who does that for a large group like this? Enough said! Congratulations to HFM for a successful fundraiser, and for raising the bar year-after-year!

## OHIO

### Rania Salem

Family and friends of the Tri-State Bleeding Disorder Foundation (TSBDF) gathered for another fantastic **Family Education Day at Coney Island** June 23<sup>rd</sup>. Beginning the day visiting industry vendors, we went on to enjoy a savory picnic style lunch, greeting old friends and making new ones. But that was only the start as Coney Island is home to the largest sunlit pool in Ohio, classic amusement rides, and golf and boating fun on Lake Como! Although rain came in, it surely did not dampen the happy spirits! The annual summer gathering never disappoints. Thanks again to TSBDF for yet another wonderful family gathering!



## MATRIX ON THE MOVE

### NEW JERSEY

#### Rich Vogel

Hey you from Jersey. I'm from Jersey! Sunday June 24<sup>th</sup>, we celebrated New Jersey by cooking up a traditional Italian dinner at Classic Thyme Cooking School in Westfield. It is a hands-on experience where we first learn about the history of the family recipes and work together to prepare the meal under the supervision of Chef David Martone and his staff. Then, like a true Italian family, we sit down together to enjoy the fruits of our labor.

The menu for this event sponsored by CSL Behring and hosted by Matrix Health Group included cavatelli, meatballs, Tuscan sausage, marinated mushrooms, roasted red peppers, sautéed escarole and wrapped it up with an Italian dessert. What's more Jersey than that?



Omar hard at work!



Trevor looks on while Chef David instructs.



Deland is ready to cook! Amy and Allison stir up deliciousness!

Our Jersey girl and motivational speaker, Milybet Cepeda, discussed resilience in the bleeding disorder community as she shared her personal story. The lively discussion continued as we broke bread, family style, because that's what the bleeding disorder community is - family.

These Matrix Health Group-hosted events are free to local community members, so if you ever find yourself in Jersey, contact [richard.vogel@biomatrixsprx.com](mailto:richard.vogel@biomatrixsprx.com) and become part of our family!

### OHIO

#### Shelia Biljes

**ALL ABOARD!** Berea Depot Restaurant was the gathering place for Shire and Matrix Health Group to cosponsor a **Ladies Night Out** for the Northern Ohio community. The June 28<sup>th</sup> dinner was served in a train car as we imagined worldly destinations. Erin Weigel, Nurse Educator for Shire, opened the conversation and turned the floor over to Rhea Hoston, who spoke about her son and the challenges of his inhibitors. She also discussed her own diagnosis of hemophilia A.

The tables were cleared to make room for a special project *Beading Your Journey* led by Michelle Stielper. The ladies made beautiful necklaces with each bead representing a milestone in their bleeding disorder journey. As Michelle explained the meaning of each bead, the ladies shared stories about their experiences. With 24 in attendance, the train car was crowded, but the closeness in body and in heart is what was felt as we ended another successful *Ladies Night Out!*



Maddie and Jen



Charlene and Dolly



Connie and Kristen



## MISSOURI

### Eva Kraemer

The Gateway Hemophilia Association (GHA) hosted its annual **Family Education Weekend** July 13<sup>th</sup>-15<sup>th</sup> at the Doubletree Hilton in Chesterfield. Families from all over Missouri were drawn together to embrace fellowship and give support to their local chapter. An exciting array of breakout sessions and activities arranged for the families made for an extraordinary educational experience.



Patrick James Lynch

There were many educational paths to choose from! Breakout sessions included topics on being prepared, *Are You Ready for the Drill?*, distinguishing pain, *Why Do I Hurt?*, emerging treatments for VWD, *Different, but the Same*, along with more great sessions covering *Positive Outcomes from Camp Notacloamungus*, *Nurturing the Couple Relationships*, *Aging Gracefully* and *Resilience*. Attendees enjoyed a special appearance by Patrick James Lynch, who presented, *Powering Through* featuring a Q & A interview session with his 3 guests, which brought a unique perspective to bleeding disorder challenges encountered on a day-to-day basis.

The weekend's finale was outstanding as families gathered by the pool to view *The Greatest Showman* on the big screen and watch the kids have a blast. There is no doubt the amount of time and effort that went into planning this year's *Family Education Weekend* was extensive and elaborate. We look forward to attending next year and the years to come!

## OHIO

### Moe Hoque and Joe Piscitello

The Cleveland Metroparks Zoo was a great attraction for the families of the Northern Ohio Hemophilia Foundation (NOHF) as they hosted their annual **Family Event!** Though the July 14<sup>th</sup> weather was positively scorching, over 70 community members arrived to engage in camaraderie and enjoy ice cold refreshments before heading out to walk through the zoo. After visiting the animals, the group headed to the Waterfowl Pavilion to enjoy lunch. The heat of the day did not stop this happy group from having a great time!



## PENNSYLVANIA

### Tina McMullen and Paul Fatula

Pittsburgh Zoo & PPG Aquarium was the place to be Saturday July 14<sup>th</sup> for the Western Pennsylvania Chapter of the National Hemophilia Foundation's **Annual Meeting**. It was an absolutely beautiful day to be at the zoo! With about 200 attending, the day began with families visiting the industry exhibit area.



Cooper and Brooke



Allyson's smile says it all!

Once the children were off to have fun of their own, adults enjoyed the educational portion of the meeting. This year's topic, *Talking to your Doctor*, focused on what questions to ask and how to get the most information out of your doctor's visit.



Siblings hand in hand.

Families were then brought together and given Zoo Bucks to enjoy the many food options available while walking through the zoo. As evidenced by their sweet little faces, the children had excitedly awaited the chance to see the animals. Executive Director Alison Yazer and her entire staff did a perfect job of hosting a delightful annual meeting!

## FLORIDA

### Hector Heer

For 35 straight years, the Florida Hemophilia Association has hosted a **Family Education Symposium**. This year's event took place July 20<sup>th</sup>-22<sup>nd</sup> at the Hilton Embassy Suites in West Palm Beach. Industry representatives were out in full force ready to share information on their company, products and services. The educational sessions were led by amazing speakers who took time to share their knowledge with the community. We applaud Debbi Adamkin and her devoted team for again hosting an outstanding event!



Johanna enjoys the event!

## ILLINOIS

### Eva Kraemer

Rain didn't stop chapter members from coming out to Bleeding Disorder Alliance Illinois (BDAl) and Shire's **Family Picnic** July 21<sup>st</sup> at Catherine Chevalier Woods in Chicago. To prepare for the activities, the first order of the day was making our way to the taco



Staying dry! Divit, Deepika and Muthukumarasamy

## MATRIX ON THE MOVE

truck so we could fill our bellies with delicious goodness! An outdoor soggy icebreaker helped us get to know one another as the rain chased us back under the pavilion. But that didn't stop the flowing of wonderful conversations and networking of community members, nor the amazing music! A great time was had by all and we enjoyed being part of the activities... AND taco eating!

### NEVADA

#### Kelly Gonzalez

Northern Nevada **Family Education Day** is a time for families in northern Nevada to gather for education, excitement and opportunities to bond with one another. This year the event welcomed more than 125 at Harrah's Reno Convention Center.

After a series of educational sessions, families walked to the Greater Nevada Field to enjoy a minor league baseball game between home team Reno Aces and Fresno Grizzlies. Fun, friendship and light-hearted laughter filled the stadium and reminded us that in our community we are one. Thank you to the NV Chapter of NHF, the Hemostasis and Thrombosis Center of Nevada and all industry partners for joining in to make this event a fantastic success!



Maureen cheers on the Aces.



Jaxon = Adorable!

### OHIO

#### Rania Salem

July 28<sup>th</sup>, friends and families of the Central Ohio Chapter of NHF (COC) gathered at the Columbus Zoo and Aquarium for the annual **Day at the Zoo**. The venue definitely did not disappoint as we gathered for



Jermaine visits the giraffes!

a chapter-happenings briefing by Executive Director Tauna Batiste and breakfast in the heart of the *African Safari*, a 43-acre region with breathtaking scenery that makes you feel as if you're in the middle of a real safari. Families were able to walk right out and feed the giraffes! After breakfast, families were free to explore and meet all 7,000 animals living at the zoo!

### IDAHO

#### Jeff Johnson

The National Hemophilia Foundation of Idaho held its **Annual Meeting** at The Grove Hotel in downtown Boise August 3<sup>rd</sup>-4<sup>th</sup>. Fifty local families attended and were treated to a powerful presentation by Chris Bombardier from GutMonkey about finding your personal mountain to climb. I was privileged to lead a breakout session discussing insurance issues facing the bleeding disorders community, beginning with a refresher course on understanding the basics of health insurance plans. Additional classes throughout the event focused on self-infusion, personal advocacy, understanding hemophilia as a new parent and how to be an effective community advocate. Wrapping up the event everyone headed to the nearby waterpark to enjoy a day together in the summer sun. It was another great event for a growing chapter, and we look forward to participating again next year!

### OHIO

#### Shelia Biljes

Many parents agree the best time of year is back-to-school time! Summer winds down and the kids are excited for a new chapter to begin. It's the perfect time to gather families in the Northern Ohio community to review school safety issues and plans for storing clotting factor at school.

BioMatrix partnered with Shire to present a **True ID Program** August 9<sup>th</sup> at TGI FRIDAYS in Brooklyn. Shire's nurse educator, Sue Kovats-Bell, RN led the back-to-school conversation and then turned everyone's attention to True ID speaker, Jordan Timura. Jordan had everyone chuckling as he shared experiences from his life. He talked about prophylaxis so that he could play sports and shared some unconventional places where he had infused including on a bus, in bleachers and in the back of a canoe as he paddled down the Missouri River. He spoke about his transition to college and the independence gained when, at a young age, he learned to infuse at summer camp. Everyone had plenty of questions for Jordan.



Carter and Madison spin the wheel for back-to-school prizes!

*Continued on page 26*



# FAMOHIO

FAMILY ANNUAL MEETING  
OF HEMOPHILIACS IN OHIO



BY RANIA SALEM

Families from all across the great state of Ohio gathered for *FAMOHIO's Annual State Event!* Held August 3<sup>rd</sup>-5<sup>th</sup> at Columbus Marriott Northwest in Dublin, this year's theme, *Together as One*, was chosen for two reasons as stated by FAMOHIO: "Firstly, we all know that together we can accomplish greater things... Secondly, we also know that opportunities for optimal medical treatment are not the same around the world."

Booths were set up in the exhibit hall representing 11 countries around the world. One attendee stated, "The Saturday night event was incredible. It gave you a taste of different countries and made you feel like you were on a journey overseas. Each booth offered an informative 10-minute rundown of how it is to live with hemophilia in the represented countries."

In addition to a fantastic Saturday night event, the rest of the weekend was filled with fun, education and camaraderie. Some of this year's sessions included *Unpacking Hemophilia: Perspectives from Living in Developing Countries* presented by Jose Mari Antonio, Development Advisor at Save One

Life. Jose discussed the lack of acceptable hemophilia care in the Philippines. Dr. Riten Kumar of Nationwide Children's Hospital led a session on *New Products and Future of Hemophilia Treatment* in which he gave a look at our past as well as our future with hemophilia treatment. Kimberly Blackwell, MPAS, PA-C, with the Indiana Hemophilia and Thrombosis Center, spoke on *Von Willebrand Disease and Congenital Platelet Disorder*. As a VWD patient herself, Kimberly discussed the symptoms and difficulties of living with VWD.

A favorite of many was *Laughing Through Stress* by Lori Kunkel. As the mother of three grown sons with hemophilia, Lori shared information on how to use humor to alleviate stress. Adding to the fun, Lori included a *Laughter While Doing Yoga* demonstration.

FAMOHIO never fails to come through with great programming. Special touches add to the popularity of the weekend and included pool time, a visit from an ice cream truck and the ever-so-popular, *Women's Comfort Room*, where ladies gathered for conversation away from the hustle and bustle of children.

This year, we said "thank you for your service" to 10-year standing president, Josh Crossgrove. Josh will continue to serve on the FAMOHIO board. We also welcomed first time president, Tina Ascough. We wish her all the best as she leads FAMOHIO forward.

A HUGE thank you to everyone who worked so hard to organize this wonderful weekend.



## MATRIX ON THE MOVE

After dinner, the children participated in a spinning wheel game which helped them identify supplies used during an infusion. The children were fast learners and came away with school supply prizes! We wish everyone a safe and fun new school year!

### VIRGINIA

#### Terry Stone and Michelle Stielper

Rain was not invited to Hemophilia Association of the Capital Area's (HACA) **Annual Family Picnic** at the Water Mine Water Family Swimmin' Hole, Saturday August 12<sup>th</sup> in Reston, but it came anyway. No worries, though! Everyone made the best of it and thanks to some very prepared moms, the kids played with trains, toys, raindrops and mud puddles. Now that's a picnic to remember!



Phil and Robin

Members enjoyed visiting with old and new friends, while lunching on a local favorite – Willard's Real Pit BBQ with all the fixings! Although the rain poured, the pavilion was dry and cozy, and filled with laughter and love! Since the return of the annual family picnic a few years ago, it has been one of the best attended HACA events. It's all about togetherness, right? Who needs a water park when we have each other... and trains!

### OHIO

#### Shelia Biljes

#### Ladies Night Out

is a popular event in the Cleveland area. In fact, it is so much fun that we meet more often than our quarterly planned schedule. This



month was no exception as 20 ladies gathered at TGI FRIDAYS in Brooklyn August 14<sup>th</sup> to welcome Roberta Smith as our guest speaker. From Salt Lake City, Utah, Roberta is a *Common VWD Advocate* speaker for CSL Behring as well as an amazing piano player. Roberta plays by ear and used that concept to tell her story as an undiagnosed child. She had everyone's attention as she shared how her doctors would play every bleeding episode "by ear." Her story has a happy ending as she now proactively treats her bleeds and lives a full life.

As we waited for our meals, the ladies took part in a game simply called *What's in My Purse*. They were given points for a variety of items such as a point for every tube of lipstick, points for pens, tissues, keys that don't

fit anything, and you would be surprised at how many women carry a snack in their purse! Snacks were worth 5 points! However, we deducted points for each credit card. The laughter flowed as we saw what strange 'essential' items we carry around!

The table was decorated with lantern centerpieces representing the fact that we are a light in each other's lives, and each took one home as a reminder. As usual, it's always great fun to get together and share stories with one another!

### TENNESSEE

#### Stephen Lawrence

Saturday August 18<sup>th</sup>, the Tennessee Hemophilia and Bleeding Disorders Foundation held their **12<sup>th</sup> Annual Pitchin' For Caleb Cornhole Tournament** at Centennial Park in Crossville. Cornhole lanes were set up for randomly selected 2-member teams to compete with one another. A lunch of barbecue, slaw and baked beans nourished the hungry crowd as we readied ourselves for the final few games wrapping up this year's tournament and celebrating triumphant winners!



Dusty Norrod, ACL Regional Director and Caleb Wood as they pitch in competition



### VIRGINIA

#### Terry Stone and Michelle Stielper

Back to school time is a great opportunity to brush up on 504s, IEPs and what food to pack that kids won't trade or trash in those designer lunch sacks! The Virginia Hemophilia Foundation answered the call and hosted a **Back to School Family Picnic** Saturday, August 18<sup>th</sup> at First Landing State Park in Virginia Beach, with much needed education on school accommodations and the all-important question... chips or Cheetos?



Vance and Shelly

The expert at the head of the class was Kelly Gonzales, former teacher and educational specialist, who shared her experiences in creating a plan for her own children with bleeding disorders. She cited current laws, the do's and don'ts of making your child's accommodations and the importance of setting them up for academic success.

Kids grow and change each year, and so should your child's accommodations. From toddlers to teens, their needs may need adjusting. Kelly offered great tips and reminded everyone to reach out if you need support. There is help to be found by contacting your HTC's social worker, your chapter and here at Matrix Health Group. Know you are not alone! We were delighted to host this informational picnic and presentation with CSL Behring. Good food, good news and good friends. That's how we picnic in Virginia!

## NORTH CAROLINA

### Xaviette Pointer-Kincy and Peggy Klingmann

Hemophilia of North Carolina (HNC) hosted their annual **Family Day Out** August 19<sup>th</sup>. Held at Tanglewood Park and Peter S. Brunstetter Aquatic Center in Clemmons, families came out to enjoy a Sunday afternoon of outdoor activities and lunch. More than 75 community members attended this amazing social event, which included plenty of time to splash around at the water park featuring wet and wild fun at a winding tubing river, exciting water slides and a splash pad playground.



Riley having fun!

Though participants had the opportunity to learn more about HNC and the services offered to the community, this event is significant as it is less educational and more social, allowing families the opportunity to connect with and learn from other members of the community. Thank you to HNC for hosting this wonderfully relaxing summer event – we were happy to offer our support!

## NEVADA

### Kelly Gonzalez

**Southern Nevada Women's Retreat** is a day set aside for women – those affected with a bleeding disorder, caregivers and spouses – to come together and learn about their health, wellness and become empowered to be strong women in the community. During the August 27<sup>th</sup> retreat at Henderson Hilton Garden Inn, ladies were treated to education, relaxation (yoga and relaxation techniques), and some Zen to bring home! Thank you NHF NV and industry sponsors for hosting this event!



## ILLINOIS

### Eva Kraemer

The Board of Directors and Executive Director Bob Robinson of Bleeding Disorders Alliance Illinois (BDAl) hosted the **2018 Meeting and Awards Dinner** August 27<sup>th</sup> at William Tell Holiday Inn in Countryside. Board President Daniel Contreras reported



Faith and Bob ham it up!

on the state of the organization. He touched upon upcoming endeavors for 2019 and talked about the history of bleeding disorders. During dinner, awards were presented to the following for their steadfast contributions: *Walk in Our Shoes* went to Faith Gately; *Award of Excellence* was graciously accepted by the Kelly Family; *Cibula Award* for outstanding volunteerism was presented to Margo Schwartz-Newton; *Outstanding Award* to BDAl was presented to CSL Behring-Kankakee Plant; and *Outstanding Support Camp Warren Jyrch Award* went to the Colburn-Keenan Foundation. The family of Bradley Krueger was also on hand to present the *Bradley Krueger Scholarship* to 4 deserving recipients, subsidizing their education costs for the 2018/2019 academic year. It was a wonderful time to reminisce about another year of success!

## CALIFORNIA

### Cindy Picos and Gaby Griffin

The 2<sup>nd</sup> annual **La Familia de Sangre** was hosted by a collaboration of Central California Hemophilia Foundation, Hemophilia Association of San Diego County, Hemophilia Foundation of Northern California and Hemophilia Foundation of Southern California. With more than 500 in attendance, the event was held September 7<sup>th</sup>–9<sup>th</sup> at the Marriott Oakland City Center. In addition to educational opportunities and entertainment, the highlight of this 3–day conference included a special dinner on the grounds of the National AIDS Memorial Grove in San Francisco followed by a trip to the California Academy of Sciences. Familia de Sangre originally arose out of comprehensive needs-assessment conducted on state and national levels and was designed as an outreach program for the Hispanic community. BioMatrix was proud to attend and sponsor the event supporting the health and future of this growing population.



## VIRGINIA

### Terry Stone and Michelle Stielper

"Behind every successful woman is a tribe of other successful women, who have their back."

It was a weekend befitting of huddling and closeness as the winds were blustery and the rains were strong. The ladies of the Hemophilia Association of the Capital Area made their way to Meadowkirk, a sanctuary in the majestic hills of Middleburg for a weekend of mindfulness September 9<sup>th</sup>-10<sup>th</sup>. This was where friendship and support crossed paths for a magical weekend. Greeted by Executive Director Brenda Bordelon, our check-in was swift, lunch was served, and the afternoon of sharing and learning got off to a great start.

It's a well-known fact that when you gather a group of women in a cozy and remote dorm with a roaring fire in the great room, a chef preparing meals, and the women have each other with time on their hands, that they somehow step back in time to the days of their youth. Oh how we remember the sleepovers, the boy talk, cheerleading, parties and all the drama of our youth.

Well we're older now and the boy talk usually surrounds how brave our sons are in dealing with a bleeding disorder, or how our girls fight for a proper diagnosis. Our cheerleading has changed to cheering for our kids when they infuse themselves or if the neighbors don't call the cops because of the screaming coming out of our house (infusion day or for other reasons!) Parties... sure, we still party. Although it's more like a Chuck E. Cheese smack down with an 8 o'clock curfew for everyone, including parents!

Yet, these moments now, with women united by blood, with some ladies still strangers, seem so familiar. It's comfortable, a

real sweet spot where we feel safe to share. Where we feel loved and heard, with women who get us, REALLY get us! In an instant, we are sisters – strangers no more... This is our tribe!

Two inspiring sessions facilitated by HFA's Anna Bell really afforded some heartfelt revelations, confessions and truth bombs that really felt good for many to let out. Remember, what happens at the retreat stays at the retreat! *Taking Care of YOU* and *Putting Stress in its Place* were presented in an open format that allowed ladies to speak freely and without reserve. We were then treated to a mindful meditation session led by HACA mom, Marcelle.

Another highlight of the weekend was an opportunity to *rock* our creative side. We painted rocks and made personalized bracelets with inspirational messages. What's not to love! Everyone showed their true talents and created beautiful keepsakes to take home and remember this experience. To wrap up the weekend, we made a circle with all of our rocks and experienced a powerful conclusion to our time together in a commitment ceremony. We entered the circle of love (made by our beautiful rocks) and one-by-one shared something we will work on, change and include in our lives going forward. After a commitment was shared, we celebrated each proclamation in whatever way they chose to be celebrated: sign language, a wave, applauding, everyone had a different way that said the same thing... we will support you, we've got your back.

"Strong Women stand together when things are rough, hold each other up when they need support, and laugh together when there's no reason to!"



## NEW YORK

### Richard Vogel

Bleeding disorders and going to school can be difficult at times. It's important to know the various resources available to you and what your child is entitled to. Do you need an Individual Education Plan (IEP) or a 504 plan? Or both? And what is the difference between the two? Well

Sunday September 9<sup>th</sup>, the New York City Hemophilia Chapter (NYCHC) addressed these issues and more with their **Bilingual Back to School Education** event, held at the NY Marriott Downtown, near the new World Trade Center.



Amiya and Leilanni visit the Matrix Health Group booth!



Opening sessions consisted of *Tips for Improving Your 504 and IEP*, presented by educator Ben Shuldiner in English. Ben discussed how to set up a 504 or IEP and the difference between the two. Simultaneously, *Infusion Training* was presented in English and Spanish in another room.

Welcome remarks by Executive Director Jeremy Griffin was followed by lunch and round table conversations. Afternoon sessions included *Resilience: Growing Through Life's Changes* presented in English and Spanish, *School Conversations* by Angie Forsyth in English, and two workshops for children: *The Art of Storytelling* for teens and *Engineering and Science* for kids 12 and under.

NYCHC events are always well attended because Jeremy and his staff do a great job in making sure there is something for everyone, from patients to caregivers, teens to children and for those whose first language is Spanish.

## OHIO

### Shelia Biljes

A downpour of rain did not stop 350 walkers from attending the Northern Ohio Hemophilia Chapter

### 2018 Unite for Bleeding Disorders Walk

September 9<sup>th</sup> at the Akron Zoo! It was close quarters under the pavilion, but no one seemed



Siblings Unite!

to mind stepping into the rain as the walk began. Due to the weather, we had the zoo to ourselves to enjoy the animals who were especially active and entertaining. After the walk, a tasty lunch was provided by Akron Children's Hospital and awards for fundraising were given. The walk raised more than \$46,000!

## PENNSYLVANIA

### Tina McMullen

It had rained for what seemed like weeks, however Tuesday September 11<sup>th</sup>, the rain stopped long enough for the Eastern Pennsylvania Chapter of the National Hemophilia Foundation (EPC) **Golf Classic** to take place. This annual scramble is held at the beautiful Rivercrest Golf Club and Preserve in Phoenixville. Seventy-plus golfers began the day with a buffet lunch before the shotgun start. The event included contests for *Men's and Women's Longest Drive*, *Putting Contest*, and *Closest to the Pin* with exciting prizes for the winners including a TaylorMade M2 Hybrid golf club, Platinum Spider putter, and a TaylorMade wedge.



The day concluded with dinner and a fantastic *Golf Ball Drone Drop*! For those who don't know what that is, a drone drop consists of purchasing a marked golf ball, which is placed into a container with all the other purchased balls. The container is air lifted over a golf hole via a drone and the container is opened. All the balls drop onto the green and the one landing closest to the pin wins a prize! Thanks to technology, a novel idea for a fundraiser is born! For an awesome view of this, visit EPC's YouTube link: <https://youtu.be/4C-IT-2ROZo>.

Thank you to Executive Director Curt Krouse and staff, Lindsay Frei and Kat Kocsi, for hosting a perfect day!

## ILLINOIS

### Eva Kraemer

More than 350 devoted participants joined the 8<sup>th</sup> annual Bleeding Disorder Alliance Illinois (BDAL) **Hemophilia Walk** September 15<sup>th</sup> in downtown Chicago's bustling Lincoln Park. The walk was slow and easy due to the sweltering temperature and took us through the very picturesque North Avenue Beach on a winding path along Lake Michigan. BioMatrix, a proud sponsor of this event, is always delighted to participate. BDAL is dedicated to improving the quality of life for persons affected by hemophilia and other inherited

## MATRIX ON THE MOVE



bleeding disorders through advocacy, consumer services, education and research. This fundraising event allows anyone and everyone an opportunity to get together to support the Illinois bleeding disorder community. This all-inclusive event brings so many of us in the community together, making this fundraiser successful on all levels. Glistening in the summer heat, we all crossed the finish line having enjoyed a wonderful workout for a fantastic cause!

## KANSAS

### Dan Hicks

Informing and empowering yourself is very important these days, especially when you're affected with a bleeding disorder. Knowing what to do, when and how to do it can be very difficult in times of elevated stress. Regulating stress can be as easy as building your network with others that are also affected. That's where being a part of your local chapter and surrounding yourselves with others you can turn to for advice or even just a shoulder to lean on, comes into play.



Brothers Omar and Diego.

Midwest Hemophilia Association (MHA) hosted its annual **Family Education Weekend** September 15<sup>th</sup>-16<sup>th</sup> at the Marriott in Overland Park. Families from all over Missouri and Kansas united to build their networks and seek education on a

wide array of topics. This meeting was packed full of informative presentations from manufacturers and other organizations, and included: *Bioverativ's Gateway to Education*; Genentech's *The Science of Hemophilia A: A Changing Landscape*; Bayer's *Factor Finger Print*; Novo Nordisk's *Learning from Experiences of Living with Hemophilia B*; Grifols' *Von Willebrand Disease*; Shire's *A Hello Talk-Resilience*; CSL Behring's *Common Factors Trivia*; Pfizer's *Planning Ahead-Aging with Hemophilia*; and Aptevo's *Factor in the Family*.

The weekend predictably ended with new bonds and relationships formed. Each year is another opportunity to connect with someone new. Bouncing ideas of advocacy off one another to better strengthen the community is one of the most important aspects of these spirited gatherings. Many thanks to MHA's leadership for hosting such a worthwhile event. We look forward to being part of it for years to come!

## MAINE

### Cheryl Ashmore and Justin Levesque

A foggy morning in scenic mid-coast Maine was the setting for Hemophilia Alliance of Maine (HAM) **Hike4HAM NHF Unite Walk** September 15<sup>th</sup>. The Hike4HAM is in fact, not a walk, but a moderately challenging 3-mile hike up a coastal mountain. One



Jill and Carrie

hiker related, "The hike up is hard, but it goes quickly when I'm surrounded by other families doing the same thing for the same reason." After folks had a chance to visit exhibit booths, have coffee and hear from the chapter's leaders, people of all ages made their way up Mount Battie in Camden.

At the summit, those gathered watched the fog burn off the harbor and village 800 feet below. The view is spectacular, truly one of Maine's treasures. Volunteers arrived to shuttle hungry kids and parents to a waiting picnic at the base of the mountain. After lunch, kids played Frisbee and soccer on the grounds, while parents had an opportunity to sit with each other, have coffee and visit for a spell. The 2018 Hike4HAM didn't disappoint – a beautiful day to be on top of a mountain with friends and family!

## NEVADA

### Kelly Gonzalez

From the early morning setup September 15<sup>th</sup> to the mid-morning walk and sunny afternoon activities,



A beautiful family - Andrés, Maureen, Sofia and Marco.

Southern Nevada's **Unite for Bleeding Disorders Walk** was nothing short of spectacular! A morning breeze kept walkers cool as they strolled along a small pond at Craig Ranch Park in the city of Las Vegas. Strong teams brought in huge donations to the tune of over \$50,000 to make the walk remarkably successful! The afternoon proceeded with opportunities to visit industry booths, watch kids play in a safe environment and for parents to marvel at how far treatment for bleeding disorders have come. Thank you to the Nevada Chapter NFH, Hemostasis and Thrombosis Center of Nevada, sponsors and participants for a great activity!



## TENNESSEE

### David Tignor and Stephen Lawrence

Ready, Set, Go! The Tennessee Hemophilia and Bleeding Disorders Foundation hosted its **1<sup>st</sup> Annual Blazin' for Bleeders 5k Run and Fun Walk** at Two Rivers Park in Nashville September 15<sup>th</sup>. Promptly at 8:15, Sam Doughty, THBDF Board President, took the mic and gave a hardy "On your mark, get ready, set, GO!" and the 5k runners were off! Shortly thereafter, the *Fun Walk* was underway as well.



Tara and Nova get their Walk on!

With over 200 registered for the event, community members, industry representatives and dedicated volunteers filled the park. This event proved to be a great opportunity for bleeding disorders awareness and successfully raised funds to assist the efforts of THBDF as they support the Tennessee bleeding disorders community. We are honored to have been part of this inaugural event!



## MASSACHUSETTS

### Cheryl Ashmore

As the summer days faded into crisp mornings this past September 21<sup>st</sup>-23<sup>rd</sup>, 43 New England women took to the woods to recharge spirits and renew friendships. The New England Hemophilia Association (NEHA) sponsored this popular **Women's Retreat** just outside Essex, a small Massachusetts seacoast village. The property's quiet shady trails, reflecting ponds and

breathtaking sculptures carefully set into the landscape lent an aura of both introspection and discovery to the weekend.

NEHA brought their best game, adding even more significant programming to an event already known for its value to the community. The weekend was a brilliant cascade of activities, each building on the previous to create a thoughtful, deliberate space for the women to stretch out of their comfort zones. Beginning with a customized group-focused workshop early Friday night, the facilitators from *Next Step* gently guided the ladies into creative sessions and free time that brought a balance of laughter and tears, fun walks and serious talks. One attendee said it just right, "It was the perfect blend of refreshment and rejuvenation, and a catalyst to personal growth. I am so grateful for the support of NEHA and our Wicked Strong Family!"

## NORTH CAROLINA

### Xaviette Pointer-Kincy

Hemophilia of South Carolina (HSC) hosted its annual **Keeping It Coastal Family Camp** September 21<sup>st</sup>-23<sup>rd</sup> at Marina Inn Grand Dunes Golf Resort in Myrtle Beach. The goal of this retreat is to unite the bleeding disorders community through educational programming and family friendly social activities. The various topics presented included *Legal Rights for Bleeding Disorders*, *Growing Through Life Changes* and *Appreciating Diversity Within the Bleeding Disorders Community*. Flooding from Hurricane Florence caused the event to end earlier than planned to ensure everyone's safe return home. Families were able to enjoy time at the beach and the opportunity to learn the latest information in the bleeding disorders community. Thank you to HSC for hosting this enjoyable event!



Amirah and Edwin ham it up!



Smile for the camera! Edwin with Xaviette.

## MATRIX ON THE MOVE



### CALIFORNIA

#### Cindy Picos

The Central California Hemophilia Foundation's (CCHF) **1<sup>st</sup> Annual Unite For Bleeding Disorders Walk** was a huge success raising almost \$30,000 benefiting the chapter's programs. The walk was held Sunday, September 23<sup>rd</sup> at Gibbons Park in Sacramento, where 175 people arrived to participate and have fun!

Attendees were treated to a carnival-style event with various industry sponsors hosting mini events at their individual booths. Families were able to enjoy bounce houses and an array of treats

including snow cones, popcorn and more. Lunch for the event was sponsored by BioMatrix. We applaud Lynne Kinst, CCHF Education Director for all her efforts organizing this event!



## UPCOMING EVENTS

### NOV. 12, 2018 FLORIDA

Florida Hemophilia Association  
305-235-0717

floridahemophilia.org

#### **29<sup>th</sup> Annual Swing for the Kids Golf Tournament**

Lago Mar Country Club

Ft. Lauderdale

### NOV. 16, 2018 TENNESSEE

Tennessee Hemophilia Bleeding Disorders Foundation

615-900-1486, thbdf.org

#### **Royal Gala**

Loveless Barn; Nashville

### NOV. 17, 2018 VIRGINIA

Virginia Hemophilia Foundation  
804-740-8643

vahemophilia.org

#### **Family Weekend Event**

Great Wolf Lodge

Williamsburg

### NOV. 17, 2018 WEST VIRGINIA

West Virginia Chapter of NHF

681-212-9255, wvnhf.org

#### **Annual Meeting**

Location TBD

### NOV. 18, 2018 NEW YORK

New York City Hemophilia Chapter

212-382-2974

nyhemophilia.org

#### **Education Day**

Crowne Plaza Times Square

New York City

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

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

## TIME FOR FUN!

ANSWERS TO PUZZLES ON PAGE 35



1. SYRINGE
2. NEEDLE
3. TOURNIQUET
4. GAUZE PAD
5. ALCOHOL PAD
6. TAPE
7. BLEED
8. INFUSION
9. HEMOPHILIA
10. R.I.C.E.
11. PORT
12. TARGET JOINT

**NOV. 30-DEC. 1, 2018 LOUISIANA**

Louisiana Hemophilia Foundation  
225-291-1675, ahemo.org  
**What A Circus! - 42<sup>nd</sup> Annual Meeting  
and Educational Symposium**  
Renaissance Hotel  
Baton Rouge

**DEC. 1, 2018 CALIFORNIA**

Central California Hemophilia  
Foundation  
916-448-0370, cchfsac.org  
**Annual Holiday Party**  
Gibbons Park; Carmichael

**DEC. 1, 2018 NEVADA**

National Hemophilia Foundation,  
Nevada Chapter  
702-564-4368, hfnv.org  
**Annual Family Conference and  
Holiday Celebration**  
East Las Vegas Community Center  
Las Vegas

**DEC. 1, 2018 NORTH CAROLINA**

Hemophilia of North Carolina  
800-990-5557  
hemophilia-nc.org  
**Annual Winter Party**  
Charlotte Motor Speedway  
Concord

**DEC. 1, 2018 OHIO**

Northern Ohio Hemophilia Foundation  
216-276-3649, nohf.org  
**Holiday Extravaganza**  
Tower City; Cleveland

**DEC. 1, 2018 PENNSYLVANIA**

Eastern Pennsylvania Chapter NHF  
484-445-4282  
hemophiliasupport.org  
**Holiday Party**  
Cannstatter Volksfest Verein  
Philadelphia

**DEC. 5, 2018 NEVADA**

NHF, Nevada Chapter  
702-564-4368, hfnv.org  
**Elko Family Day and Winter  
Celebration**  
Hilton Garden Inn; Elko

**DEC. 6, 2018 NEVADA**

NHF, Nevada Chapter  
702-564-4368, hfnv.org  
**Reno Family Day and Winter  
Celebration**  
Hunsberger Elementary School  
Reno

**DEC. 8, 2018 CALIFORNIA**

Hemophilia Foundation of Southern  
California  
626-765-6656  
hemosocal.org  
**Snowflake Festival**  
Santa Ana Zoo; Santa Ana

**DEC. 8, 2018 ILLINOIS**

Bleeding Disorder Alliance Illinois  
312-427-1495  
bdai.org  
**Holiday Party**  
William Tell Holiday Inn  
Countryside

**DEC. 8-9, 2018 MAINE**

Hemophilia Alliance of Maine  
207-631-7550  
mainehemophilia.org  
**Winterfest**  
Samoset Resort; Rockland

**DEC. 8, 2018 SOUTH CAROLINA**

Hemophilia of South Carolina  
864-350-9941  
hemophiliasc.org  
**Annual Holiday Party**  
Embassy Suites; Columbia

**DEC. 8, 2018 VIRGINIA**

Hemophilia Association of the  
Capital Area  
703-352-764  
hacacares.org  
**Holiday Gathering**  
Community Center; Falls Church

**DEC. 9, 2018 CONNECTICUT**

Connecticut Hemophilia Society  
860-495-0006, cthemophilia.org  
**Annual Meeting**  
Crowne Plaza; Southbury

**DEC. 15, 2018 ILLINOIS**

Blood Bond Bleeding Disorder  
Network  
773-653-1963  
bloodbond.org  
**Holiday Meeting**  
Midway Holiday Inn; Chicago

**DEC. 16, 2018 MARYLAND**

Hemophilia Foundation of Maryland  
410-661-2307  
hfmonline.org  
**Holiday Breakfast with Santa**  
Gaylord Resort & Convention Center  
National Harbor

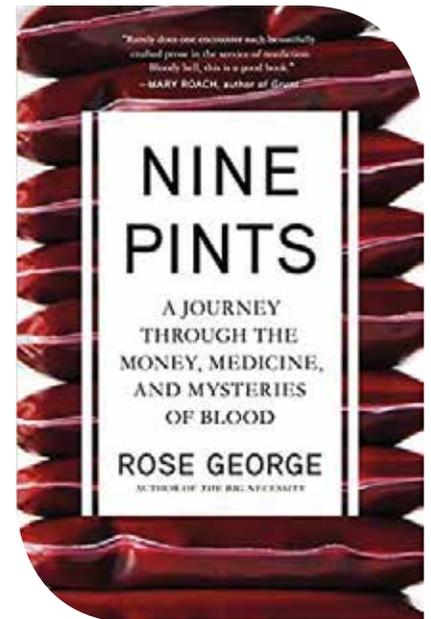


## BOOK REVIEW

# NINE PINTS

A JOURNEY THROUGH MONEY,  
MEDICINE, AND MYSTERIES OF BLOOD

BY ROSE GEORGE



BY SHELBY SMOAK

There's an old riddle that asks: What travels 12,000 miles but never goes anywhere? The answer: Blood. By the time it travels the though our veins, arteries and capillaries—it has journeyed 12,000 miles. This is a statistic among many found in Rose George's *Nine Pints: A Journey Through Money, Medicine, and Mysteries of Blood*. Her non-fiction investigative reporting carries the reader through a plethora of topics - blood donation and transfusion, leeches, HIV, hemophilia, menstruation, trauma, and even vampirism. *Nine Pints*—whose title refers to the number of pints of blood circulating in our bodies—is part history, part essay, and part investigation. It is a conversational narrative whose brisk-pace flows along faster than, well, blood.

One of the most rewarding chapters concerns leeches. The bloodsucking worm rose to prominence in an era that believed illness resulted from too much blood. Thus, began bloodletting, by which the leech gained importance. In 1816, the King of England endured 36 leeches when he fell ill. In 1825, the Russian Emperor begrudgingly accepted leeches on his head when he caught a fever. However, the leech took off in France, when a surgeon in Napoleon's army encouraged leeches as therapy for trauma and inflammation.

By 1833, France was importing 41.6 million leeches. George brings this fascinating history to the present by visiting the British company Biopharm who breeds and exports leeches for medical purposes. In 2004, the FDA crowned leeches as "a marketable medical device," and today, leeches are used for salvaging body parts such as fingers and ears. According to *Nine Pints*, in cases of severe bleeding in areas with many tiny capillaries, only a leech will do.

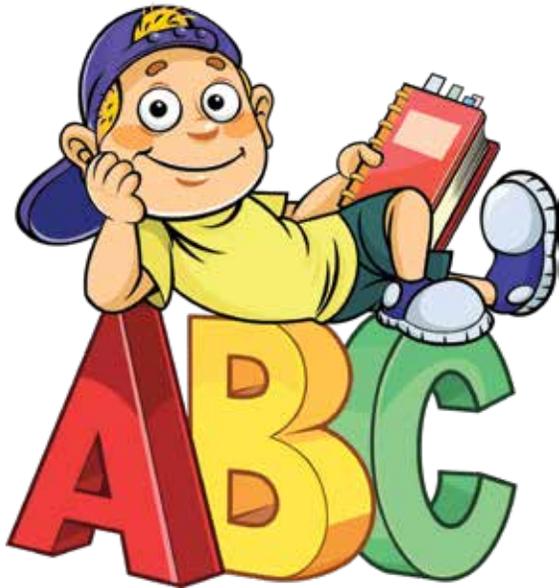
One section profile the Vaughans, the couple who started the world's first blood donor pool and who

ushered in the blood collection system. George visits South Africa where she investigates circumstances that contribute to a high HIV prevalence. *Nine Pints'* chapter on plasma, *The Yellow Stuff*, oscillates between people dependent on the blood product—those with hemophilia—and those responsible for making it. Hemophilia crippled its sufferers until factor plasma products arrived as therapy. But then, as countless sources tell us, these products were infected with HIV. George revisits the unsavory practice by plasma manufacturers of recruiting donations from U.S. prisoners, and she provides evidence of the manufacturers' knowledge of HIV and hepatitis C in their products during the 1980s. An ethical debate of paid versus volunteer donations percolates in this section, with George claiming paid donors "are more likely to lie" about their health. She suggests the U.S. may be most at risk since it pays the most for donations and allows people to donate more frequently than any other country.

*Nine Pints* is a fascinating read. George invites the reader to learn about figures such as the "Menstrual Man" who invents an affordable pad-making system for disenfranchised women, and Jesse Karmazin who runs a company that transfuses "young blood" into willing patients. Always able to uncover the remarkable nugget within her work—such as the Chinese counterfeit sanitary-napkin ring whose operation netted \$22.7 million before its end—*Nine Pints* is full of surprises.

George's tightly-woven research propels the reader through the stories of blood—its wholeness, its parts; its relationship to therapy and disease, to people and places. A certain joy exists in reading a book so packed with unique and vital information. The book delivers on its promise: this superbly researched work is indeed a captivating journey through the histories and mysteries of blood.

# TIME FOR FUN!



George has a bleeding disorder. He's great at lots of things like self-infusing, playing guitar and writing stories, but he isn't a great speller. He made a list of things related to his bleeding disorder, but every word on his list is misspelled by one letter. Can you fix George's list? Remember, you should not move any letters; just change one letter to reveal the correct word.

Note: All the words are related to having a bleeding disorder. Answers are on page 32.

1. SYRINLE                      1. \_\_\_\_\_
2. DEEDLE                     2. \_\_\_\_\_
3. JOURNIQUET               3. \_\_\_\_\_
4. GAUZE PAK                4. \_\_\_\_\_
5. ALCOHOL PIPE            5. \_\_\_\_\_
6. TAME                        6. \_\_\_\_\_
7. BLEEP                      7. \_\_\_\_\_
8. INFUTION                 8. \_\_\_\_\_
9. HEMOFHILIA             9. \_\_\_\_\_
10. M.I.C.E.                 10. \_\_\_\_ . \_\_\_\_ . \_\_\_\_ . \_\_\_\_ .
11. SORT                      11. \_\_\_\_\_
12. TARGET POINT           12. \_\_\_\_\_

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

## Sudoku!

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

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

# Matrix Health Group

A BIOMATRIX<sup>SpRx</sup> Company

Corporate Office  
3300 Corporate Ave., Suite 104  
Weston, Florida 33331

Toll Free: 877-337-3002  
Office: 954-385-7322  
Office Fax: 954-385-7324

[www.matrixhealthgroup.com](http://www.matrixhealthgroup.com)  
[fb.com/matrixhealthgroup](https://fb.com/matrixhealthgroup)



## DEDICATED TO MAKING A DIFFERENCE

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

### BIOMATRIX FAMILY OF COMPANIES

