# BIOMATRIX

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**NEWS** 

### DEDICATED TO MAKING A DIFFERENCE

WINTER 2020 VOLUME 15 | ISSUE 1 Everyone smiles in the same language.

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### ABOUT BIOMATRIX

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

BioMatrix offers accredited, comprehensive specialty pharmacy and support services for a range of chronic health conditions. Our clinicians and support staff offer a tailored approach to every therapeutic category, improving quality of life for patients and producing positive outcomes along the healthcare continuum.

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

### **MISSION + VISION**

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

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

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

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

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

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

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

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

### **FINE PRINT**

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

The purpose of BIOMATRIX NEWS is to provide information such as current news, upcoming events, educational matters, personal stories, and a variety of opinions and views on topics of interest to the bleeding disorders community. The information and opinions printed in this newsletter do not necessarily reflect the views and opinions of the partners, employees, or others associated with BIOMATRIX NEWS or that of BioMatrix. Health-related topics found in BIOMATRIX NEWS are for informational use only and are not intended to take the place of treatment or medical advice provided by healthcare professionals or hemophilia treatment centers. Please consult with healthcare professionals when medical questions arise.

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### A NOTE FROM THE EDITOR

#### Dear Readers:

With the flurry of last year's holidays behind us, we set our sights on new beginnings and realizing our resolutions for 2020. This is a special year by the fact that the first two digits match the second, and for most of us on this great Earth – a once-in-a -lifetime experience!

What's in store for your new year? At BioMatrix, the year started with a bustle of activity as our corporate office in Florida moved 11 miles away to a new location! With our recent company growth, we were needed a larger, more efficient space.

As we begin the 15<sup>th</sup> year of our newsletter, we continue to strive to make each issue interesting, informative and useful to the bleeding disorders community. Having said that, if there is a topic you would like to hear about, we are always open to your ideas as we welcome and encourage feedback! Please reach out to your Regional Care Coordinator, email us at info@biomatrixsprx.com or send your ideas directly to me.

We hope 2020 brings you *more* of everything good *more* happiness, *more* laughter, *more* family and friends, *more* kindness, *more* wonderful memories, *more* prosperity, *more* good health, *more* peace, *more* joy... I could go on and on, but above all, *more* love!

Happy Special New Year!

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

### BIOMATRIX PROUDLY ANNOUNCES THE 2019/2020 MEMORIAL SCHOLARSHIP RECIPIENTS!

In 2019, BioMatrix offered six \$1,500 scholarships for bleeding disorders community members seeking higher education. Our program has awarded \$50,000 to 44 students since 2013. These scholarships honor the memory of several individuals who impacted the bleeding disorder community in unique ways. BioMatrix partners with the Hemophilia Federation of America for administrative support and independent, thirdparty evaluation of applicants.

It is with great pleasure we announce the 2019 recipients of our Memorial Scholarship Program. Thank you to everyone who applied and we wish you great success in your bright futures! Without further ado, we introduce you to our scholarship recipients!



### LENA COOK

Mark Coats Memorial Scholarship Recipient Junior, California State Polytechnic University, Major: Kinesiology

Growing up as a female with hemophilia, Lena Cook encountered many challenges related to her diagnosis. "I've had to fight continuously for treatment and to keep my diagnosis," she shares. Lena learned to advocate for herself and is determined to help others. Volunteering within the bleeding disorders community has ultimately led her to pursue a career in healthcare, where she is determined to help others "live the healthiest lives they possibly can."

Congratulations, Lena!



### **KENADIE HAMBLIN**

Millie Gonzalez Memorial Scholarship Junior, Utah Valley University, Nursing

Von Willebrand Disease has been a positive influence in the life of Kenadie Hamblin. While it presented challenges growing up, her parents guided her to speak up and advocate for herself. The bleeding disorders community is where she ultimately met her husband and two best friends. "This community has been a place where I have always felt supported and encouraged to grow," she shares. Today, Kenadie has her sights on becoming a pediatric hematology nurse.

Congratulations, Kenadie!



### **DANIEL LIEDL**

Ron Niederman Memorial Scholarship Recipient Doctoral Degree, West Virginia University; Sociology

By obtaining a Ph.D. in Sociology, Daniel Liedl plans to teach at a university and use sociological research to identify the needs of rare genetic disorders in rural communities. Understanding that rural healthcare facilities are not often knowledgeable in bleeding disorders and that government agencies utilize sociological research to identify needs, Daniel states, "By researching rural communities and learning what is missing and/or required to address these issues, future generations can avoid the hardships of the past."

Congratulations, Daniel!



### **ISAIAH REEVES**

Tim Kennedy Memorial Scholarship University of Iowa Carver College of Medicine: Medicine

Greatly influenced by the dedicated medical personnel who treated his hemophilia throughout his childhood, Isaiah Reeves is inspired to pursue a doctoral degree to become a pediatric hematologist/oncologist. Isaiah shares, "As a doctor, I will use my personal experiences, abilities and knowledge to support and enrich the lives of children. I will seek to emulate physicians from my own life who have been so impactful in making me the person I am today."

Congratulations, Isaiah!

### **GRACE REZNIKOV**

Mike Hylton Memorial Scholarship Recipient Sophomore, Virginia Tech; Neuroscience

A loving relationship with her stepmother was a vital component in Grace Reznikov's life. When her stepmother had a son with hemophilia, Grace realized how inequitable life could be, "What resonates with me most is the undeniable strength of the human spirit." Grace believes the experience made the family stronger, "Our more worldly outlooks can hopefully inspire those around us to do good and, more than anything, love unconditionally, because nothing is guaranteed."

Congratulations, Grace!



### LAVANG VU

Joe Holibaugh Memorial Scholarship Recipient Freshman, University of Dallas, Biology and pre-medical studies, Minor Music

Guiding Lavang Vu away from sports, his parents encouraged music. Playing various instruments and singing was a way to relieve the stress of living with hemophilia; it grew into a passion resulting in achieving state-level success. "I used the challenges that hemophilia gave me as a way to make my music making better." After suffering a severe infection resulting in a 49-day hospitalization, Lavang's life direction shifted and he now aspires to become a pediatric hematologist.

Congratulations, Lavang!

The 2020–2021 school year application process opens March, 2020 and will run through August 1, 2020. Apply online by visiting: http://bit.ly/BioMatrix-Scholarship



**Joe Holibaugh (1971-2006)** \$1000 Scholarship For MEN and WOMEN with hemophilia AND an Inhibitor



**Tim Kennedy (1962-2011)** \$1000 Scholarship For MEN with hemophilia



Millie Gonzalez (1953-2001) \$1000 Scholarship For WOMEN with hemophilia or von Willebrand Disease





**Mike Hylton (1945-1998)** \$1000 Scholarship For MEN with hemophilia or VWD and their immediate family members

For MEN with hemophilia or VWD and

their immediate family members

Ron Niederman (1950-1999)

\$1000 Scholarship



Mark Coats (1956-1963) \$1000 Scholarship For MEN and WOMEN with hemophilia

### IS IT THE FLU? IS IT A COLD?

### BEING SICK IS NOTHING TO SNEEZE AT.

By Nanette Vaughn, RN and Maria Santucci Vetter



### NO ONE WANTS IT, YET EVERY FALL AND WINTER IT REARS ITS UGLY HEAD. HOW CAN YOU TELL IF IT'S INFLUENZA AND WHAT CAN YOU DO ABOUT IT?

Influenza (flu) is a highly contagious respiratory virus that is easily spread among people typically through sneezing, coughing, talking or even just by breathing. The virus can be transmitted 24 hours before a person exhibits any symptoms.

The virus can also be spread by touching contaminated surfaces such as countertops or door handles on which the virus can live up to 48 hours. Symptoms of the flu can range widely from mild, cold-like warning signs to symptoms so severe that medical intervention is necessary. Sadly, in some cases, the flu proves to be fatal.

Most healthy adults don't need medical treatment for the flu. However, medical care should be sought



without delay for those whose symptoms are severe or who are in a high-risk group: children under 5, adults over 65, are pregnant, immune-compromised, very obese, live in a nursing home, have lung disease or live with a chronic condition such as diabetes, heart, liver or kidney disease, or asthma.

Physicians may want to treat such patients with antiviral medication. The most commonly prescribed flu medications are antivirals such as Tamiflu, Relenza, Rapivab and Xofluza. These drugs are most beneficial if given within 48 hours of the onset of symptoms. They can shorten the illness by 1 or 2 days, but more importantly, they can prevent complications such as pneumonia, sinusitis, bronchitis, heart problems and ear infections. At first, the symptoms of the flu

resemble those of a cold. The difference is flu symptoms begin abruptly and progress quickly.

Having the flu can cause additional problems for those with a bleeding disorder. For example, violent vomiting or coughing can cause a bleed in abdominal or back muscles, or bleeding in the throat. Harsh nose blowing can lead to a bloody nose.

Some providers will take a nasal or throat swab to do a rapid influenza diagnostic test. Results take only 15-30 minutes, but falsenegative results are common. Viral cultures, also obtained by swab, are more accurate but take 1- 8 hours to get results. Important to note, a positive flu test is not necessary to be prescribed an antiviral. Physicians will make that decision based on the severity of symptoms and any underlying risk factors.

Once someone has the flu, protocol calls for drinking plenty of fluids, avoiding contact with others, frequent handwashing and getting plenty of sleep. Stay home while feverish and for 24 hours after the fever has

subsided. And it's not just a myth or tall tale - chicken soup does help. Some scientists believe it has anti-inflammatory properties, plus the warmth can help soothe the throat and break up sinus congestion. As

a bonus, try adding garlic, pepper or curry powder to your soup. These spices help thin mucous and garlic helps rev up your immune system.

Warm and cool mist vaporizers are equally effective and can help ease congestion. To avoid accidental burns, a cool-mist vaporizer is safer in a home with small children. With any vaporizer, it is important to wipe it down daily with a solution of 9-parts water and 1-part bleach to prevent the growth of bacteria and mold.

There are multiple over-the-counter medications and treatments specifically for flu or cold symptoms. Be aware of combination medications. Many contain antiinflammatories like aspirin or ibuprofen.

If you have a bleeding disorder these should be avoided. If you are unsure about what to take, consult with your doctor or pharmacist regarding ingredients



that may cause bleeding. Additionally, many people benefit from saline nasal rinses. Sleeping with your head elevated may also be helpful.

The best way to treat the flu is to avoid getting it in the first place. Though not entirely preventable, simple habits can help reduce your exposure and can help you not spread it if you already have symptoms:

# Having the flu can cause additional problems for those with a bleeding disorder

• Get the flu vaccine – it's the number one way to prevent the flu! Everyone over 6 months old should get a flu vaccine! The vaccine will last about 6 months and should be repeated every year.

Vaccines are available at your doctor's office, neighborhood pharmacies, urgentcare centers, county health departments, college health centers, even several grocery stores and supermarkets offer flu shots.



The CDC offers an online search-by-zip code service to find locations in your area offering flu vaccines: https://vaccinefinder.org/

- Wash your hands frequently with soap and water for at least 20 seconds or use alcohol-based hand sanitizer if soap and water are not available
- Cover a sneeze or cough in the crook of your elbow or use a tissue and toss it in the trash
- Keep hands and fingers away from your eyes, nose and mouth
- Stay home if you are sick
- Disinfect countertops, surfaces and handles (doors, toilet, sink, fridge, etc.) with germ-killing products such as Lysol or a bleach mixture
- Avoid crowds
- Avoid sick people
- Practice a healthy lifestyle to help keep your immune system strong

Following is a chart to help identify the flu versus a cold and when to seek treatment.

FIGHT THE FLU!

### FLU OR COLD... HOW CAN YOU TELL?

SYMPTOMS:	FLU vs	COLD			
Onset of Symptoms	Abrupt, usually multiple symptoms	Gradual, often starts with 1 symptom			
Fever	Usual for 3-4 days (100-102 degrees)	Rare, usually lower grade temp			
Aching Muscles, Pain	Usual, often severe	Sometimes, milder			
Chills and Sweats	Common	Uncommon			
Fatigue/Weak	Usual, can last up to 3 weeks	Sometimes a couple days			
Extreme Exhaustion	Usual, at the beginning of the illness	Never			
Sneezing	Sometimes	Common			
Nasal Congestion	Sometimes	Common			
Sore Throat	Sometimes	Common			
Chest Discomfort/Cough	Common, can be severe	Sometimes, mild/moderate, hacking			
Headache	Common	Sometimes/Rare			
Vomiting/Diarrhea	Sometimes, more common in children	None			



### TREATING A FLU

- Consider a prescription flu medication
- Drink lots of fluids though limit caffeinated drinks
- Get plenty of rest
- Humidify the air
- Treat fever and aches with over-the-counter pain relief medicine; non-aspirin for those with a bleeding disorder and no aspirin for children under 19
- Ease a cough or sore throat with lozenges

### SEVERE WARNING SIGNS NECESSITATING MEDICAL TREATMENT

### **ADULTS:**

- Labored breathing or shortness of breath
- Persistent fever
- Pain or pressure in the chest or abdomen
- Sudden dizziness
- Confusion
- Severe or persistent vomiting
- Persistent coughing and congestion
- Persistent headache
- Symptoms improve, then return with fever and worsening cough

### **CHILDREN:**

- Labored fast breathing
- Bluish skin color
- Fever with rash
- Not drinking enough fluids
- Lack of appetite
- Not waking up or interacting
- Symptoms improve, then return with fever and worsening cough

### **INFANTS:**

- Inconsolable crying or irritability
- No tears when crying
- Significant reduction in wet diapers (signs of dehydration)
- Symptoms improve, then return with fever and worsening cough



References:

CDC - website https://www.cdc.gov/flu/prevent/index.html WebMD - https://www.webmd.com/cold-and-flu/default.htm Mayo Clinic - https://www.mayoclinic.org/diseases-conditions/flu/symptoms-causes/syc-20351719

### BIOMATRIX ATTENDS NATIONAL HEMOPHILIA FOUNDATION'S 71<sup>st</sup> ANNUAL BLEEDING DISORDERS CONFERENCE

OCTOBER 3 - 5, 2019 ANAHEIM, CALIFORNIA



**By Justin Lindhorst** 

The bleeding disorders community is entering a new era. Novel therapies are changing how bleeding disorders are managed, outreach to underserved populations is increasing, and new challenges to healthcare access are emerging. The National Hemophilia Foundation's Bleeding Disorders Conference is a perfect venue for the community to discuss, plan, and navigate toward a better future for patients with bleeding disorders.

For the 71<sup>st</sup> year running, patients, caregivers, chapters, healthcare professionals, and other industry representatives gathered for three days of learning, networking, and community building. BioMatrix is proud of our role in the bleeding disorders community and this year we continued our longstanding support for the National Hemophilia Foundation's annual conference. The exhibit hall was bustling with activity. Attendees had the opportunity to connect with BioMatrix Regional Care Coordinators to discuss our commitment to the bleeding disorders community and



learn how our specialty pharmacy services are making life easier for patients and caregivers. "Connecting with the community is the best part of my role with BioMatrix," Regional Care Coordinator Rich Vogel noted. "Knowing our services are helping provide the tools and resources for patients to maintain and improve their health is a feeling that cannot be beaten."

Visitors to our booth also had the unique opportunity to participate in a one of a kind virtual reality experience. Donning a VR headset, participants used a virtual reality



program to draw, paint, and create a world born of their imagination. The activity was a nod to the new reality the community is entering with new tools, resources and means to paint a brighter tomorrow.

Whether a patient, caregiver, significant other, medical professional or chapter staff member, NHF provided educational sessions for everyone. Tailoring programming in 12 distinct tracks allowed members to attend sessions most relevant to their specific circumstances.

From *Hemophilia 101* to women with bleeding disorders, rare bleeding disorders, advocacy, new therapies, physical therapy and everything between, the educational sessions were designed to bring the attendees up to speed with current events and latest news in the bleeding disorders community. The meeting wrapped up with an amazing final night event. Everyone was provided the opportunity to step outside of conference rooms and hotel lobbies into the welcoming open air of California.

A live band played crowd favorites, kids enjoyed crafts and face painting as attendees were treated to an array of food from around the world. It was a wonderful opportunity for the community to celebrate together one last time before heading home.

BioMatrix was proud to participate in the 71<sup>st</sup> Bleeding Disorder Conference. We greatly enjoyed greeting old friends and making new connections. Welcome new readers!

Next year, the 72<sup>nd</sup> Annual Bleeding Disorders Conference will convene in Atlanta, Georgia in August. We hope to see you there!









For the fifth year running the Teen Impact Awards ceremony was held on the first night of the NHF conference. Founded by the creator of "Stop the Bleeding," Patrick James Lynch, the program provides well-deserved recognition for young leaders in the bleeding disorders community. Check out this year's honorees at <u>https://www.teenimpactawards.com/</u> Posing with Patrick James Lynch, *Matthew Stone*, son of our very own Regional Care Coordinator Terry Stone, is a recipient of a Teen Impact Award for leadership.



# BLOOD WORK V

This year BioMatrix continued their founding support of the Blood Work art exhibition. Blood Work is an annual program by FOLX – an organization aiming to promote the inclusion, visibility and empowerment of people from diverse backgrounds within the bleeding disorders community. This year the creative talent of the community was prominently displayed in the center of the NHF exhibit hall.

"It's incredible to see this project come together every year," shared Justin Levesque, a founding member of

> FOLX. "Artistic expression provides a positive outlet and coping mechanism for our community. Blood Work helps celebrate that expression while raising awareness for the unique and collective experience of life with a bleeding disorder. We're thankful BioMatrix has been so supportive of the Blood Work program."

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### NATURAL BORN ADVOCATE

**BY SHELBY SMOAK, PH.D.** 

When I am among friends in the bleeding disorders community and we are talking about healthcare issues, I often remark that anyone with a chronic illness is a natural-born advocate. To survive, persons with chronic illnesses have to find their voice and must speak up for the things they need. A failure to do so is often a failure of getting their healthcare needs met.

I think, however, there is sometimes confusion about what is meant here by "advocacy." In its plainest definition, advocacy is, according to Merriam-Webster, "the act or process of supporting a cause or proposal." Immediately, we envision the grassroots letter-writing campaign, or the suit and tie trips to state legislatures and Congressional halls. More often than not, however, advocacy is a very personal cause and has nothing to do with state capitals nor Washington DC. Often, advocacy is a very small, but invaluable thing.



This year, two years beyond my total knee replacement and ten years from my total hip replacement, I advocated for a permanent handicapped placard. After I had knee replacement surgery in 2017, I was given a 6-month placard by the orthopedic surgeon but was denied

HANDICAPPED PARKING

SPECIAL PLA REQUIRED

UNAUTHORIZED VEHICLES MAY BE REMOVED

AT THE OWNERS

ATE

### ADVOCACY: THE ACT OR PROCESS OF SUPPORTING A CAUSE OR PROPOSAL

renewal, even though I was still experiencing bleeding in the tissue surrounding the new joint. The orthopedist replied that my mobility issues were "no longer related to his department." Surgery had turned out great and I was, in his opinion, "recovered"– his words.

I turned to my hemophilia treatment center (HTC), but they initially resisted issuing one. When they saw me, I was often at my best: mobile without any active knee or ankle bleeds. In other words, I walked just fine and did not appear to need special parking accommodations. Also, they had the successful advocacy work of The American Association of Persons with Disabilities (AAPD), which had changed state policies for issuing handicapped placards. The AAPD had been raising awareness about the abuse of handicapped placards and sought tighter restrictions. Disabled persons, they advocated, were losing valuable handicapped spots to able-bodied persons who abused the privilege for personal or financial gain. States responded with greater scrutiny and higher penalties. In fact, falsifying information to receive a placard in New Jersey can lead to a \$10,000 fine and up to 18 months in jail. So clearly, AAPD's advocacy worked. Yay for them, but their action

resulted in a counter-reaction. Issuers (i.e. doctor's offices) of handicapped placards were now on guard, and, as I believed in my case, were blocking me from getting the placard I needed. So, I had to advocate.

I compiled my bleed logs over the past year and counted the number of bleeding episodes, especially those in my knee and ankle joints, and the average length of recovery time before I was able to walk normally again. Then I did perhaps what is one of the hardest things for any advocate to do: I initiated the discussion about my cause. This cause is difficult to bring up for other reasons. Is it truly every boy's dream to one day have to fight for a handicapped placard? To have to admit such physical limitations? So, overcoming those hurdles, admitting our weaknesses or needs, is its own obstacle to advocacy. However, the time was upon me, and I knew what needed doing for those bad bleed days.

While at my yearly HTC appointment, I brought up the issue to my doctor and nurse and armed with my data, I laid out my case. I wanted the handicapped placard for times when I leaned on a cane, was aided with an Ace bandage and was in pain. I saw the placard as another tool I would need to recover. I did not intend to always use the placard, I said. In truth, the additional walking on days I could is good for me: it was more steps, more exercise, and could improve my joint health, but I returned to those days when my joints failed me and when parking a wee bit closer to the door would mean everything in helping me hurt less and heal.

The doctor nodded and let out a tiny exhale. "Ok," he said. "I see your point and agree." He said he'd sign the DMV form. This was a big win! Celebration was upon me. "I've done it," I said to myself! As I was soon to discover, my advocacy wasn't yet over.

I emailed the Virginia DMV form to the doctor's office. They filled it out and returned it via email. I printed it and went to the local DMV where I waited an hour and a half before my number was called. I was having a good day as I walked to the window and laid out my completed and signed form for a permanent handicapped placard. The lady looked me over. She held my form up to the light and gazed upon it. Then she studied me.

"Is this an original signature?" she asked.

"Yes, ma'am." I shifted my feet. "From my doctor."

"Um-hum." She lay the sheet on her desk. "Is it a copy?"

"No. It's an original signature, ma'am."

She cleared her throat. "No. I mean how did you get it?"

"Email," I said. "The doctor emailed the completed form to me."

"I see." She pushed the form to me. "Well, we have to have the original form here."

My heart sunk. I was crestfallen.

She leaned back and flipped the switch for the next number to be called. "You can have the doctor fax it to our direct line," she said. "We can accept that. Here's the fax number," she said reading out the number which I hurriedly jotted down.

I walked away from the counter and called the HTC who agreed to send a fax. I let the lady, who was helping another customer, know a fax was coming. She pushed herself up from her chair and went in back, but when she returned, she shook her head no. "Give it some time," she said while sitting back down. I waited another fifteen minutes and she checked again. "No."

I called the HTC who said it had been faxed five times. I confirmed the number and then asked for one last attempt to which they agreed. I waited five more minutes, but the lady returned to her seat with another "No. You will just need to get the original copy and come back another time."

I left, feeling only half an advocate. What good was a doctor's approval for a handicapped placard if the DMV refused to issue it? This was not a win. My advocacy for this cause was not yet done.

Now writing for this newsletter's deadline, I have not yet received my handicapped placard. The HTC nurse has mailed the original copy which I am waiting for, and when it arrives, I will return to the DMV and try again. In the meantime, I hear Winston Churchill's voice chanting in my head: "Never give up! Never surrender!" Okay, perhaps that's a bit much for a single handicapped placard. But is it?

Ultimately, this is what I mean about being a naturalborn advocate. It is not something done only 2-3 times a year, although advocating to public leaders for those days is another vital component of advocacy work. It is not something done only because you have time. And frankly, it is not often done just because you want to. Aren't there more rewarding ways to spend one's time? Sometimes, advocacy may just be trying to get something as simple as a handicapped placard for your car.



### BOOK REVIEW

### THE BODY: A GUIDE FOR OCCUPANTS

Author: Bill Bryson Doubleday .446 pp. ISBN: 0385539304

### **BY SHELBY SMOAK**

Did you know that we have 10,000 taste buds, can detect 1 trillion different smells, and exhale almost 150 chemical compounds with each breath? Well, author Bill Bryson does, and he packs that information and more (much more) into his newest nonfiction work

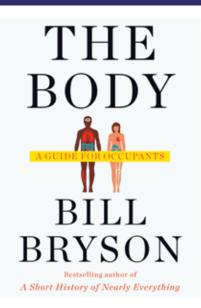
The Body: A Guide for Occupants. A writer of eclectic, sometimes humorous, always informative writing—especially evidenced by his bestseller A History of Nearly *Everything*, Bryson turns his gaze to the human body with his new book. *The Body* is not by any means a biased view, nor it is focused solely on hemophilia or bleeding disorders. The Body is expansive, a panorama of stories about people, history, medicine, and yes, body parts. It is packed with delightful nuggets alongside startling statistics and intriguing facts. In fact, the work is so compressed with interest and detail that reading it straight through only one time does the book a great disservice.

For example, in the chapter "The Brain," Bryson relates that the brain is 70-80% water and holds 200 exabytes of information-a size roughly equal to the entire digital content available in the world today. He then ventures into lobotomy and Walter Jackson Freeman, who from the late 1940s and well into the 1960s traveled the country "performing lobotomies on almost anyone brought before him." As Bryson shares, Freeman's methods were deemed crude by professionals, yet he continued with lobotomies until his retirement in 1967.

Bryson takes up the opioid crisis in "Nerves and Pain", writing that more

than 40% of Americans experience chronic pain. He notes that while America has only 4% of the world's population, we consume 80% of its opioids and every year the drug claims about 45,000 American lives. Similarly, in "Food, Glorious Food," Bryson raises concerns about American obesity. Today, he writes, we consume 25% more calories a day than in the 1970s; we eat 268 pounds of meat a year, compared to the average Brit who takes in 185 pounds and we consume 22 teaspoons of sugar daily. While short on suggestions for improving this troubling behavior, Bryson concludes with this advice: "The prudent option, it seems, is to have a balanced and moderate diet. A sensible approach is, in short, the sensible approach."

"The Heart and Blood" takes a statistical tour of those things, with hemophilia even getting a mention. Bryson relates that one drop of blood contains four thousand different types of molecules and that plasma makes up half of the blood's volume and is 90% water! Ever heard of James Homer Wright? As chief pathologist at Massachusetts General in 1910 he discovered platelets key role in clotting, a thing Bryon describes as "tricky business" since blood "must be perpetually on alert to clot at a moment's notice." Within the same chapter, Bryon traces the development of blood types to Vienna and Karl Landsteiner who originally intended Type O as Type 0 (zero) since it demonstrated "zero" clumping when mixed with other blood types. Dr. Allan Doctor (ves, that's his real last name) of Washington University in St. Louis enters to discuss nitric oxide



(different from the laughing gas, nitrous oxide) and its vital role in almost all blood processes like maintaining blood pressure, fighting infection and regulating blood flow.

The Body has a keen knack for unearthing the forgotten wonders of health and medicine. There is Walter Bradford Cannon who pioneered our understanding of the digestive system by X-raying his students while they consumed food. Or Peter Medawar who won the Nobel prize for his research on the immune system and helped to explain why skin grafts are often rejected from outside donors. Or Theodor Escherich who devoted his life to studying stools; while that may seem like a sorry job, it led to the discovery of E. coli, now "the most studied microbe on the planet."

Ultimately, Bryon has produced a compelling, overly engaging work that is written for anyone interested in the human body. *The Body* is a book that one can imagine being dipped into here and there for a long time.



### A CHAMPION AMONG US

**Interview by Sarah Henderson** 

Alexander is a 17-year-old high school student who lives with severe hemophilia A. Despite the challenges of his bleeding disorder, Alexander makes a point of volunteering in his community, staying active and not letting anything get in his way of living life to the fullest. I recently had the opportunity to interview Alex and his mother, Stacy, and have learned much about their strength and tenacity. Read on!

### How are you making a difference in your hometown?

Alex: I have helped deliver food for the "Cardinal Baskets" program. Cardinal Baskets are filled with food and stuffed animals for needy families in our area and are given out during the holiday season. They are a way to help other people during the holidays. My scout troop has helped collect and deliver food to the food pantry.

**Stacy:** Alex helps with the volunteer fire department dinners and breakfasts with set up, bussing and tearing down tables. He has also helped a local church by clearing trees and other large debris from the parsonage. With his scout troop, Alexander helps the local Veterans group properly dispose of old and worn American Flags.

### How are you involved in the bleeding disorders community on the regional or national level?

Alex: I go to bleeding disorder walks

that raise awareness and donations. I attend local chapter meetings and also go to the National Hemophilia Foundation's national meeting. I help other kids with their infusions by encouraging them to do their treatment by themselves.

**Stacy:** We hold fundraisers to support our walk team and attend as many bleeding disorders events as we can. He is also interested in becoming a counselor at camp. Alex strives to be a good role model for younger kids with a bleeding disorder.

### How have you learned to selfadvocate?

Alex: I've led presentations for scouts explaining what to do in case of a bleed or emergency. I've also presented for my school, the local fire departments, the local junior college, and at BioLife, a local plasma donation center.

**Stacy:** During the presentations for the scouts and local fire departments, Alex explains what hemophilia is,



how it affects him and what to do in an emergency. He has also demonstrated self-infusions.

### How are you a good example to others?

Alex: I try to set a good example in school and I don't let things like my bleeding disorder get to me. I am respectful. I help people if they need help. I always try to do good for others.

**Stacy:** His teachers continuously tell us he is a very respectful student and has a good attitude. He does have a visual perception disorder that makes math, reading

Alex has made several difficult decisions and compromises in his life due to hemophilia. He wants to try new activities but is also very aware that certain activities may not be a good fit. Due to bleeds or the risk of getting one, he has backed out of Taekwondo tournaments and has left scout camping trips early - sometimes opting not to go on the trip. Most 17-year-old boys don't have to be too concerned about what to pack for a scout's camping trip, how much factor to bring, and weighing if it's even worth the risk. His troop leaders are impressed with how he handles himself when he has a bleed and how well he makes

"Living with a bleeding disorder has taught me responsibility and has connected me to a community of caring individuals."

and writing very difficult. Due to this, most of his schoolwork is completed on a laptop using PDF worksheets to allow him to type his answers and have them read back to him via the computer. The school gave him this learning opportunity through a pilot program because he is a good example of a hardworking student and always listens and tries his best.

### What has living with a bleeding disorder taught you?

Alex: My bleeding disorder has taught me to advocate for myself. I have learned to be self-sufficient and learned to do my treatments by myself. It has taught me perseverance. For example, I once got a bleed during a Taekwondo class and had to miss a few classes. When my bleed was over, I was able to return and worked hard to catch up with my class.

**Stacy:** He is a very caring person; he understands what it feels like to be different and wants to keep others from feeling that way. He extends friendship to everyone. decisions regarding his health. In Taekwondo, Alex had a long road in earning his blue belt, but still has his sights on earning a black belt. He is also working toward becoming an Eagle Scout. He works closely with his troop leaders to determine alternatives to requirements that may present challenges with his bleeding disorder. Alex has experienced challenges, a few setbacks and obstacles over the years, but he's never let it stop him from working toward his goals.





### Has your bleeding disorder given you an advantage in life?

Alex: It's allowed me to make friends across the country. I've traveled all over the U.S. to meetings and I've had the opportunity to speak publicly about what it's like living with a bleeding disorder. Living with a bleeding disorder has taught me responsibility and has connected me to a community of caring individuals.

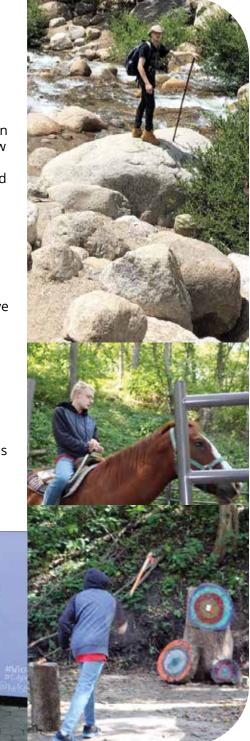
**Stacy:** I feel Alex is a more compassionate person. He knows what it feels like to be in pain and sitting out on activities he'd like to participate in. He is more sympathetic toward others who are different. He is also a very strong individual in his values and beliefs. He's matured faster than others his age because he's had to learn about his bleeding disorder, how to treat, and advocate for himself.

Most 16-year-olds don't know how to call in a prescription refill, know the name of their specialty pharmacy or what insurance coverage they have, but Alex has been aware of all this since his early teen years. He also needs to be aware of future jobs and career options and choose one that can provide the necessary benefits he will need as an adult.

By going to camp and attending other bleeding disorder related events, Alex has met many people in the community. He has learned how to hold a conversation with adults as well as with peers and has gained public speaking skills. He's had the chance to see what is possible by talking to previous generations and what they have accomplished in spite of having hemophilia.

Members of our community and event speakers have made a positive impact on how he feels about himself. After all, if one person can climb mountains, play baseball or golf, why can't he?

Alex has been an example to our community of how we should pursue life. He has set goals for himself and gone after them. He has encountered stumbling blocks that he went over instead of giving into. Despite his bleeding disorder, he is enjoying his best life.



### **ANSWERS TO PUZZLES ON PAGE 39.**

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### ILLINOIS Eva Kraemer

About 350 dedicated community members, family and friends came out to the Annual Bleeding Disorder Alliance Illinois (BDAI) *Hemophilia Walk* in downtown Chicago September 14<sup>th</sup>. As we meandered around North Avenue Beach with Lake Michigan as the backdrop, we made our way through the picturesque Lincoln Park Zoo. BioMatrix, a proud fundraiser for this event, is always delighted to participate.

BDAI is dedicated to improving the quality of life for persons affected by hemophilia and other inherited bleeding disorders through advocacy, camp, consumer services, education and research. This fundraising event allows everyone an opportunity to get together to support the Illinois bleeding disorder community. This all-inclusive occasion brings so many of us in the community together, making this fundraiser successful on all levels. The day was pristine, one of the most beautiful we've seen this summer, as we crossed the finish line appreciating the workout for a fantastic cause.

### **NEVADA**

### **Kelly Gonzalez**

The Nevada Chapter of NHF kicked off their second **Unite for Bleeding Disorders Walk** of the year at Bartley Ranch Regional Park in Reno September 14<sup>th</sup>. With more than 100 people in attendance, it was great to see all the families and interact outside of the medical

office setting. This successful annual event brings in nearly \$70,000, to help support the chapter. Thank you to the Nevada Chapter and all the volunteers for hosting this event and for your continued community support!



Erin, Kelly Gonzalez, Lisa and Richard

### OREGON

Jeff Johnson The Hemophilia Foundation of Oregon held its *Annual Meeting and Education Day* September 14<sup>th</sup> at Portland's Oregon Zoo. Nearly 200



chapter members from Oregon and SW Washington attended. A teen track began the previous evening and included an overnight stay in the zoo for teens and their chaperones. During the meeting, attendees had time to visit with each other, check out industry displays, listen to several speakers, honor recipients of annual awards and find out upcoming chapter events and news.

Jeanne White-Ginder spoke about her experience with her son, Ryan, in fighting HIV/AIDS in the 1980s, and brought the room to tears more than once with the power of her son's story and all that he overcame during his short time in this world. Speakers from NHF and HFA discussed challenges being faced by those in the bleeding disorders community concerning access to care, insurance and availability of new treatments.

After lunch, Executive Director Madonna Maguire Smith shared chapter news. Summer camp awards were presented and a camp highlight video was shown. Immediately following the conference, the Blood Brothers had a brief meeting, followed by time to explore the 64-acre park and oldest zoo west of the Mississippi River. Everyone rejoined to see the Pacific Northwest showing of *Bombardier Blood*, a documentary featuring Chris Bombardier's historic ascent of Mount Everest, becoming the first person with hemophilia in the world to reach the summit of the world's tallest mountain.

Many thanks to the Hemophilia Foundation of Oregon for hosting this amazing event!

### VIRGINIA

### **Terry Stone**

Once upon a dream, there was a man with a bleeding disorder named Chris Bombardier who loved adventure and set out to climb the seven summits of the world. In doing so, he was the first person with hemophilia to climb Mt. Everest, the world's tallest mountain. Thus, a gripping film documentary titled *Bombardier Blood* came to be.

September 15<sup>th</sup>–16<sup>th</sup> at the Hilton Norfolk, the Virginia Hemophilia Foundation in partnership with the Hemophilia Association of the Capital Area changed the standard programming of their **Annual Family Weekend** and not only brought this film to their members to view,



Heather, Skylar, William and Lizzie with Chris Bombardier and cinematographer Rob Bradford

they also welcomed the man himself – adventurist Chris and his cinematographer Rob Bradford to share the movie, sign books and answer questions post-showing.

Chris was brave, he was inspired and he did not let anything stop him from making his dream come true. And so, it was soon to pass that this courageous man did climb the seven summits. As part of his climb on Mt. Everest, Chris joined with fellow hemophiliac Patrick James Lynch, who's award-winning production company Believe, LTD, chronicled the journey. Chris cared for his bleeding disorder every step of the way. He shares the preparation, the conversations and concerns, and then the journey to the top of the world. Equally emotional is that the movie shares visits with other hemophiliacs in the shadow of Everest and highlights the extreme needs and challenges of people living with hemophilia around the world, and the work of Laurie Kelly and Save One Life, for which he is the new executive director.

Chris and Rob, thanks to you both for being present and for sharing this inspiring movie. Let it continue to inspire many to be bold and to reach farther to make their dreams come true. Obstacles are only bumps in the road to greatness! For more information, visit bombardierblood.com. To learn more about how you can sponsor a child with hemophilia around the world, visit saveonelife.net.

### MARYLAND

#### **Terry Stone**

Education is one of the greatest gifts you can give yourself. Never stop learning! The Hemophilia Foundation of Maryland (HFM) works hard to offer many opportunities throughout the year to gather and be educated consumers. They welcomed all of their members to join them for a *Family Dinner* and presentation to learn more about Hope for Hemophilia and their grassroots work Saturday evening, September 21<sup>st</sup> at the BWI Marriott in Linthicum Heights. Industry exhibitors were set up and regional reps were eager to greet HFM members and share their news and updates with all who visited. From the newly diagnosed to the seasoned legacy members who have been part of the community for years, it was great to break bread together and enjoy the evening. Thanks to Kim Epstein from Hope for Hemophilia for sharing your organization's mission and how HFM members may benefit from the outreach you do.

### **CALIFORNIA** John Martinez

Teams arrived with matching shirts to show their support for family and friends Sunday, September 22<sup>nd</sup> at Gibbons Park in Carmichael as Central California Hemophilia Foundation (CCHF) hosted their 2<sup>nd</sup> Annual **Unite for Bleeding Disorders Walk**.



Michael stops by the BioMatrix booth

This event attracted over 175 participants from both within the bleeding disorders community and the public at large. It was a beautiful sunny day in northern California with entire families enjoying the weather as well as the park facilities. The variety of and imagination shown on T-shirt designs provided even more enthusiasm during the event.

The walk began with recognition for raising the most funds, both individually and as a team. Several community members participated in a Pinwheel Ceremony to remember those we have lost in the community. The pinwheels also represent hope for a better future for all people with a bleeding



Maria, Amado, Samantha and Vanessa enjoy the sunny day



Nicholas, Ryan, Lisa, Nicholas, Nadia and Angelo check out the photos in the BioMatrix *Spectacular Life* calendar

disorder. Participants then began a brisk walk around the park area with a great deal of energy and gusto.

When the walk was completed, everyone gathered for a barbeque lunch of hot dogs and hamburgers. The community was very appreciative of the effort put forth by the foundation and all of its supporters. Raising over \$25,000 with the hope of continued fundraising to the end of the month, this walk was another successful event for CCHF due to their dedication to the community and their team of devoted volunteers.

### ILLINOIS

#### Eva Kraemer

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

Dancers delivered a marvelous display of traditional Mexican dances and typical Mexican fare was



Enjoying the event! Jorge, Marisol, Anita, Israel, Jorge Jr., Eva Kraemer, Maria, Baldomero and Veronica

provided for the Hispanic/Latino bleeding disorders community. Deep in the heart of Pilsen, a well-known Mexican neighborhood in Chicago, this event of approximately 75 took place September 22<sup>nd</sup> at the National Museum of Mexican Art.

Merriment, dance, food and pride for a rich culture were enjoyed by all.



#### NEW MEXICO Felix Garcia

A special bilingual event was held by Sangre de Oro, Inc. so all community members with Hispanic bloodlines could attend and enjoy the programming. The inaugural *Hispanic Heritage Day Event and Community Salsa Challenge* took place Sunday, September 22<sup>nd</sup> at the Albuquerque Marriott Pyramid North. Plenty of educational and interesting sessions were available in Spanish and English including one by BioMatrix Educational Specialist, Kelly Gonzalez, who presented *Awareness to Advocacy*.

Though the programming was spot on and the food a spicy deliciousness, the day would not have been complete without the Folklorico dancers from Baila! Baila! Dance Academy. These talented Mexican folk dancers wore beautiful traditional attire. The only thing missing was salsa! Ah, but it wasn't... Monic G., community member and enthusiastic Sangre de Oro volunteer, won first



prize in the Community Salsa Challenge. She came away with a wonderful salsa-themed prize basket. Congratulations, Monica! Sangre de Oro is anticipating this to be a welcomed event every year!



Maria, Bernadette, Kelly Gonzalez and Arlene



Excited winner of the Community Salsa Challenge, Monica, accepts her prize from Ryan Crowe

### NEVADA

**Kelly Gonzalez** The September 22<sup>nd</sup> Las Vegas Hemophilia Walk hosted by the Nevada Chapter of NHF seemed completely revitalized this year! The allinclusive family fun day took place at scenic Floyd Lamb State Park. Fresh new faces ioined the walk with a slew of new volunteers to boot! With so many additions to the walk, the longevity of this event is that much more solidified. It was a great day to be a member of the Nevada bleeding disorders community!



Kyle and Jamie with children, Connor and Cora

### **FLORIDA**

#### **Peggy Klingmann and Marcy Foertsch**

On the evening of September 26<sup>th</sup>, BioMatrix and Bayer hosted an **Educational Dinner** at 400 Beach Seafood and Tap House in St. Petersburg. Though the food and atmosphere were awesome, it



Stephanie and Colter with Andrew

was the group of people who were second to none! Bayer provided an open panel discussion and fielded consumer questions regarding their long-acting factor product, Jivi. We at BioMatrix love these gatherings allowing us to visit with our local bleeding disorders community members.

### **FLORIDA**

### **Hector Heer**

Fort Lauderdale ambiance, a quaint Mediterranean restaurant, Maza Mediterranean Cuisine, and an assembly of supportive women was the setting for an

**Educational Dinner - Women Bleed Too** September 26<sup>th</sup>. Education Specialist Kelly Gonzalez presented the



BioMatrix team members, Ken Trader, VP Managed Care and Kelly Gonzalez, Education Specialist

session, which empowered the ladies to take control of their health by learning the signs and symptoms of a bleeding disorder, demonstrating how to track and document care and steps to having a productive dialogue with their medical providers. Sponsored by CSL Behring and BioMatrix, this event provided an opportunity to discuss the challenges of being a woman with a bleeding disorder. Thank you to the attendees for raising questions and sharing your stories!

### **CONNECTICUT** Kelly Gonzalez

Taking place the weekend of September 28-29, Connecticut Hemophilia Society community members relished a breath of fresh air as they enjoyed CHS **Family Weekend in Mystic**. The event began at Mystic Seaport and set the perfect backdrop to explore the marina and aquarium while learning more about our community.



Maddie and Maddy

Maddie and Logan

Families were better prepared to help their children manage a bleeding disorder while at school after participating in a session on *504 Plans and IEPs*. As a BioMatrix Education Specialist, my favorite part of the weekend was being able to present a session titled, *Transition to Self-Infusion*. With the support of Connecticut Children's



Big smiles! Amanda and Kelly

Medical Center nursing staff, this hands-on activity had everyone feeling proud and accomplished. The very best part of this event was that families were able to come together and to learn and bond with one another – a fantastic event enjoyed by all!

### TENNESSEE

### LeAnn Wilson and David Tignor

Springfield's Honeysuckle Hill Farm was the site for Tennessee Hemophilia and Bleeding Disorders Foundation's (THBDF) **Annual Fall Festival** September 28<sup>th</sup>. Although it proved to be a peculiarly hot day for the festivities, families in the bleeding disorders community were not deterred from enjoying the activities the farm had to offer. Activities included ziplines, hayrides, a fantastic pumpkin patch, a variety of slides, a climbing wall, a clever corn maze and a pumpkin train just to name a few!



Families enjoyed lunch and visiting with industry

LeAnn, Anna and little Ava

representatives. There were also a variety of picturesque spots to pose for a great photo. Later in the day, THBDF drew names for raffle items. We look forward to next year's event!



Evan, Charlotte and Daniel climb onto the big chair Sweet smiles from Arlo and Nova

### VIRGINIA

### **Terry Stone and Francis Brayshaw**

It was a magnificent sunny day Saturday, September 28<sup>th</sup>, and everyone was ready to meet up with their besties and take a stroll around Lake Accotink in Springfield. After all, the **Fall Festival and Walk** supports the Hemophilia Association of the Capital Area and is the largest fundraiser and family event of the year. HACA groupies showed up in droves, but



Three teams, one mission and a little dog: Veronica, Miss Hazel (the pup) Terry Stone, Ian, Ivory, Marissa and her son

the weather... holy heatwave! We were certain Mother Nature did not get the memo to provide a cool, gentle wind and low humidity for this wonderful event.

Yes, it was warm and humid and with the sun shining brightly, walkers glistened as they strolled for a cause they love. With great purpose and dedication from so many supporters who came to show HACA what this organization means to them, the walk brought in a record \$95,000! WOW! After the walk, industry representatives were on hand to educate and celebrate such a successful event. There were games, goodie bags and great food for all!

### **NEVADA**

### **Kelly Gonzalez**

Our third **Self-Infusion Class** of the year went well! A few new families were in attendance, as well as returning families who wanted a refresher. Hosted by

**BioMatrix and** the Hemostasis and Thrombosis Center of Nevada. the group met October 9th at the treatment center in Reno. This event was powerful and empowering as spouses learned to infuse each other and parents were infused by their children. It was an enlightening experience!



Under supervision of a nurse, Monique practices infusing Lisa Preciado of the Hemostasis and Thrombosis Center of NV

### FLORIDA

**Peggy Klingmann and Marcy Foertsch** Novo Nordisk and BioMatrix hosted an *Educational Dinner* October 11<sup>th</sup> at Sweet Pete's Candy in Jacksonville. Vaughn Ripley presented a lively interactive discussion about his journey with hemophilia and as an



Back row: Ajie Attawia, Peggy Klingmann, Alexis, Marlene and Vaughn Ripley. Front: Ronin, Cody and Brenda Montgomery King

ambassador for Novoeight, how the brand of factor has been impactful for him. Conversation throughout the evening proved to be engaging and informative. Brenda Montgomery King with BioMatrix was also in attendance to handle everyone's questions regarding community resources and insurance issues. These dinners are always fun-filled and informational for all who attend!

### LOUISIANA LeAnn Wilson

The Louisiana Hemophilia Foundation hosted its **43<sup>rd</sup> Annual Meeting and Educational Symposium** October 11–12 at the Embassy Suites in Baton Rouge. The event kicked off with everyone heading to the exhibit hall to mingle and visit industry reps. Happy voices and laughter rang throughout the room.



Sophie, Sierra, Sasha and Sara

Presentations included discussions on how the bleeding disorder community has changed with a nod to its history. We were reminded that even though things are looking hopeful we must never forget where we came from. Afterward, dinner was served and if you have ever been to Louisiana this will be of no surprise to you – the dinner was awesome.



eAnn Wilson and Benjamin at the craft table

Shelby Smoak, LeAnn Wilson and Benjamin look on as Cruz makes a monster headband

The next morning after breakfast more informative sessions followed. Closing out the programming and bringing harmony to the event was our very own BioMatrix speaker, Shelby Smoak. His popular session, *Singing to Heal*, highlighted the scientific facts of how music affects our brains and how music can help heal the soul and change our mood one note at a time. Shelby placed us into groups and challenged us to change the lyrics of popular songs to words associated with bleeding disorders. Listening to the new renditions had us all laughing and, at least for a little while, forgetting our struggles. The evening's Halloween party was held at Louisiana State University's Hilltop Arboretum. An extraordinarily beautiful venue, guests had fun with a variety of games, arts and crafts, slime making and freshly made cotton candy. The talented deejay entertained with a variety of music that had folks of all ages hitting the dance floor. Such an enjoyable way to wrap up the weekend! We look forward to seeing what next year's meeting holds!

### OHIO

Rania Salem Families of the Central Ohio Chapter of NHF gathered October 11-13 at beautiful Deer Creek State Park in Mt. Sterling for an Education Retreat.



A personal favorite of the weekend is a session on learning to self-infuse. As a registered nurse, I had the opportunity to contribute to this activity and was on hand to teach parents of newly diagnosed children the basics and help veterans identify new veins to infuse. Several patients were VERY successful in infusing themselves for the very first time ever! The highlight of my career is knowing I can make a difference by helping patients take charge of their disorder by learning to advocate for themselves and successfully self-infuse. These are the moments I live for as a nurse.

Other enlightening sessions included topics on empowerment, resiliency and self-advocating. Kudos to Executive Director Wendy Perkins and her team for an extremely well-constructed and valuable weekend!

### NEVADA

### **Kelly Gonzalez**

Nestled on the banks of the Truckee River, the Renaissance Reno Hotel was the ideal spot for the **Annual Northern Nevada Women's Retreat** October 12<sup>th</sup>. The location was spectacular and when not in sessions, participants were able to get lost in nature, surrounding themselves with a plethora of trees, all in the midst of changing colors. Hosted by Nevada Chapter of NHF and organized by BioMatrix, Octapharma and Aptevo, this retreat truly proved to be a poignant weekend. The women offered support to each other and talk about the challenges and struggles they face. No matter a patient, wife, mother, sister or

caregiver, everyone was welcomed with open arms and were able to recharge to be better participants in their own lives.

Becki Berkowitz of the Hemostasis



and Thrombosis Center gave a presentation about disclosure of a bleeding disorder and a revitalizing yoga session was led by Jacey Gonzalez. Those who attended the retreat had nothing but words of delight and appreciation for this wonderful opportunity and as a representative of BioMatrix, I am honored to have been a part of it.

### **WEST VIRGINIA**

### **Michelle Stielper**

The **Spokes Men for Bleeders** never disappoint! Every year Steve Nicks and his riding crew pedal 100 miles in a day to raise money for the West Virginia National Hemophilia Foundation Chapter. This is no easy feat as these riders tackle the ride head-on regardless of weather conditions, with a worthy cause in mind. Riding from Harpers Ferry to Washington D.C. and back in one day - October 12<sup>th</sup>, is nothing short of heroic. We love helping celebrate and support this amazing endeavor. This year was their best fundraising year ever, raising a whopping \$15,865! Way to Go Team Spokes Men!



Spokes Men For Bleeders ready to ride – Paul, Tim, Tim, Bob and Steve Nick

#### OHIO Shalia Bi

### Shelia Biljes

The chilly weather of October 12<sup>th</sup> was just the right temperature to put everyone into a fall season mood as the Northern Ohio Hemophilia Foundation (NOHF) community members gathered at Mapleside Farm in Brunswick for an *Insurance Workshop*.

Miriam Goldstein, JD, from HFA updated the group

on what to be aware of while buying marketplace insurance, copayaccumulators and what to expect from commercial plans going forward. Katie Back, RN, Ohio CMH, offered details on how to obtain assistance from available Ohio programs. Randi Clites, NOHF's Assistant Director, filled everyone in on what assistance the Foundation can provide. An especially



You don't have to be a pumpkin to have a big grin

helpful feature of this meeting is that the speakers were available for individual discussions.

Lunch soon followed and then it was time to enjoy everything Mapleside Farm has to offer, including one of the nation's largest bounce areas. Pig races, cow train ride and tractor rides through the apple orchard seemed to top the favorites! After spending the afternoon exploring the farm, goodies were available – apple cider slushies, pumpkin doughnuts and pumpkin ice cream, just to name a few! It was the perfect setting and perfect weather to spend with family and friends!

### PENNSYLVANIA

Tina McMullen Families and members of the bleeding disorders community could not have asked for a more beautiful day for Eastern Pennsylvania Hemophilia Foundation's **Annual** Trick or Trot Family Walk October 13th at the Philadelphia Zoo. Twenty-two teams brought more than 400 walkers to this fantastic event! The walk started before the zoo opened so families had time to visit the fascinating



3-year-old Antonio watches over the BioMatrix booth

animals before the crowds arrived.

Under the exhibit tent, participants had the opportunity to visit several industry booths while children of all ages enjoyed a morning full of face painting, moon bounces, tattoos, music, and of course, snacks and drinks. Awards were given for best adult and best child costumes.

The walk concluded with Executive Director Curt Krouse presenting a \$10,000 grant to Dr. Ruben Rhoades from the Thomas Jefferson University Hospital HTC for his project *Outcomes of Patients with Hemophilia and von Willebrand Disease Undergoing Major Surgery*. Kudos to community members for offering so much support to the chapter! Curt and his staff, Lindsay Frei and Kat Kocsi did an amazing job in giving the families a wonderful day at the zoo!

### ILLINOIS

### Eva Kraemer

Set at the Columbia Yacht Club on Lake Michigan, the Bleeding Disorder Alliance Illinois (BDAI) hosted its annual **Autumnal Wine Dinner and Auction** October 18<sup>th</sup>. Champagne Sponsor Jim Hurster of CSL Behring selected superb red and white wines to sample for

nearly 100 guests. Many generous and talented people donated gift baskets to be auctioned in support of BDAI in their mission to provide education to the Illinois bleeding disorder community. The chill in the air coming off Lake Michigan made inside even cozier while enjoying the captivating backdrop of the evening Chicago skyline. Many thanks to CSL Behring, BDAI and all who came to make the evening an elegant success!



Cheers from Mark, Eva Kraemer, Jen and Jim with CSL's Jim Hurster (center)

### CALIFORNIA Kelly Gonzalez

As we have come to expect, Hemophilia Foundation of Northern California's (HFNC) *Female Factor 5<sup>th</sup> Annual Retreat* exceeded all expectations! Taking place October 18<sup>th</sup>–20<sup>th</sup> at Monterey Tides Hotel, the retreat was made even more special with the addition of a Spanish track.

The kindness, support and love that abounds at this event enriches and uplifts every attendee. The many revelations, both personal and community-based truly made an impact on everyone. Hats off to HFNC for the impressive programming and support offered to the women of the bleeding disorders community!



### VIRGINIA

### **Terry Stone**

The day had arrived. The planning, fundraising and preparation were done. The loyal walkers of the Virginia Hemophilia Foundation woke up to a dark, chilly Sunday sky covered in clouds and rain – pouring rain – the day of Virginia Hemophilia Foundation's **Unite Walk** October 20<sup>th</sup>. Robious Landing Park in Midlothian was soaked, but the walkers were stoked and showed up with their fashionable umbrellas and water-repellant best and they walked! No longer is the postman's oath their own, although we changed it up to capture the moment, "Neither snow nor RAIN nor chill nor gloom of day keeps these devoted VHF supporters from their mission to raise money and awareness and complete their appointed rounds." Thanks to everyone's efforts. the chapter will put more than \$36,000 to good use. Rainy days never get us down.



Terry, Matt, Kelly and Michelle staying dry while the rain pours

### CALIFORNIA

Gabriela Griffin

What a perfect day for the **Annual Unite for Bleeding Disorders Walk** - not too hot, not too cold, just a wonderful southern California day! On the morning of October 20<sup>th</sup>, community members began arriving at San Diego's beautiful Liberty Station Park. Before the walk began, everyone had the opportunity to socialize and visit industry booths. President of Hemophilia Association of San Diego County Sean Pentz welcomed the walkers and the teams took off! The air was filled with excitement, joy and a sense of pride as teams achieved their goals. When everyone crossed the finish line, we enjoyed a delicious lunch of freshly made tortilla tacos. What a treat! Thank you to the staff of HASDC for all their hard work and effort in making this walk a memorable one!



Fel, Liz and Rita with Gabriela Griffin walk for a great cause

### WASHINGTON DC Terry Stone and Michelle Stielper

When it comes to the Nation's Capital, there are so many wonderful activities to enjoy. For example, you can do some sightseeing of the memorials and monuments, or a ride through Embassy Row, or dine on the Potomac River in Georgetown, or fishing. WAIT... what? YES, FISHING! Thanks to Brandon Young of Country Boy Fishing, generous sponsors and an adventurous chapter, both novice and experienced fishermen cast their lines and we fished October 21<sup>st</sup> at the Constitution Gardens Pond in the heart of DC in the shadow of the Washington Monument for *HACA Family Fishing Day*!



Fishing on the National Mall #bucketlist!

Nothing is cuter than some pint-size kids learning to hold a worm, bait a line and cast. These little sportsmen, along with bigger versions of that cuteness (also known as grown-ups), circled the pond until they found that magical spot. Brandon shared his experience and was on hand to help, but the beauty of the day was seeing parents and children sharing moments. That is where the magic happens. It wasn't so much the special spot they selected, but in the magic of the moments shared.

I'd love to tell you we caught some really big fish, and I COULD tell you that, but it would be one of those "fish stories" about the one



Phil giving Jack, his l'il fisherman, some pointers

that got away. Rather, I'm happy to share everyone that cast their line caught the fever for the love of the sport. To keep this momentum going, Brandon gifted all of the kids with their own brand-new fishing rod. Thanks, Brandon!

Fishing in DC was the coolest event ever. After all, it gets the family outside, it's totally bipartisan, and it's just FUN. Brandon Young of Country Boy Fishing, you are the best. Thanks to Octapharma and Aptevo for partnering with us at BioMatrix to bring such a fun family event to Washington DC!

### PENNSYLVANIA Tina McMullen

Spooky Nook Sports and Warehouse Hotel in Manheim was the place to be Saturday, October 26<sup>th</sup>. This is where the Eastern Pennsylvania Hemophilia Foundation held **Adventures in Learning**, a day of education and camaraderie!

Before the programs began, families had the opportunity to mingle and visit industry booths. Keynote Speaker Darlene Shelton kicked things off with her presentation on *Emergency Preparedness When Living with a Rare Disease*, which covers protocols prohibiting paramedics and emergency room physicians from administering specialty medications carried by rare disease patients. Darlene and her family realized the danger and started Danny's Dose Alliance in 2015, beginning a journey to make a change.

Additional speakers included Colleen Farrell, RN BSN Nurse Coordinator Hemophilia Treatment Center of Central PA, Charles Gilbert, ACSW, Angela Forsythe, PT, DPT and Veronica Conde of Hemophilia Federation of America. Sessions included topics such as *Teen Session on Safety Topics, Nurturing Couple Relationships* and *Parenting Children with Health Issues.* It was a full day of learning for all!



Bubble Ball fun

After a day of learning, community members relished downtime at the largest indoor sports complex in North America boasting backyard games, a Ninja Warrior course, bubble ball and much more! It was a fulfilling day for the bleeding disorders community of Eastern Pennsylvania. Thank you to Executive Director Curt Krouse and his staff along with the Consumer Advisory Board of the Central PA Hemophilia Treatment Center for hosting this valued event!

### **TEXAS**

Brushy Creek Lake Park in Cedar Park is set around a 38-acre lake with trails, a playground, fishing pier and wildlife viewing area. The park proved to be an incredible backdrop for the Hill Country **Unite for Bleeding Disorders Walk** hosted by the Lone Star Chapter of NHF October 26<sup>th</sup>. Raising over \$29,000 for the chapter, cool temperatures did not dampen the enthusiasm of over 200 participants and donors who arrived on the crisp, cool fall morning. Contributing to the event, a local high school cross country team who came to show support and increase bleeding disorders awareness.



Walking for a cause on a beautiful day

### ILLINOIS Eva Kraemer

Bleeding Disorders Alliance Illinois (BDAI) hosted its annual Statewide Family Education Weekend October 26-27 at the



October 26-27 at the Chicago Marriott Midway. After a warmhearted welcome from Executive

Eva Kraemer and Kelly visit at the BioMatrix booth

Director Bob Robinson, *Open Enrollment 2020* was discussed followed by a group activity facilitated by board member Nichelle Stigger about going beyond a bleeding disorder and looking at differences in cultures.

After lunch, we heard about changes in current and new hemophilia treatments from Dr. Lisa Boggio, Hematology – RUSH University Medical Center in Chicago and Dr. Rohith Jesudas, Staff Hematologist, Bleeding and Clotting Disorders Institute in Peoria. Members of the community facilitated a round-robin, seated at different tables to discuss topics of sibling support, time management to get the most out of your day, and how to be in the moment - mind, body and soul.

As everyone proceeded to dinner, children delighted in trick or treating along the way dressed in their most creative Halloween costumes.

Sunday morning found facilitators Kim Isenberg and Clemencia Casas-Byots discussing the power of sharing your own story to help you and others in the community learn and grow. As always, the weekend promoted networking, camaraderie and good feelings all around. Thank you to BDAI for this much-anticipated event!

### RHODE ISLAND Cheryl Ashmore

In late October, an unseasonal warm wind followed over 300 attendees to the Crowne Plaza in Warwick. The stillbrilliant foliage brightened the weekend of October 26<sup>th</sup>–27<sup>th</sup> as the community gathered for **Fallfest**, New England Hemophilia Association's (NEHA)



Syrus and Dr. Sidonio stop to smile for the camera

largest annual event. Heather Abbott, an amputee and survivor of the Boston Marathon bombing, presented the keynote address, a tale of resilience, courage and giving back that provided an inspirational tone for the rest of the event.

NEHA organized and presented two days of significant, relevant programming with tracks for adults, youth and teens. Gene therapy research with Dr. Sidonio, a medical provider panel on emerging therapies, rap and breakouts sessions for parents, partners, affected men and new families set the pace Saturday. Tim Ringgold's *Music Therapy For Stress Management* followed, a highenergy, new perspective look at ways music alters the body's stress response.

After a rousing demonstration from the talented youth of *Mastery Martial Arts*, the evening found folks mixing it up on the dance floor Halloween style – witch hats of every size and color were the accessory of the night. Several well-deserved awards were announced for advocacy, philanthropy, service and volunteer of the year.



Where are Carter, Nadia, Bonnie and Kaytrien?

Sunday was a welcome wind-down, offering a wide variety and great diversity of sessions including a standout look at personal advocacy for women with bleeding disorders, *Women Bleed Too*, presented by BioMatrix Education Specialist, Kelly Gonzalez. The event truly was a testament to the commitment of the New England community, some of whom drove 7 or more hours to spend time in a vibrant fall venue with blood brothers and sisters. Thank you, NEHA, for another meticulously planned and executed masterpiece!

### NEVADA

#### **Kelly Gonzalez**

In the parking lot of their building October 28<sup>th</sup>, the Las Vegas Hemostasis and Thrombosis Center hosted its **Annual Trunk or Treat Halloween Event**. Parked vehicles donned scary "costumes" while local members of the bleeding disorders



community and industry supporters helped hand out candy to adorably excited children. Games, prizes, raffle and pizza added to the fun of the evening – families had a blast!

### **NEW YORK** Richard Vogel

There is nothing better than a beautiful early fall day in upstate New York to enjoy the Bleeding Disorders Association of Northeastern New York's (BDANENY)



Charity and Katrina

**Annual Meeting**. With the smell of fireplace smoke in the air and the leaves just starting to change colors, community members turned out October 28<sup>th</sup> for a day of fun and information at Six Flags Great Escape in historic Queensbury.

After consumers gathered information in the exhibit hall on new products and services from manufacturers and specialty pharmacy representatives, Chrislene Adams presented an HFA session about cultivating independence and steps for parents to help teach kids to be independent.

It's always good for families to relax together and there is no better place to do so than an indoor water park. Children and adults enjoyed an afternoon of fun at Six Flags Great Escape courtesy of BDANENY. Many thanks to those involved in planning this enjoyable event!

### CALIFORNIA

**John Martinez** Families were

treated to 3 delicious meals all in an outdoor setting that provided opportunities to reconnect with each other November 2<sup>nd</sup>, as Hemophilia Foundation of Northern California held its annual



Girl Power! Elliana, Maileen and Delilah

**Family Education Day**. Taking place on a lovely, sunny day at Evergreen Valley College in San Jose, sessions were held in both English and Spanish to provide the community with updated information regarding new therapies and advocacy. While parents attended the various informational sessions, children interacted with indoor and outdoor activities that kept them busy and engaged.

Families were encouraged to ask questions of the many industry partners in attendance. Conversations ranged from new therapies and medications to what parents can expect as their child grows up in this community. Overall, the family environment was one of energy and anticipation about where the bleeding disorder community is going over the next decade.

After enjoying dinner in the twilight hours, everyone was invited to watch the first showing of the extended cut of *Bombardier Blood*. This inspiring story of Chris Bombardier accomplishing his goals and not letting hemophilia define his life left many attendees emotional, including myself. The round of applause at the end of the film was heartfelt and well deserved. It was a wonderful way to end a day of learning and fellowship.

### **CALIFORNIA** Gabriela Griffin

The day before Hemophilia Foundation of Southern California's (HFSC) **11<sup>th</sup> Annual Unite for Bleeding Disorders Walk**, the Atwater Village fire had erupted a mile from Griffith Park in Los Angeles where the walk was to take place. We were very fortunate that



Kelly Gonzalez and HSFC ED Michelle Kim rock out in MTV t-shirts

California firefighters got the flames under control expeditiously. When the morning of November 2<sup>nd</sup> arrived, everything seemed just perfect. Community members, family and friends arrived to show support for their respective teams.

**BIOMATRIX NEWS** 



Team BioMatrix walks for Unite!

The Walk boasted an 80's theme with cool 80's music and many participants donning 80's attire from scrunchies to leg warmers and everything in between! Executive Director Michelle Kim gave a warm welcome and a short talk about how life was for community members back in the 1980s. Then 8-year-old Scarlett belted out a phenomenal rendition of the National Anthem, stirring the crowd to excited unity as together they began the 3-mile walk for a great cause!



Mickey and Kelly 80's throw back

At the finish, there was pizza and ice cream for all. Thank you to Michelle, her staff, and to the 50+ volunteers that made the Walk such an awesome and positive event! HFSC events never disappoint and are always a reminder that we are not alone - our community is here for us!

### **FLORIDA**

#### **Peggy Klingmann and Marcy Foertsch**

BioMatrix and Bayer partnered to host an **Educational Luncheon** at Orlando's WonderWorks November 2<sup>nd</sup>. *My Journey with Jivi*, presented by Novo Patient Speaker Ryan Moulton, was well attended by central Florida's bleeding disorder community. By engaging with Ryan and sharing their own personal stories, all felt like they learned a lot from the presentation.

WonderWorks is an amazing combination of education and entertainment, offering a 6D motion ride, laser tag, ropes course and over 100 hands-on science exhibits! Following a catered lunch, the afternoon rocked!



Paulette and Tony with Brenda King (center)

### MISSOURI

Eva Kraemer

Gateway Hemophilia Association (GHA) hosted its annual **Trivia Night Fundraiser** November 2<sup>nd</sup> at Jefferson Barracks Park in St. Louis. Dressed in their finest Western gear and accessories, 200 Missouri bleeding disorders community members came to support this worthy cause. With the proceeds to benefit 2020 GHA programming, the silent auction items never disappoint! Most of the trivia questions were about a time when the Wild West was being settled



CSL's Jim Hurster looking dapper

and lots of friendly competition between teams was enjoyed - the potluck was bountiful. The evening was a huge success and I had so much fun participating!

### OHIO Shelia Bilges

It's been said that gratitude turns what we have into enough! Not sure who said it, but they would have loved to have been present as community members spent time together contemplating all for which they were thankful at an **Educational Dinner** November 7<sup>th</sup> in Brooklyn.



Amber is thankful for family

Everyone was appreciative of the wonderful meal prepared by TGI Fridays. Pumpkin cookies and fall colored pastries completed the meal. Co-sponsoring the event with BioMatrix, CSL Behring presented facts about Afstyla and the programs offered through the manufacturer.

As the waitress took orders, guests were handed a pumpkin chalkboard to share their thankful thought upon and while



Star and Tony express thankfulness

dinners were being enjoyed, speaker Kelly Gonzalez presented *Putting on the Mask*, a program drawing attention to the needs of caregivers for persons with a chronic illness. Hearing someone else's story often makes one more appreciative of your situation. Guests lingered and shared stories as delicate, fluffy snow began to fall. All were reminded to be thankful the year through and to share gratitude with those around you.



Alaina with Shelia Biljes: Panda sisters!

### time to visit with friends who have communicated via social media for the past year and to see how big everyone's babies have grown.

OHIO Shelia Biljes

It's the most wonderful

about the holidays quite

yet, but rather about the

Annual Meeting! Taking

Inn, it's a chance to get

place November 8<sup>th</sup>–9<sup>th</sup> at

the Independence Holiday

away from home with your

family for the weekend, a

Foundation's (NOHF)

Northern Ohio Hemophilia

time of the year! Not talking

The event began with social time, greeting and mingling with friends, meandering through the exhibit hall to speak with sponsors, manufacturer and home care reps, including at the BioMatrix booth where folks picked up some fun virtual reality goggles. Over dinner, Jay Chakravanthy of Takeda presented an overview of insurance changes expected for 2020. After dinner, BioMatrix sponsored a fun family event, consisting of nachos, popcorn and a magic show by entertainer Joe Kennedy. Guests watched in amazement and roared with laughter at his magic and one-liners, and there was no shortage of audience volunteers to be part of the show. Later, the hotel pool remained open with many families taking a relaxing swim before bedtime.

Saturday morning started early with a buffet breakfast and more time to visit exhibitor booths. NOHF leadership presented its annual report and reviewed their offered programs. Dr. Mallory of Akron Children's Hospital followed with a presentation on mental health. The group was very engaged and felt safe sharing thoughts and situations.

Being a chapter member is a great way to find support and education, and this Annual Meeting offers both! Thank you NOHF!



Chantel and Angela volunteer for Magician Joe. How did he do that?



Hannah and Miya serve nachos; Alaina loves sweets!

### **FLORIDA**

**Peggy Klingmann and Marcy Foertsch** BioMatrix teamed with Octapharma and Aptevo to present an *Educational Dinner and Painting Event* November 9<sup>th</sup> at Tampa's Painting with a Twist.



Octapharma Coagulation Specialist Sherryl Rojhani presented a session on *Bleeding Disorders and Dental Care*. The talk centered on the importance of maintaining proper dental health and offered information on resources and navigating coordination of care.



The presentation was followed by a very artistic and enjoyable activity where everyone created a special and unique work of art to take home, along with a BioMatrix goody bag filled with dental necessities.

### **ILLINOIS**

### Maria Santucci Vetter and Eva Kraemer

Great educational sessions, fantastic community involvement and a wonderful team of Coalition representatives proved to be the recipe for a successful gathering of factor 9 families! The Coalition for Hemophilia B wrapped up its 2019 Meetings on the **Road** November 9<sup>th</sup> at the Chicago Marriott Schaumburg.

Following a warm welcome by Dr. Lisa Hensley, Rick Starks kicked off the day by encouraging participation in a calming yet invigorating session of TaiChi Movement and Meditation. More presentations followed such as Living with *Hemophilia* B by Dr. Sandeep Rajan, Kinesiology and Joint Support Workshop with Dr. Michael Zolotnitsky, and a Group Rap Session led by community member, Rocky Williams.

The meeting wrapped up with a presentation by Novo Nordisk's Community Advocate



Sarah and Zachary with sons, Oliver and Vancent displaying their artwork



Happy, little November is amused by her daddy, Rocky

Emili Lee, who shared stories of her family's experiences with bleeding disorders. She described how various family members are affected by a bleeding disorder and the steps they are taking to manage the challenges.

Many thanks to Community Relations and Advocacy Manager Christian Villarreal, JD, for heading up another splendid gathering, and special congratulations on her 5<sup>th</sup> anniversary with The Coalition for Hemophilia B TEXAS

On occasion and sometimes even several times a year, members of the Lone Star Chapter of the NHF come to Houston's medical district for their routine and emergency medical appointments. However, on the morning of November 9<sup>th</sup>, they made their way to the area for a different reason – something a lot more fun. Over 400 patients, family members, caregivers and members of their support system showed up to participate in the Unite for Bleeding Disorders Walk held at the 55-acre Houston Zoo located within Hermann Park in the heart of the medical district. When the walk concluded and the recognition ceremony wrapped up, participants had the opportunity to enjoy the zoo, which houses over 6,000 animals from 900 species. This highly successful event raised over \$43,000 for the chapter's educational and bleeding disorders awareness efforts. Congratulations to the Lone Star Chapter!



### **NEW HAMPSHIRE Cheryl Ashmore**

On a cozy Saturday, the New England Hemophilia Association (NEHA) hosted its 2<sup>nd</sup> Annual vWD Retreat November 9<sup>th</sup> in Portsmouth. With the support of "Wicked Strong Family" volunteers (NEHA members!), this important event connected patients, HTC staff, HFA and community organizations.

Dr. Nathan Connell, Chief of Hematology, Brigham and Women's Faulkner Hospital in Boston delivered a comprehensive keynote presentation and knocked it out of the park. His depth of knowledge, passion and willingness to explore spontaneous, interactive questions from the audience was refreshing, and it was clear many families had "lightbulb" moments and were able to follow up with him after the presentation.

As the afternoon ensued, NEHA staff and guest panels facilitated various rap sessions, which contained a wealth of personal and experiential information straight from community members to the people who needed to connect the most. Several other sessions addressed topics such as types of vWD, menstrual cycles and



Debra and Kathy welcome attendees

healthy living. A notable presentation was offered by BioMatrix Education Specialist Kelly Gonzalez who spoke on Safe Travels. Kelly discussed and answered all sorts of questions from emergency preparedness while traveling and safe storage and transport of medications. to documentation to have on hand.

NEHA provided a safe space for childcare and for teen tracks to free the parents to attend valuable sessions, have social time and strengthen relationships with friends, old and new. Thank you, NEHA, for a valuable vWD family retreat!

### **NEW MEXICO**

#### Felix Garcia

BioMatrix teamed up with Bayer to bring a **Breaking Blood Men's Group** program to the men of Sangre de Oro, Inc. November 14<sup>th</sup>. Meeting up at Main Event in Albuquerque for dinner, Bayer brought in Bayer Patient Advocate Zachary Castillo who shared his story of growing up with hemophilia, the struggles he's encountered and how he has triumphed over them. Bayer's representative Giovanny Pernudi followed up with the latest update on Jivi's side-by-side study released earlier this year.

Following Giovanny, I was fortunate to talk about What

Do You Do Now? - a

discussion on what to do

if a patient is interested

in switching to or trying another product. After

all, we all want to walk

into our doctor's office as knowledgeable as

possible. Free time



Gabriel and Jordan show their pool skills

followed at the billiards table. Thanks to everyone who came out for this informative gathering!

### **FLORIDA**

#### **Kelly Gonzalez**

The waves crashing on the beach playing in perfect symphony with the breeze blowing and birds chirping, all of which became the ideal setting for Florida Hemophilia Association's *Girls Weekend Getaway*. Generously sponsored by CSL, the event began Friday, November 15<sup>th</sup> at Del Ray Sands Resort in Palm Beach with ice breakers, dinner and an artful painting project.

The next morning ladies gathered on the beach for fresh air, friendship, sun salutations and yoga. Filling the rest of the day, educational sessions were presented on nutrition, insurance and caregiver burnout.

Many thanks to Executive Director Debbi Adamkin, her team and CSL Behring for hosting this opportunity to share and support the community! WEST VIRGINIA



Morning beach yoga

### Michelle Stielper & Tina McMullen

The West Virginia Hemophilia Foundation **Annual Meeting** was quite an event this year! Attendance was high as families from all over the wild and wonderful state met in Bridgeport for a fun-filled

day with excellent programming and invaluable together time. Topics presented included *Self-Advocacy, Gene Therapy* and *Cognitive Conversations*. Great presentations were also given on joint health and new technology offered at the Charleston Area Medical Center.



Fernando presents Steve and Lisa with the 2019 Volunteer of the Year award

and new developments involving hospital expansion and more room and resources for the West Virginia University HTC. New Executive Director Fernando Andrzejevski outdid himself for his first annual meeting! We are so looking forward to seeing what he plans for the chapter in 2020!

### **NEW YORK**

Richard Vogel For me, the holidays start when the New York City Hemophilia Chapter (NYCHC) holds their *Gala and Education Day Weekend* just before Thanksgiving. NYCHC held its



Blood Brothers Rich and Tommy

annual **Gala** weekend November 16<sup>th</sup> at NYC's Crowne Plaza Hotel, raising money to support its mission of advocacy, travel grants, and education. The event also celebrates community and friends. Those honored were:

- Advocate of the Year and clinical psychologist in New York City, Dr. Regina Legere-Buccellato became a true advocate for her children in 2009. She is a tireless supporter of the bleeding disorders community and has traveled to Albany, NY and Washington DC to share her family story with lawmakers so the bleeding disorders community can have better access to care.
- Volunteer of the Year, Yasmin Parvi initially became involved to learn more about her son's condition.
  After receiving help and education from NYCHC, Yasmin decided the way to give back was to volunteer for the chapter and the community.
- Award of Distinction was bestowed upon the entire Cirelli family. Dino, Erin, John and Nicholas have the distinction of raising over \$750,000 for NHF

Judith Graham Pool Research. This phenomenal feat has been accomplished by hosting a fundraising walk in their town and getting support from their local community, almost all with no connection to bleeding disorders.



Dino, Erin, John and Nicholas receive the Award of Distinction



Dinner and dancing into the evening followed and the next day, NYCHC held their **Educational Day and Holiday Celebration** at the Crowne Plaza in Times Square. The day started with plenty of time to visit and talk with industry and specialty pharmacies before the educational workshops began. Key session *Gene Therapy* with Dr. Pedro Sanchez provided a general overview of types being

Pat Torry

investigated, and questions that existing trials are trying to answer. The lunch session, *Prioritizing Your Self Within Your Diagnosis* by Pat Torrey of GutMonkey, took us on a journey and challenged us to not just manage a bleeding disorder but to embrace it and cultivate a fulfilling life in spite of it.

Additional sessions throughout the day addressed concerns currently facing the bleeding disorders community such as mental health, women with bleeding disorders regarding the bias and underdiagnosis, and new therapies and safety. Daycare for ages 0–5 and a youth track for ages 6–12 led by NYC Children's Theater was available so young families could attend sessions without distraction. Teens enjoyed an indoor camp session hosted by Hole in the Wall Gang – something for everyone!

No NYCHC education day would be complete without the holiday party and this year was no exception. As Santa arrived to spread festive cheer, the ballroom rocked to the sounds of our very own community member, Deejay Omar. *Now* I'm ready for the holidays!

### **FLORIDA**

#### **Peggy Klingmann and Marcy Foertsch**

BioMatrix and Takeda teamed up to present an *Educational Dinner* November 20<sup>th</sup> at Tampa's Maggiano's Little Italy Restaurant. Everyone listened intently to Takeda Nurse Educator Patricia Espinosa, who gave a synopsis on von Willebrand Disease, and the shared participation was interesting and informative to all. Well-attended by bleeding disorder members, it is safe to say that the Italian cuisine was enjoyed to the fullest.

### **NEW MEXICO**

#### Felix Garcia

School was out at 2:20 pm and registration for the Sangre de Oro, Inc. **Patient and Family Education Weekend** opened at 3:00! With bags packed and ready, families headed to the Albuquerque Marriot Pyramid North November 22-24 for a family weekend of fun,

camaraderie and, of course, education, with other New Mexico bleeding disorder families. Over 200 attendees – old friends from years past and new families attending their first time - were met with open arms.

Friday evening began



Thumbs up from Miguel, Maribel, Michelle, Miguel, Jr. and Felix Garcia

with a presentation by American biotechnology company Sanofi Genzyme and was followed by a chapter announcement that for the first time, the entire community was going to be able to elect their board members. Over a dozen educational sessions followed on Saturday, wrapping up with a BioMarin presentation on gene therapy after dinner. Then it was time for adults in the Sangre de Oro community members to nominate and vote for Executive Board, Board of Directors and Advisory Board seats. A tremendous response ensued with the board growing from 6 to 18 members!



Felix Garcia with Alfonso and Aptevo's Steve Calderon

I am personally grateful to have been elected to serve as a board member for 2 more years and BioMatrix is proud to support this growing organization. Congratulations Sangre de Oro on a wonderful event!



Smiles light up the room! Rania Salem and Marissa

opportunity for the bleeding disorders community to get together for a memorable afternoon of fun, food and fellowship! The event was hosted by KHF President Ursela Kamala and her amazing staff who did an incredible job organizing a wide array of activities to keep all ages well entertained! Some of these included a baked-goods contest, silent auction items, door prizes, a hip DJ who offered us festive sounds of the season and a buffet dinner including sweet holiday cookies. Santa even took time from his busy schedule to attend the celebration carrying a sack chockfull with gifts for the children. He even paused to enjoy his favorite milk and cookies snack! Many thanks to KHF and their dedication to yet another happy gathering!

**KENTUCKY** 

**Bill Wilbert and Rania Salem** 

The Kentucky Hemophilia

Foundation (KHF) held its

**Event** Sunday, December

1<sup>st</sup> at Louisville's Holy Trinity

was a wonderful conclusion to

Thanksgiving week offering an

Clifton Campus. The event

annual Year-End Family

### **FLORIDA**

Peggy Klingmann and Marcy Foertsch

BioMatrix and Bayer hosted an **Educational Dinner** at St. Petersburg's 400 Beach Seafood Restaurant December 5<sup>th</sup>. Jessica Lover Camp, RN with Bayer presented an overview of Jivi. Following was a discussion by our own



Mason and Sarah bask in the holiday glow

Education Specialist Shelby Smoak, Ph.D., speaking on *Open Enrollment*. It was a timely and important discussion shedding light on changes within the health insurance landscape providing information beneficial to the bleeding disorder community. Shelby was informative, engaging and remained accessible for attendee questions after his presentation.

The evening ended with a holiday ornament exchange and the opportunity for everyone to take in the festive holiday lights at the lovely North Straub Park.

### **NEVADA** Kelly Gonzalez

Las Vegas weather was a winter wonderland for few brief moments December 7<sup>th</sup> as snowflakes drifted down, eventually melting on the ground. The chilly weather prepared us for Santa's arrival at the *Las Vegas Family Day and Winter Celebration* 



Chapter advocacy team Emily, Kelly and Jamie

hosted by Nevada Chapter of NHF at the **Orleans** Convention Center in Las Vegas. Over 150 members of Nevada's bleeding disorders community gathered for lunch, industry visits and to learn about advocacy, school visits, insurance issues, vWD and gene therapy. Teens and children attended sessions on paint therapy, crafting and to be expected, a little goofing around!

After sessions wrapped up and a chapter update was shared, the room was quickly converted into Winter Celebration including a cookie bar,



Friends! (back row) Maddie, Sofia, Faith, Natalie and Joey, (front row) Andres, Joey, Jaxon and Jacoby



Natalie, Sofía, Faith and Joey – all hugs and smiles

hot cocoa, crafts, games, a silent auction, and of course, a visit from the big man himself – Santa! Thank you to the Chapter for this festive opportunity to bring the community together!

### PENNSYLVANIA

### Tina McMullen

Holiday celebrating was in full swing for 170 people who attended the Eastern Pennsylvania Hemophilia Foundation **Annual Holiday Party**! Held at Philadelphia's Canstatter Volksfest Verein Saturday, December 7<sup>th</sup>, the party began with a holiday feast followed by entertaining family activities.

lcing and sprinkles flowed at the BioMatrix table, sometimes in great mounds, as children and parents

decorated their own cookies. Other activities included decorating stockings or Santa hats and playing a big game of Connect Four. The day also featured comedian Jungle John and his sidekick "Frostbite" the snowman puppet in his Winter Wonderland Magic Show.

After the show and before Santa arrived it was make-your-own sundae time with lots of chocolate syrup and whipped cream to go around. To the joy of children, the star of the day finally appeared – Santa Claus! It was truly an amazing holiday celebration for the families of eastern Pennsylvania!



Cora shows off her frosting skills



Eva Kraemer, David and Hiro share their holiday wishes with Santa

### ILLINOIS Eva Kraemer

The Bleeding Disorder Alliance Illinois celebrated its annual **Holiday Party** Saturday, December 7<sup>th</sup> at Countryside's William Tell Holiday Inn. About 75 bleeding disorder community members, family and friends feasted on a buffet while a warm fire burned at the hearth and in our hearts. Everyone felt jolly while creating homemade ornaments. Santa made a special appearance, just in from the North Pole, to spread goodwill and presents to children of all ages, sitting for keep-sake photos to be cherished for years to come. We delighted in story sharing from the year gone by while looking forward to a very happy and healthy 2020!



Not sure whether the conversation had to do with naughty and nice lists, but everyone was excited to visit with Mr. Grinch!



### OHIO

Shelia Biljes

Whose heart cannot keep from growing three sizes when the little ones of the Northern Ohio Hemophilia Foundation gather for a **Holiday Dinner**! This year was extra special as Mr. Grinch came down from Mount Crumpit to attend a festive gathering at Akron's Stan Hywet Hall December 7<sup>th</sup>. He was smothered in holiday cheer as 150 guests gathered to celebrate.

A delicious dinner of "Who Hash and Roast Beast," well, actually lemon chicken, pasta and roast beef with cheesecake for dessert were enjoyed by all. Children spent time at each sponsor booth – Bayer, CSL, Aptevo, Takeda, and Sanofi – to make various Grinch crafts and participate in a coloring contest, while adults had fun playing a holiday trivia game.

Before the evening came to an end, families were invited to delight in a Deck the Hall Tour of the very beautiful home of Goodyear's co-founder, F. A. Seiberling. Now a National Historic Landmark, it is noted to be one of the largest homes in the U.S. The gorgeous mansion displayed a spectacular exhibit of twinkling splendor that amazed both children and adults alike!



Well, not *everyone* was eager to visit Mr. Grinch. Little Evelyn needed a bit of coaxing from her sister, Madeline!

### MAINE

### Richard Vogel and Cheryl Ashmore

Maine at this time of year is like being in a Hallmark movie. If you need to get into the holiday spirit, there is no better place than the Samoset Resort in Rockport where the Hemophilia Alliance of Maine (HAM) held **Winterfest** December 7<sup>th</sup> and 8<sup>th</sup>.



Terry Rice building confidence

Saturday began early with breakfast and time to visit with industry before the presentations. First up was Executive Director Tracey Gideon who reviewed the past year's accomplishments and what's in store for 2020. The large crowd then broke into groups for rap sessions where conversation flowed freely. Next up was a presentation on NHF's Unite for Bleeding Disorders giving pointers on how to participate in the popular community walks – so very important because funds raised help HAM increase education, support services and advocacy in Maine.

Jeanne White-Ginder spoke about her son Ryan and the prejudice they encountered when he contracted HIV/ AIDS from contaminated factor in the 1980s. After such a moving story that still touches this community today, it was time to enjoy the holiday season and celebrate our community. While some went on a snow-covered breakwater walk, others decided to stay warm and paint snowmen. With Maine's winter wonderland, it's no surprise Santa Claus made an early appearance with gifts for all the children and young adults.

Sunday morning Genentech partnered with UPENN to present *The Science of Optimism*. The interactive presentation focused on overcoming adversities and turning negatives into positives. In one exercise, each group had to build a pyramid of plastic cups without touching them using only a string and rubber band to build the highest pyramid.

As in all holiday Hallmark movies, everyone found the true meaning of the holidays - being with family.

### UTAH

### **Kelly Gonzalez**

Caffé Molise in Salt Lake City provided the perfect setting December 10<sup>th</sup> for a **Holiday Educational Dinner**. Attendees gathered to hear an

discussing caregiver burnout. Holiday

illuminating program, Self-Care,



crafting and fun soon followed! Sponsored by Octapharma in conjunction with BioMatrix, the holiday gathering was 'happening!'

### NEVADA

Kelly Gonzalez The flurry of winter weather was not surprising as we all assumed Santa brought it in with him for *Elko Family Day and Winter Celebration* December 11<sup>th</sup>



Maureen, Becki, Mrs. Clause, Santa, Lisa and Kelly had a great time organizing the event

at the Hilton Garden Inn! After an educational presentation on advocacy, a variety of holiday dishes were served for dinner. Then it was time for a special visitor! Jolly Ol' St. Nick arrived to visit and share in a reindeer craft with all the families. This holiday event was brought to the community by the Nevada Chapter of NHF, Hemostasis and Thrombosis Center of Nevada, Octapharma and BioMatrix. We were very happy to have so many families join us! Thank you!





Lisa Preciado and Kelly Gonzalez pause to smile

Maureen and Kelly snap their annual photo

### NEVADA

### **Kelly Gonzalez**

Cheer and excitement echoed through the halls of Hunsberger Elementary School on the evening of Thursday, December 12<sup>th</sup> as the setup for Santa's arrival for the Nevada Chapter of NHF's **Reno Family Day and Winter Celebration** began. Before the special visitor's arrival, parents became more empowered with an educational advocacy overview while younger community members had fun with stations for activities, games, crafts and a raffle. Suddenly there was a loud thud followed by the jingle of bells as Jolly

Ol' Santa landed in Reno for a visit! Joyous squeals of excitement from the kiddos confirmed that this night was one to remember. Thank you to all those who made this celebration of the season possible!



Kelly Gonzalez looking jolly with Elizabeth and Maureen

**BIOMATRIX NEWS** 

### **UPCOMING EVENTS**

### **JAN. 17, 2020 NEW MEXICO**

Sangre de Oro, Inc. 505-341-9321, sangredeoro.org **Breaking Blood Men's Group** ABQ Axe, Albuquerque

### JAN. 19-20, 2020 VIRGINIA

VA Hemophilia Foundation/HACA 804-740-8643, vahemophilia.org *Richmond Days* Omni; Richmond

### FEB. 7, 2020 NEVADA

NHF, Nevada Chapter 702-564-4368, hfnv.org *Winter Wine Fest and Silent Auction* Brio Town Square; Las Vegas

### FEB. 8, 2020 MARYLAND

Hemophilia Foundation of Maryland 410-661-2307, hfmonline.org *Meeting & Educational Dinner* Four Seasons; Baltimore

### FEB. 15, 2020 MARYLAND

Hemophilia Foundation of Maryland 410-661-2307, hfmonline.org **Bull & Oyster & Shrimp Feast** UAW Hall; Baltimore

### FEB. 20, 2020 ALABAMA

BioMatrix with CSL Behring Cyndy Coors 251-243-1623 cyndy.coors@biomatrixsprx.com *Music Therapy* Marriott; Birmingham

### FEB. 22, 2020 PENNSYLVANIA

Eastern PA Hemophilia Foundation 484-445-4282, hemophiliasupport.org **Bowling for Fun** Devon Lanes, Devon

### FEB. 22-23, 2020 OHIO

Tri-State Bleeding Disorders Foundation 513-961-4366, tsbdf.com **TSBDF Family Education Conference** Great Wolf Lodge; Mason

### FEB. 29, 2020 CALIFORNIA

Hemophilia Foundation of Southern California 626-765-6656, hemosocal.org **Advocacy Forum SoCal EmPOWERment** & 4<sup>th</sup> Annual Bloody Hot Salsa Challenge Pickwick Gardens; Burbank

### FEB. 29, 2020 NEW JERSEY

Hemophilia Association of New Jersey 732-249-6000, hanj.org *Winter Gathering* iPlay America, Freehold

#### MARCH 7-8, 2020 MASSACHUSETTS

New England Hemophilia Association 781-326-7645 newenglandhemophilia.org

*First Connections (Family Retreat)* Sheraton Monarch Place Hotel Springfield

#### MARCH 7-8, 2020 VIRGINIA

VA Hemophilia Foundation 804-740-8643, vahemophilia.org **2020 Medical Symposium** Richmond Marriott Short Pump Glen Allen

#### **MARCH 13-14, 2020, VERMONT**

Connecticut Hemophilia Society 860-997-4525, cthemophilia.org **16<sup>th</sup> Annual Alpine Walk** Mount Snow, Dover

#### MARCH 13-15, 2020 PENNSYLVANIA

Eastern PA Hemophilia Foundation 484-445-4282 hemophiliasupport.org **Women's Retreat** 

Chubb Hotel and Conference Center Lafayette Hill

#### MARCH 28, 2020, CONNECTICUT

New England Hemophilia Assoc. 781-326-7645 newenglandhemophilia.org **Consumer Medical Symposium** Sheraton Hartford South Hotel; Rocky Hill



### NATIONAL EVENT! MARCH 19–22, 2020 FLORIDA

The Coalition for Hemophilia B 212-520-8272, www.hemob.org

> Annual Symposium Renaissance Orlando at SeaWorld

### MARCH 28, 2020 NEVADA

NHF, Nevada Chapter 702-564-4368, hfnv.org **Springfest: Spring Education** Circus Circus Convention Center Las Vegas

#### MARCH 28, 2020 VIRGINIA

703-352-7641, HACAcares.org *Annual Family Education Day* Northern VA Community College Annandale

#### APRIL 3-5, 2020 MICHIGAN

Hemophlia Foundation of Michigan 1-734-544-0015, hfmich.org *SpringFest 2020* Amway Grand Hotel; Grand Rapids

### APRIL 18, 2020 FLORIDA

Foundation Hope & Life USA 786-534-2900 www.fhlusa.org **7<sup>th</sup> Annual "Light of the World Candlelight"** Mansion Las Vegas Ranches Cooper City

### APRIL 18, 2020 ILLINOIS

Bleeding Disorders Alliance Illinois 312-427-1495, bdai.org *Spring Gala* Itasca County Club; Itasca

### **APRIL 18, 2020 WEST VIRGINIA**

West Virginia Chapter, NHF 681-212-9255, wvnhf.org *Industry Symposium & WVU vs Kansas State Basketball Game* Monongalia County Ballpark; Morgantown



### NATIONAL EVENT! APRIL 23–26, 2020 MARYLAND

Hemophilia Federation of America 202-675-6984, hemophiliafed.org **Annual Symposium "Charting Our Future"** Hilton Baltimore Inner Harbor

## TIME FOR FUN!



HI KIDS!

Trimble is a trivia game and a word jumble all in one! To play, first
answer the questions, then cross out all the letters used. Rearrange
the remaining letters to reveal another bleeding disorders related
word. Good Luck! Answers can be found on page 17.

/	Α	Α	Α	В	D	D	Е	Ε	Ε	Ε	Е	Е	Ε	Е	F
F	G	G	Н	н	Т	1	1	1		Т	L	L	L	Μ	Ν
Ν	Ν	Ν	Ν	0	0	0	0	Ρ	Ρ	Ρ	U	U	U	U	U
Q	R	R	R	R	S	S	Т	т	Т	Т	Т	Y	Y	Ζ	

(2 words)\_\_\_\_

1. A small square of cloth that is used to cover the infused vein after the needle is removed.

(2 words)\_\_\_\_

- 2. A device that holds liquid medicine and is then used to push medicine into the vein through a needle.
- 3. A strap used to temporarily limit the flow of blood to a limb so that the vein plumps up making it easier to infuse.

- 4. A device that is implanted under the skin that allows easy access into a person's vein.
- 5. A device that is very sharp on one end and has "wings" to hold onto. It is often used to give liquid medicine to patients.
- 6. A way to deliver liquid medicine into a vein.

### WORD JUMBLE: \_\_\_\_ \_\_\_

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

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

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

# BIOMATRIX]

### **Corporate Office**

855 SW 78<sup>th</sup> Ave., #C200 Plantation, Florida 33324

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

Visit us online: bleedingdisorders.biomatrixsprx.com fb.com/BioMatrixBleedingDisorders

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