Matrix Health Group

A BIOMATRIX SpRx Company

NEWS

DEDICATED TO MAKING A DIFFERENCE

Summer 2018
VOLUME 13 | ISSUE 3

> **What seems to us as bitter trials are often blessings in disguise.**
>
> **- Oscar Wilde**

VOLUME 13 | ISSUE 3
SUMMER 2018

A NOTE FROM THE EDITOR

Dear Readers:

With summer weather comes an explosion of bleeding disorders community events across the nation. We hope you take advantage of these events hosted by hemophilia chapters, organizations, manufacturers, and specialty pharmacies. The education, the networking and most importantly, the friendships and bonding that take place by meeting and interacting with people who walk in our shoes is invaluable!

Though my children are now grown, friendships made and events attended through the years will always have a special place in my memory and in my heart. Would I have been happy to walk another path? Maybe, but I'll never regret being part of this incredibly loving, caring, supportive and special group of people.

Enjoy your summer and please enjoy this issue of Matrix Health Group News!

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

MISSION + VISION

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

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

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

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

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

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

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

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

FINE PRINT

Editor-in-Chief: Maria Santucci Vetter, Consultant with US Health Group
Editors: Susan Moore and Justin Lindhorst, Consultants with US Health Group

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

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

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

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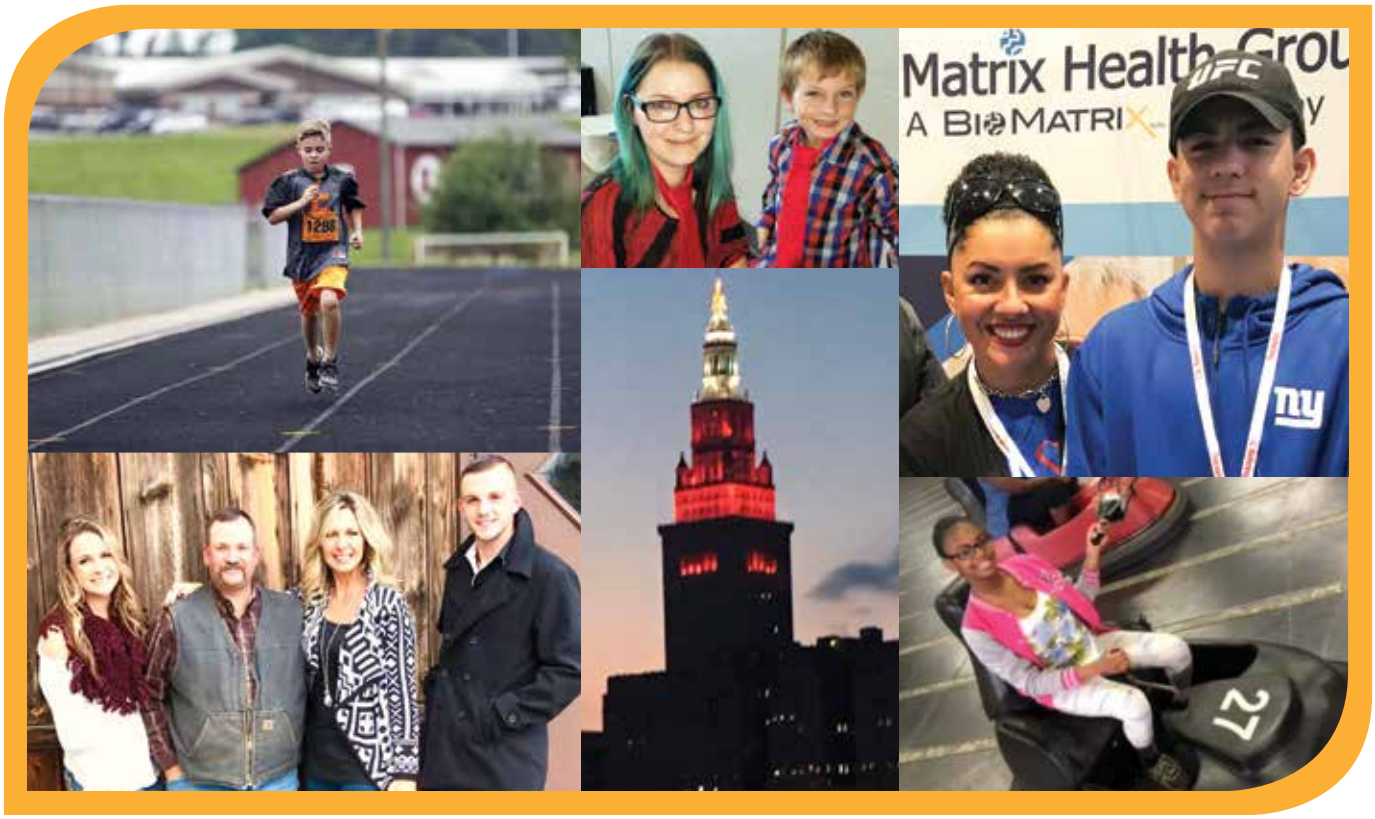

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INFO@MATRIXHEALTHGROUP.COM
WWW.MATRIXHEALTHGROUP.COM

Experienced, compassionate Care Coordination Team with a personal contact assigned to each patient for pharmacy, reimbursement and support services

Professional Pharmacy Team with extensive knowledge of bleeding disorders available 24 hours a day, 7 days a week

Pharmacies in California, Florida, Illinois, New Jersey, Ohio, Pennsylvania, Tennessee and West Virginia. Our services span across the nation

24-hour standard delivery; emergency shipments when needed

Coordination of home nursing services specializing in bleeding disorder care

Highly trained billing and reimbursement staff are well equipped to assist with insurance coverage issues, both public and private

Multifaceted team approach promoting adherence to treatment plans, resulting in positive health outcomes

Informative quarterly newsletter, Matrix Health Group News

NEW RECOMBINANT VWD THERAPY AVAILABLE AT BIOMATRIX

BioMatrix Specialty Pharmacy is now an authorized provider of Shire's limited distribution drug, Vonvendi™ [von Willebrand factor (Recombinant)]. Vonvendi is the first recombinant product indicated for on-demand treatment and control of bleeding episodes in adults diagnosed with von Willebrand disease (vWD).

Vonvendi is infused intravenously to replace missing or dysfunctional von Willebrand factor (VWF). It is the first product to offer recombinant von Willebrand factor (rVWF) independent of recombinant Factor VIII (rFVIII), allowing for a more tailored, patient-specific treatment approach. Phase 3 open-label clinical study data demonstrated 100% treatment success using Vonvendi to control bleeding episodes.

"As a specialty pharmacy with extensive experience helping people with bleeding disorders effectively manage their condition, we are pleased to offer Vonvendi," said BioMatrix Chief Clinical Officer Marc Stranz. "We are committed to connecting patients with the products, resources, and support to live a healthier life."

BioMatrix is Dedicated to Making a Difference for the bleeding disorder community. Our experienced team will obtain timely authorization for service and connect you with resources and support to effectively manage your condition. Complete a no-obligations referral or reach out to your local Regional Care Coordinator today!

Accepting Applications for the 2018/19 School Year!

BIOMATRIX MEMORIAL SCHOLARSHIP PROGRAM

APPLY ONLINE BEFORE AUGUST 1st!

http://bit.ly/2018-BioMatrix-Scholarship

The BioMatrix family of companies offers six $1500 educational scholarship opportunities to students diagnosed with hemophilia or von Willebrand Disease, and in the case of two of the scholarships, immediate family members may also apply. These scholarships are in memory of several amazing individuals who brought remarkable qualities and skills together in a way that truly touched the community they were dedicated to serving. Their efforts to make a difference in the lives of people with bleeding disorders will not be forgotten and shall be carried on with these scholarship opportunities.

We have partnered with the Hemophilia Federation of America (HFA) to administer our scholarship program. Partnering with HFA allows us to streamline and enhance our growing program with an organization that knows and understands the bleeding disorders community. The scholarship application may be accessed and submitted to HFA online or by visiting:

https://matrixhealthgroup.com/scholarships/

Joe Holibaugh (1972-2006)
- $1500 Scholarship
- For MEN and WOMEN with hemophilia AND an Inhibitor

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

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

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

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

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

THE 2018 NHF REDTIE CAMPAIGN™

FOR ALL BLEEDING DISORDERS

APRIL 17th WORLD HEMOPHILIA DAY!

BioMatrix and US Health Group team members participated in the Red Tie Challenge!

The Red Tie Challenge was created by the National Hemophilia Foundation to raise awareness and funds for the bleeding disorders community.

https://redtiecampaign.org/

THE RISK OF ARTHRITIS AMONG WOMEN WITH BLEEDING DISORDERS

Paul R. Brayshaw, M.P.H.
Community Advocate, US Health Group

Hemophilic arthropathy (joint disease) is well defined in males with hemophilia and other bleeding disorders, and the effect of excess bleeding into a joint is a long-established comorbidity. But while hemophilic arthropathy is well known and studied in men with bleeding disorders, what of women? Women with bleeding disorders or those who are at risk may be exposed to challenges associated with arthritis when a proper diagnosis and treatment regimen is delayed, or if care is denied.

"Arthritis is the leading cause of disability in the US... Doctor-diagnosed arthritis is more common in women (26%) than in men (18%)," according to the Arthritis Foundation website (www.arthritis.org).

While it may seem obvious, hemophilia related arthritis is not gender specific and data to establish this relationship is limited. A 2014 study by Sidonio, et al., published in the American Journal of Hematology sought to provide evidence of the relationship between women with bleeding disorders and the shared risk profiles among this population.

The study concluded that female hemophilia carriers of all ages had evidence of joint abnormalities as early as the pre-teen years regardless of the severity of hemophilia symptoms, and suggested joint bleeding might be occurring before the adolescent years. The study established a statistically significant reduction in range of motion in all severities and in all age groups of women who were enrolled (Sidonio RF, 2014).

The increased rate of arthritis development among women may be due to delayed diagnoses, misdiagnoses, and/or initiation of treatment. Other possible contributing factors that may increase the risk of arthritis among women with a bleeding disorder involve biological factors like childbearing, genetics, and hormones. The exact connections are not completely clear between these factors, but the ability to give birth requires more flexible tendons and musculoskeletal differences to enable childbearing. Also, rates of osteoarthritis among women are greater than men, especially after menopause.

Additional studies are critical to establishing the connection between increased rates of arthritis among women with bleeding disorders. Until those studies are complete, women who are at risk of having a bleeding disorder should consider visiting a hematologist for a proper diagnosis, and coordinate a possible treatment regimen that may include clotting factor. The options for the treatment and management of a bleeding disorder are greatly improved and risk of arthritis development significantly reduced with an appropriate diagnosis and treatment.

Reference:
Sidonio RF, Mili FD, Li T, et al. Females with FVIII and FIX deficiency have reduced joint range of motion. American Journal of Hematology. 2014;89 (8):831-836. doi:10.1002/ajh.23754.

INFUSING LOVE AND NEVER GIVING UP

Our son, Dakota was not diagnosed with severe hemophilia at birth – as a matter of fact, he wasn't diagnosed until he was 13-months-old. How could this go undetected for so long?

BY KIMBERLY ROSENFELT
Community Member

At about 7 months of age when he started crawling and pulling himself up to the sides of furniture, Dakota began showing signs of something being wrong. We began inquiring about the deep "scary" looking bruises on his body. His pediatrician initially brushed it off saying he was a large baby – Dakota was in the 100th percentile, and yes, he did like to eat! My husband and I didn't give up on searching for a reason for those terrible bruises.

During this time, I attended the University of Kansas Medical Center to complete my Bachelor of Science in Respiratory Therapy and had access to the medical library on campus. Over the next few months, I researched and printed off pages and pages of information and brought my findings to the attention of Dakota's pediatrician. However, instead of listening to my concerns, the pediatrician had his own agenda. While I asked for blood tests with each visit, he was busy documenting the number of bruises on Dakota, noting the severity of each one. He would later report us into the Division of Family Services where we were interrogated, along with our family and neighbors, on the type of parents we were. That would prove to be one of the scariest, most frustrating and embarrassing times of our lives.

The pediatrician defended his actions by stating the disorders I brought to his attention were not possible since there was no family history of any of them. He discounted every single one of my thoughts and concerns, saying they were invalid since the disorders listed were all hereditary conditions. Following the accusations of child abuse and despite all obstacles, we continued on our mission to find a solution.

For fear of going through the accusations all over again, we continued to use the same pediatrician. Finally, the day came that proved our instincts regarding our child having some sort of bleeding disorder was "spot on!" There was no swelling, no redness and no bruising, but my little boy's calf muscle was hard as a rock. We took him to the emergency room where his pediatrician met us. I again demanded a PTT or *Partial thromboplastin time* which is a blood test that measures how long it takes for blood to clot. It was finally drawn. Sadly, it took us threatening the pediatrician with legal action to finally have tests run to get a diagnosis.

The next day, Dakota was officially diagnosed with severe hemophilia A by a hematologist at the local hemophilia treatment center. At that point, the diagnosis did not come as a shock, nor were we surprised it was due to a spontaneous mutation.

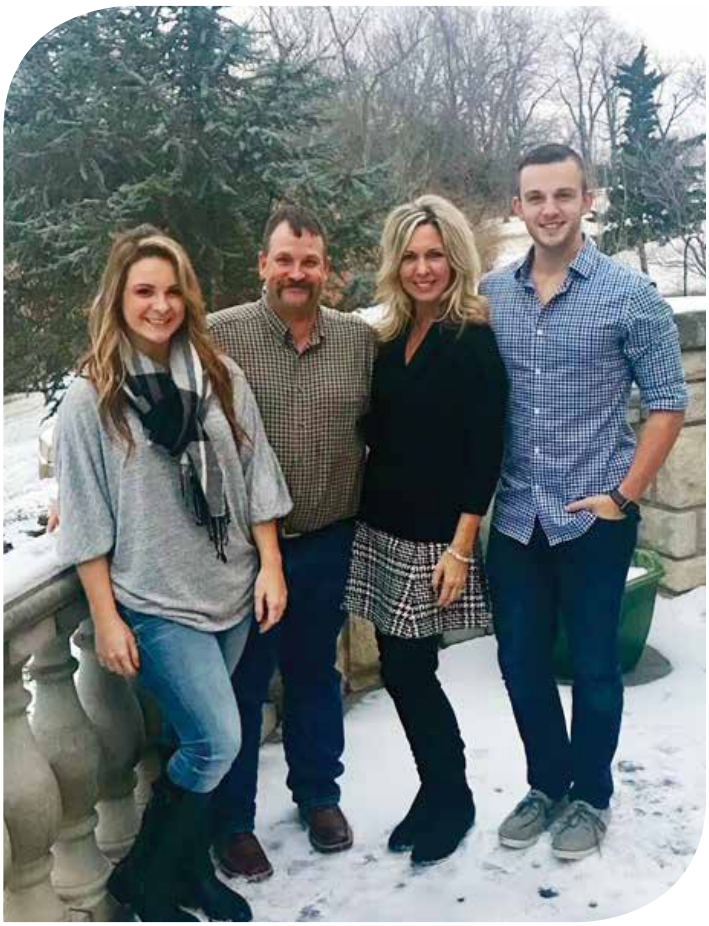
We are truly fortunate and blessed to have a very supporting and loving extended family. As a family, we wanted to educate ourselves and learn every aspect this disorder entailed. Soon we were all involved with our local chapter and through the years, have networked with many families in the bleeding disorders community. We quickly learned we were not alone and those very important connections helped us cope, provided resources and taught us many valuable lessons.

We began teaching Dakota to learn to manage his hemophilia at a very early age. As young as 3 years old, we taught him how to mix his factor. By the time he was 6 or 7 years old, with a little assistance, he became responsible for logging his infusions. A major step toward teaching our son to independently manage his care was to learn to self-infuse! The wonderful nurses at our summer camp for children with bleeding disorders took this leap of faith and taught Dakota to self-infuse at the age of 10!

Just a few years later, he took part in a study and had to use a rather cumbersome device to track his infusions. It was during the time when smartphones were becoming popular. I resisted utilizing anything but paper logs, as they were always tried and true, and easily customizable to fit my needs, but Dakota figured there had to be a better and simpler way to track his bleeds and log his treatments.

In 2010, Dakota presented an idea to create a mobile app to address his needs and that would provide a simple, effective way to continue with the independent management of his care. Our family jumped into action to help Dakota fulfill his dream of creating something beneficial, not just for him, but also for his much-loved bleeding disorder community.

Dakota is interviewed by a local news station regarding hemophilia, self infusion and tracking treatments.



Dakota with his parents and sister.

And thus, HemoTool was born! Unfortunately, the following trials and tribulations tested his abilities. In due time, the original app's platform and its language had become extinct, but Dakota was not giving up. Once again, our family sprang into action to help keep his dream alive. Through hard work, more research, and input from our amazing community members, the new HemoTool was born in 2017!

My hope is that by sharing this short story of our journey, we can inspire others to never give up. There are no excuses - you may have to change direction, but just keep going! Dakota is now 23 years old. He attends University of Kansas Medical Center School of Pharmacy and will complete his PharmD in 2019. He has never used his hemophilia as an excuse - he has lived his life figuring out alternatives and has always believed there are no limits except for the ones we set ourselves! Become that advocate for yourself, for those you love, and for those that cannot advocate for themselves! He strives to be that mentor who encourages everyone he encounters to be the best they can be!

*HemoTool is a non-branded multi-feature treatment logging app created by Dakota for his community. It is available for download from the Apple Store and from Google Play. To find out more about HemoTool and Dakota, visit www.HemoTool.com or follow HemoTool on Facebook, Instagram and Twitter.

MEDICARE

TOP THINGS YOU SHOULD KNOW

BY SHELBY SMOAK, Community Advocate and Educational Specialist, US Health Group
and **CHRISTOPHER TEMPLIN**, Community Advocate, US Health Group

Currently, Medicare services about 55 million persons, roughly 15% of the US population. Indeed, Medicare is a great program offering healthcare coverage to persons over 65 and those under 65 with disabilities, but Medicare's complexity cannot be overstated. Its rules have sub-rules, and those sub-rules have caveats and restrictions, and many of the decisions initially made during Medicare enrollment affect a person's access to care immediately and, in some cases, for the life of the program. Ultimately, Medicare is not a program that can easily be understood. However, we have gathered a list of helpful tools for navigating the program. We offer a very brief overview of Medicare and its parts, provide some key things to know, and close with a focus on Medicare for those with disabilities. Hopefully, some clarity regarding Medicare can be found below.

- Medicare has 5 parts that offer different coverage and out-of-pocket responsibilities. Here is a quick hit for understanding those parts and their coverage:

PART A is hospital insurance and covers in-patient care (semi-private rooms, meals and supplies). There is a yearly deductible but, once met, PART A pays days 1–60 of a hospital stay at 100%; day 60 plus, the coverage amount is set by Medicare. If a person and/or their spouse has 10 years of qualified work, there is not a PART A premium. If less than ten years, a premium will be required.

PART B is medical insurance and covers physician services, hospital outpatient care and home health care. There is a yearly deductible but once met PART B generally pays 80% of covered services. Clotting factor is covered under PART B!

PART C is Medicare Advantage and is an alternative to PART A and PART B plans, often called "Original Medicare." This plan is offered by private insurance companies and is an inclusive PART A/PART B coverage, often adding in prescription drug coverage. Premiums, copays and deductibles vary in these plans. PART C participants are not eligible for MEDIGAP coverage.

PART D is prescription drug plans. There are several different PART D plans offered and they vary in their coverage, out-of-pocket cost, and covered medications. MEDIGAP INSURANCE is also available from private companies to cover costs not paid by Medicare. These policies can be bought within 6 months of being PART B eligible.

MEDIGAP INSURANCE is also available from private companies to cover costs not paid by Medicare. PART C participants, however, are not eligible for MEDIGAP coverage. These policies can be bought within 6 months of being PART B eligible.

- There are two primary ways to be eligible for Medicare:

1. Most are eligible when they turn 65; persons receiving Social Security benefits will be automatically enrolled for PART A. Persons must notify the administration to elect for PART B benefits. Those not receiving Social Security benefits can enroll three months prior to their 65th birthday to have Medicare take effect at 65.
2. Some are eligible under 65 if they are diagnosed with a condition that has left them disabled and they have been receiving Social Security Disability Insurance (SSDI) for 2 years.

KEY THINGS TO KNOW

- Medicare communicates primarily through regular mail. READ THE MAIL. If the mailing is confusing or you need assistance in understanding it, let our team help you. CALL US!
- There is not an out-of-pocket limit on yearly cost for Medicare UNLESS you have supplemental coverage.
- Medicare Advantage PART C plans have yearly out-of-pocket cost limits. However, these can be high-cost. Original Medicare with a supplemental policy can be less expensive. Supplemental/Medigap plans cannot be bought with Medicare Advantage plans.
- Plan changes can be made each year during the enrollment period Oct. 15–Dec. 7. At that time, a person can change between a Medicare Advantage

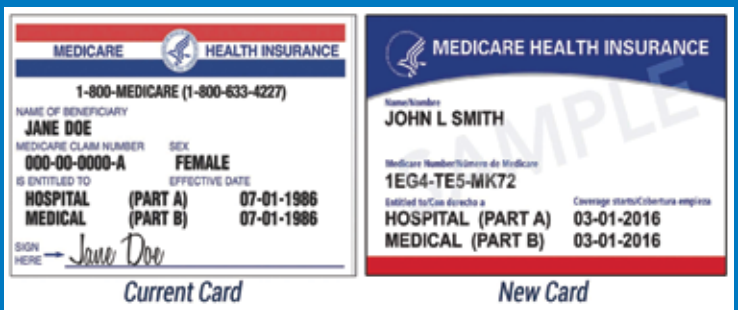
plan and Original Medicare. However, a person cannot change their actual Medicare Advantage plan.

- If a participant does not sign up for PART B during initial enrollment, they will be required to pay a late enrollment penalty of a higher monthly premium should they enroll later. To avoid this higher premium, if a person later expects to use PART B, one suggestion is enroll in PART B and suspend participation.
- If a participant does not sign up for PART D during initial enrollment, they will be required to also pay a late enrollment penalty. A higher rate will be required for every month a person delays coverage unless a person can prove other coverage was provided during that time.
- PART B and PART D premiums are based on income. In 2018, individuals earning less than $85,000 or filing jointly earning less than $170,000 will pay $134/month for PART B and the plan premium without an additional fee for PART D.
- PART D deductibles vary, but cannot be more than $405.
- PART D copayment and coinsurance kicks in after the deductible is met. Copayments charge a flat rate per prescription ($10 for example), while coinsurance asks participants to pay a percentage of the cost per prescription (20% for example).
- PART D has a "donut hole" whereby when beneficiaries reach their out-of-pocket threshold ($3750 in 2018), they then pay 100% of the drug costs until they spend the required out-of-pocket amount ($5000 in 2018). Then, PART D pays again at 95%, but the person will be responsible for the other 5% in perpetuity. This coverage gap renews annually.
- A PERSON ON MEDICARE IS NOT ELIGIBLE FOR MANUFACTURER COPAY CARDS
- A PERSON ON MEDICARE, HOWEVER, IS ELIGIBLE FOR SUPPORT FROM OTHER RESOURCES. CALL OUR TEAM TO FIND OUT MORE ABOUT THESE RESOURCES.

FOR PERSONS WITH DISABILITIES

- Persons with disabilities are only eligible for Medicare after 2 years/24 months of receiving Social Security Disability Benefits (SSDI). On the 25th month of receiving SSDI, participants will be enrolled in Medicare PART A and PART B.
- Upon receiving a declaration of medically disabled, it takes 5 months for SSDI to kick in. The two year wait for Medicare eligibility begins at the start of SSDI payment, not upon receiving disability status. Therefore, it will take 2 years and 5 months for persons with disabilities to be eligible for Medicare after their case is determined and settled. Medicare disability will be retroactively applied to the date the application was submitted. On average it takes 12-18 months for disability approval. Example: Patient A applies for disability Jan. 1, 2016. They receive disability approval Jan. 1, 2017. Disability benefits and Medicare eligibility go back to the date of filing, Jan. 1, 2016. SSDI will be valid 5 months out from that date, beginning May 1, 2016. On June 1, 2018 Medicare eligibility begins.
- Depending on income, disabled persons receiving SSDI can apply for state Medicaid to cover medical bills.
- If a person files for disability, he or she is eligible for COBRA extension of 29 months as an accommodation for the Medicare waiting period.
- While receiving disability and/or SSDI payments, income must be below $1180/month. If a person earns over that, they lose their SSDI benefits, but can stay on Medicare for several years on Medicare's *Ticket to Work* program.
- PART D has many plans. Read through them.
- Under-65-Medicare disability is paid for and supported at the state level, rather than federal level. It is subject and beholden to state laws, which vary widely. Thus, Medicare for medically disabled persons under 65 will be transitioned to a Medicare program that is supported by and run by the state the person lives in.
- Federal law does not require insurance companies to sell MEDIGAP supplemental policies for persons on Medicare under 65. Therefore, some states do not have MEDIGAP policies (Virginia, for example), and other states underwrite MEDIGAP policies with higher costs and restricted access. ALL STATES VARY IN THEIR MEDIGAP COVERAGE for Medicare beneficiaries under 65. Finding out about the state rules for MEDIGAP coverage is an essential step in understanding coverage. Please contact our team for questions about your state.

EFFECTIVE APRIL 2018 - NEW MEDICARE CARDS



BLOOD VIBRATIONS:

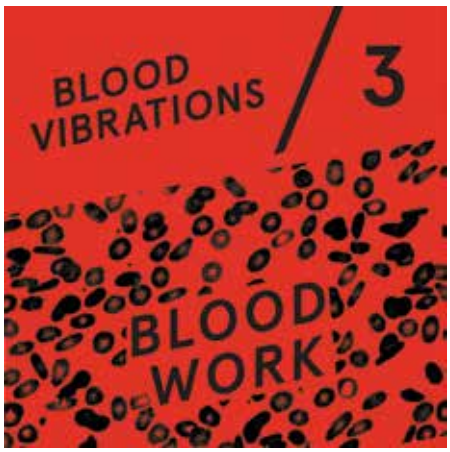
AN INTERVIEW WITH

BILLY GOLDMAN

BY SHELBY SMOAK, Community Advocate and Educational Specialist, US Health Group

BLOOD VIBRATIONS: 1
ARTIST: BILLY GOLDMAN

BLOOD VIBRATIONS: 2
ARTIST: CONSANGUINITY COLLAB



BLOOD VIBRATIONS: 3
ARTIST: JUSTIN LEVESQUE

As a musician and man behind the band *Bleeder*, it was inevitable I would stumble upon the great and ambitious project *Blood Vibrations* involving Billy Goldman, an avid music lover and member of the bleeding disorders community. Blood Vibrations aims to collect, share and catalogue music made by persons with bleeding disorders.

Yearly, Blood Vibrations is released as a digital compilation available for streaming and download on Bandcamp.com, a popular online music streaming site for musicians, and I look forward to hearing other musicians channel their bleeding disorder experiences into the emotional rhythms captured on this compilation. Recently, I had the pleasure to catch up with Billy Goldman and discuss the origins and motivation behind Blood Vibrations.

> **"THE FACT IS, THE MOST IMPORTANT MUSIC IN THE WORLD IS THE MUSIC BEING MADE RIGHT NOW."**
>
> IAN MACKAYE

Tell us about the origins of Blood Vibrations. What inspired this project?

The project seeks to provide a gathering place or archive for original music created by people in the bleeding disorders community. Having such a forum would ideally; 1.) encourage musicians to share their music with others in a way that they may not have done in the past and; 2.) allow the bleeding disorders community and beyond a place to experience music created by their members. It was important to us from the inception to keep blood vibrations free for participants and to not accept external funding—namely, there is no monetary aspect to the project.

The forum for this was a Bandcamp website (bloodvibrations.bandcamp.com). Music is available for unlimited free streaming and download by request. In addition, the website allows for biographies where people can express anything and everything about their music, creative process, living with a bleeding disorder and so on.

How has music been important in your own life?

Music has been a force in my life since I can remember. The radio, tuned to a pop or Top 40 music station, was always on when my father worked and I played in the basement as a child. When in high school, music provided a focus for my passions and a comfort to my grief following my father's death. I immersed myself fully into the world of albums, magazines and concerts. This was a nourishing activity for me alone, and with others. Years later, I began adapting my writings and poems into song and playing music with others in a variety of bands. The band experience was extremely fulfilling, engaging and empowering.

What would your life be without music?

My life and music are a unity, a oneness. I have a sense of my

"BRING SOMETHING INCOMPREHENSIBLE INTO THE WORLD!"

GILLES DELEUZE AND FELIX GUATTARI

internal music and of the external music in the world - the symphony and cacophony of everyday life. For me, music is ever-present and undeniable. Independent of this innate awareness, recorded and performed music have been so integrated into my living, in a way similar to hemophilia, that I cannot imagine a life without its presence.

What relationship do you think exists between music and illness?

To the extent listening to and creating music has fed and continues to feed my mind, body and spirit, music contributes to my health. Music supports me in the management of pain from joint bleeds and arthritis, and in the psychological challenges of living and thriving with a bleeding disorder. There is a long and significant history and literature of music and vibration as healers. In fact, some of the biographies of artists involved with Blood Vibrations mention the importance of music in their wellness.

Tell us about the community support and reaction you've received since doing this project.

Support has been wide-ranging from the Hemophilia Federation of America, the National Hemophilia Foundation, the World Hemophilia Federation, local organizations/ chapters and privately run groups such as FOLX (folxfolx.org), Hemohelper (hemohelper.com) and LA Kelley Communications, Inc. (kelleycom.com). Overall, the reaction has been one of excitement, encouragement, and gratitude.

"THE JOY OF MAKING MUSIC BELONGS TO EVERYONE."

COMMUNITY MUSIC CENTER SAN FRANCISCO

What advice would you give to a musician with a bleeding disorder interested in Blood Vibrations? What criteria do you require when considering submissions?

Create music as only you can. Share it on blood vibrations and thereby with the bleeding disorders community and beyond. Any type of exploration in sound is encouraged. All ages. Any style and approach. Fidelity across the spectrum from boom box field recordings to multi-track recording studio extravaganzas. With or without music. With or without voice. The only requirements are that someone has a bleeding disorder and that the music is original, though it can be a sampling mash-up creation.

Music submissions and any questions can be addressed to: bloodvibrations@yahoo.com. Submissions are also welcomed for album cover art. All album covers have been created by members of the bleeding disorders community. Music and album cover art submissions are accepted on an ongoing basis. A current goal for the project is to engage participation of people from a variety of gender identities and of people living outside of the United States. Spread the good word about Blood Vibrations to one and all, near and far. Word of mouth, physical and digital, is the way!

Tell us about Blood Vibrations: 7!

Beginning with Blood Vibration: 3, a new album has debuted during the NHF Annual Meeting at the Blood Vibrations Listening Center as part of the Blood Work exhibition by our partner FOLX. Blood Vibrations: 7 is anticipated to debut during the next annual meeting in Orlando, Florida this October. We invite everyone to check us out!

BLOOD VIBRATIONS: 4
ARTISTS: JUSTIN LEVESQUE AND PAT MANCINI

BLOOD VIBRATIONS: 5
ARTISTS: CHRISTOPHER STATTON AND MEGAN WILSON

BLOOD VIBRATIONS: 6
ARTIST: DOUG RICE

HEMOPHILIA FEDERATION OF AMERICA 2018 SYMPOSIUM

A RECAP

BY SHELIA BILJES
Regional Care Coordinator, US Health Group

The Hemophilia Federation of America is well known for the educational classes offered at their Annual Symposium and the 2018 Symposium in Cleveland was no exception! Each day of the Symposium, April 26–28, was jam-packed with a full array of sessions ranging from advocacy, industry innovations and inhibitors to legislation related to bleeding disorders, mental health issues and pain management. Some of the sessions I found most interesting are summarized below.

Dr. Sanjay Ahuja, Director of Hemostasis & Thrombosis Division of Hematology and Oncology at University Hospitals Rainbow Babies & Children's Hospital, is an amazing physician when it comes to innovation and information on new products. He presented *What's on the Horizon?* with great detail, speaking about promising products currently in clinical trials and gene therapy. With Dr. Ahuja was Cathy Tiggs, Adult and Pediatric Social Worker, University Hospitals Cleveland Medical Center, who highlighted that with so many changes and options coming, fears are normal. She stated, "One reason people resist change is because they focus more on what they are losing rather than on what they have to gain." She reminded everyone to make a list of questions for their HTC staff and always discuss their fears.

A huge topic in America today is the abuse of opioids. Kirsten Langdon, PhD, Clinical Psychologist at Lifespan Recovery Center in Providence, Rhode Island, and Dr. Kimberly Mauer spoke openly about its effects on the bleeding disorders community in a session titled *Opioid Prevention and Dependency*. In the bleeding disorder arena, physicians have started to use Naltrexone to reduce opioid use. Lidocaine IV is being used along with other therapies, including physical and behavioral. Diet is now also playing a large role in pain relief. Gluten-free diets eliminate inflammation and

help reduce pain, according to the speaker. "Finding balance is the key."

In another session, the same Dr. Kimberly Mauer teamed up with Samantha Carlson, LMSW, Director of Patient Support Services at West Michigan Cancer Center & Institute for Blood Disorders to address the topic of *Pain Management: Comprehensive Care and Medical Marijuana*.

Successfully being used for other disorders, it was emphasized that medical marijuana needs to be used under a doctor's care and must come from a dispensary on the federal list of approved dispensaries as street marijuana can be laced with questionable agents. Also for pain control, consumption is usually by ingesting, whereas smoking is never recommended. As Samantha shared, medical marijuana is legal in her state of Michigan and the treatment center works closely with their patients and it's use. Also noted, it is important to know your state laws, and to discuss questions with your treatment center.

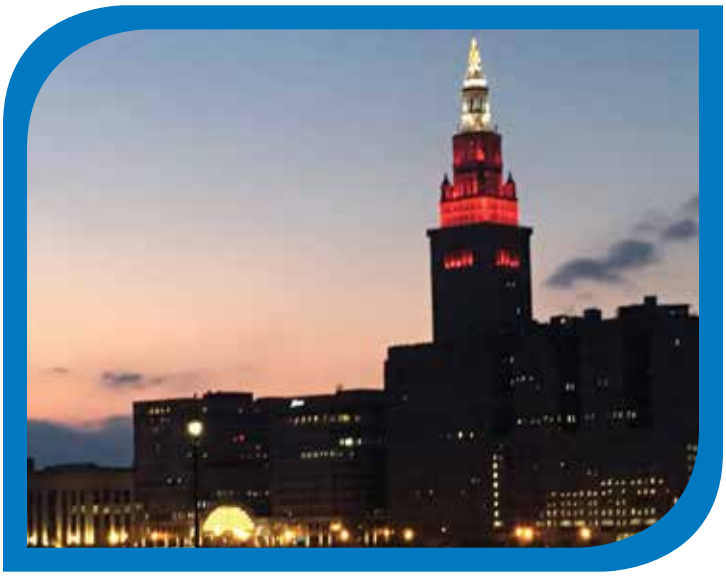
Women bleeders are never forgotten at HFA. Danielle Nance, MD Hematologist at Banner MD Anderson Cancer Center in Phoenix, Arizona, spoke on *What's Love Got To Do With It*, which focused on the subject of hormones, bleeding and aging in women with bleeding disorders. She stressed the importance of early diagnosis when family history is present and that women with vWD should consider factor treatment before undergoing small procedures, including breast biopsies. She ended her session by reminding women to take care of themselves first so that they are able to care for their family members.

Have you ever wondered why your physician takes so many lab tests each year? Dr. Ahuja answered this question in a session called *Can You Pass the Test?* It focused on how physicians use lab tests to make our lives better and how to identify the tests, analyze the results, and explain their value. Common tests done yearly may include a factor assay, PK study (to check levels while factor is in use), genotype (carrier status), inhibitor and hepatitis C testing. As recommended by MASAC, yearly inhibitor testing is especially important because early diagnosis and treatment provide greater success in clearing the inhibitor.

In addition to enlightening educational sessions, the memory of those who have passed was kept alive in a special memorial service called *Remembrance Service: Lest We Forget*.

Education is always the main focus, but all work and no play is not the HFA way! The Symposium wrapped up with a final night party at the Rock and Roll Hall of Fame sponsored by Novo Nordisk. Cleveland trolleys transported all guests from the Hilton Convention Hotel to the Hall, which sits on the edge of beautiful Lake Erie. Buffet stations supplied a large variety of great food and drink. Exhibits throughout the museum held the interest of everyone old enough to remember the "good bands." Entertainment was provided by *56 Daze*, a Toledo band that had everyone tapping their feet, clapping their hands, hitting the dance floor and singing along!

The city of Cleveland pulled out all the stops and honored the bleeding disorders community by lighting its Terminal Tower in red at night during the Symposium. Executive Director Tanya Ricchi and Special Events Coordinator Dawn Evans of the Northern Ohio Hemophilia Foundation did an amazing job of helping everyone feel welcome and experience what Cleveland has to offer. Next year's Symposium in San Diego, California, will celebrate its 25th anniversary April 4-7, 2019. Hope to see you there!



SPOTLIGHT ON RESEARCH
A RACE FOR A CURE

In the last Spotlight on Research, we focused on gene therapy becoming a reality, highlighting the breadth of clinical trials in gene and cellular therapies as well as the three FDA approved gene therapies in 2017. In this issue, we draw attention to the eminent clinical trials in gene therapy for hemophilia and a race for a cure.

BY DIANE HORBACZ
Research & Educational Development Specialist
US Health Group

In preparation for surgery, my son was given a high dose of factor to obtain a factor VIII level of 100%. He typically has a relatively poor response to factor, so his levels are often extremely low. "I'm loaded with factor," he exclaimed. "I feel like Superman!" Given the fact my son is 20 years old, I laughed until I realized he really did feel different. A major part of his life is an incessant awareness of limited factor. How would a single dose gene therapy treatment permanently resulting in normal ranged factor levels change his life?

A RACE FOR A CURE...

According to Investor's Business Daily, "BioMarin Pharmaceuticals, Spark Therapeutics and UniQure are racing to be the first to market a gene therapy that treats hemophilia."[1] Progress on the clinical, regulatory and manufacturing fronts are proof we are on the cusp of a significant change in the way we treat hemophilia. With several clinical trials in phase 1/2, preparing for phase 3 and one in phase 3, we are only a few years away from gene therapy products dramatically improving the lives of those living with hemophilia and revolutionizing the bleeding disorders community.

CLINICAL TRIALS IN HEMOPHILIA

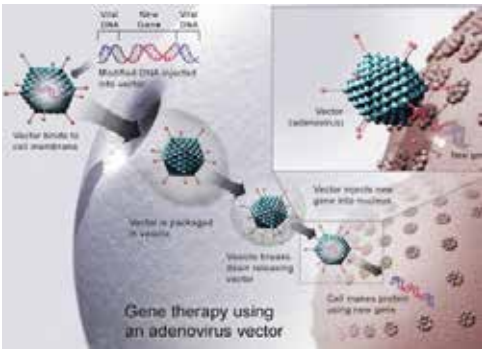
BIOMARIN

Valoctocogene Roxaparvovec / formerly BMN 270 (Hemophilia A) PHASE 3 CLINICAL TRIAL

After successfully demonstrating normal or near-normal sustained factor VIII levels in patients with severe hemophilia A during phase 1/2 clinical trials, valoctocogene roxaparvovec is the first gene therapy for hemophilia to enter phase 3 trials. This investigative new therapy for hemophilia A, also referred to as Valrox, uses an AAV5 vector containing a human B-domain deleted factor VIII gene contrived from an insect manufacturing platform. After receiving *Breakthrough Therapy* designation from the FDA in October 2017, BioMarin launched their phase 3 program, which consists of 2 studies: GENEr8-1, a high dose cohort, enrolling the first patient in December 2017; and GENE r8-2, a low dose cohort, enrolling the first patient in January 2018. To date, a total of 3 patients have been dosed in phase 3. Estimated enrollment is 130 participants for the high dose trial and 40 participants for low dose trial. The only updates expected this year would be regarding progress toward study enrollment.

According to a Bloomberg Intelligence report, patients in BioMarin's phase 3 study should be carefully monitored for liver enzymes, which can interfere with the efficacy of gene therapy treatment. In reference to the higher dose platform, Bloomberg noted, "a push toward higher doses must be balanced with safety concerns."[2] While phase 1/2 did show a mild increase in liver enzyme levels, only one patient experienced a decline in factor VIII levels.

In addition to their phase 3 program, BioMarin has begun BMN 270-203, a phase 1/2 study to evaluate the safety and efficacy of Valrox in 10 severe hemophilia A patients who have tested positive to pre-existing AAV5 vector antibodies. The goal of this trial is to better understand how to treat a patient using gene therapy who would otherwise not be considered a viable candidate given an immune response. This study consists of 2 separate cohorts, patients with higher levels of antibodies and patients with lower levels of antibodies. In a May 15, 2018 announcement, the first patient with pre-existing antibodies was dosed.



In anticipation of commercial demand, BioMarin has built an 18,000 sq. ft. gene therapy facility in Novato, California, earning recognition as *2018 Facility of the Year Category Winner for Project Execution* by the International Society for Pharmaceutical Engineering (ISPE). During a first-quarter conference, Jean-Jaques Bienaime, President and CEO, stated, "Our gene therapy manufacturing plant is coming along as planned and any day now, patients in our registrational studies will receive their single dose of Valrox with commercial-scale material from our new facility."

VALROX (BMN 270)
Phase 1/2 Update
Presented at WFH World Congress, May 22, 2018

Valrox (BMN 270) was well-tolerated with favorable safety profile; currently:

- **No subjects in either cohort have FVIII activity levels above the upper limit of normal ALT levels within normal limits in all subjects**
- **All subjects remain off corticosteroids**
- **No inhibitors to FVIII**
- **Only 2 serious adverse events as previously reported**

In the high dose cohort, 2 years (104 weeks) data showed:

- **Overall annual bleed rate (ABR) was reduced by 97%, with no spontaneous bleeds and elimination of all bleeds in target joints in the second year**
- **Overall annual infusion rate (AIR) was reduced by 96%**
- **Mean factor VIII activity levels at 104 weeks post vector-infusion was 59%**

In the low dose cohort, 1-year (52 weeks) data showed:

- **Overall ABR was reduced by 92%**
- **Overall AIR was reduced by 98%**
- **Mean factor VIII activity levels at 53 weeks post vector-infusion was 32%**

A recent phase 1/2 update from BioMarin was presented at World Federation of Hemophilia (WFH) World Congress in May 2018. Encouraging results showed mean factor VIII activity level for high dose and low dose groups as 59% and 32%, respectively. According to Bloomberg Intelligence, "The higher dose continues to show durability, and while activity levels in the updated data have waned, this suggests levels stabilize, lowering any risk of blood clots."[3]

SPARK THERAPEUTICS

SPK-9001 (Hemophilia B) in collaboration with Pfizer PHASE 1/2 CLINICAL TRIAL
SPK-8011 (Hemophilia A) - PHASE 1/2 CLINICAL TRIAL

Spark Therapeutics also received *Breakthrough Therapy* designation from the FDA for two gene therapy drugs, one for hemophilia A and one for hemophilia B. Spark's clinical programs use a lower dose of its gene therapy compared to BioMarin. According to Spark Therapeutics, the objective for their lower dose is to reduce risk of serious adverse events (SAEs). In a recent statement, Jeff Marrazzo, Chief Executive Officer, emphasized, "It is important that we have a clear safety profile for a gene therapy for hemophilia and that includes not only the absence of serious adverse events, but also the absence of inhibitors as well as no thrombotic events."

SPK-9001 in collaboration with Pfizer (Hemophilia B) uses a bio-engineered vector (AAV-Spark100) containing a human Padua factor IX gene contrived from a mammalian manufacturing platform. This phase 1/2 clinical dose-escalation clinical trial started September 2015 with the FDA granting *Breakthrough Therapy* designation in 2016. Data as of November 2017 showed a 97% reduction in annual bleed rate (ABR) and 99% reduction in annual infusion rate (AIR) in 10 participants, beginning 4 weeks post-vector infusion, and sustained factor IX levels within acceptable range. Also reported last November, Spark plans to enroll up to 5 additional participants in the current phase 1/2 clinical trial using SPK-9001 generated from an enhanced manufacturing process.

As part of an amendment to their license agreement with Pfizer, this plan is in preparation for phase 3 clinical trial. The goal of adding participants is to test comparability of SPK-9001 generated from the enhanced manufacturing process to the SPK-9001 received by the initial 10 participants. In Spark's first quarter update, they reported completing the expanded enrollment for a total of 15 participants and expect to complete the transition of the program to Pfizer by summer 2018. Additionally, Spark expects to deliver a batch of the gene therapy drug to Pfizer, enabling Pfizer to begin a phase 3 clinical trial.

Promising data from 13 participants was presented at World Federation of Hemophilia 2018 World Congress: ten initial participants treated with SPK-9001 and three newly added participants treated with SPK-9001 using the enhanced manufacturing process. Length of time necessary to achieve steady-state factor IX levels, levels more than 12%, is 12 weeks. At the data cutoff date of May 7th, 3 of the 5 additional participants treated with SPK-9001 using the enhanced process were past 12 weeks. The other two participants were at 11 and 5 weeks. Data for the 3 new participants shows SPK-9001 was just as effective when it was produced using the improved manufacturing. According to Katherine High as reported in Bloomberg, "The results are comparable, and in fact they are a little better."[4]

SPK-8011 (Hemophilia A) uses a bio-engineered vector (AAV-Spark200) containing a B-domain deleted human factor VIII gene contrived from a mammalian manufacturing platform. This phase 1/2 dose-escalation clinical trial started in December 2016 with the FDA granting *Breakthrough Therapy* designation to SPK-8011 in February 2018. Preliminary data presented at the American Society of Hematology (ASH) Annual meeting in December 2017 showed a 100% reduction in annual bleeding rate (ABR) and 98% reduction in annual infusion rate (AIR) in the first 4 participants as well as sustained factor levels within acceptable range. Since then, Spark has treated additional patients (current total of 9 patients) with SPK-8011 and is continuing to enroll patients as they move ahead in preparation for phase 3 clinical trials (anticipated early 2019).

Updates from the clinical trial are expected third quarter 2018. Katherine High, President/Head: Research and Development, stated during a first-quarter conference, "For the third quarter, we expect to have a much longer follow-up time and an additional dose cohort so we feel we will be in a much better position to delineate the therapeutic benefit of our gene therapy for hemophilia A."

SPK-9001
Phase 1/2 Results
Presented at WFH World Congress
May 22, 2018

- None of the 15 participants experienced serious adverse events
- All 15 participants had discontinued prophylactic infusions of factor IX
- There were no thrombotic events or factor IX inhibitors
- Overall ABR was reduced by 98%, 4 weeks post vector infusion
- Overall AIR was reduced by 99%, 4 weeks post vector infusion
- Steady-state factor IX levels for the first 10 participants treated with the original version of SPK-9001 ranged from 14.3 to 76.8%
- Steady-state factor IX levels for 3 participants treated with SPK-9001 using the enhanced process ranged from 38.1 to 54.5%

UNIQURE

AMT-061/061 (Hemophilia B)
PHASE 1/2 CLINICAL TRIAL

AMT-060 uses an AAV5 vector containing a human "wild-type" factor IX gene contrived from an insect manufacturing platform. Phase 1/2 clinical trial started May 2015 with the FDA granting *Breakthrough Therapy* designation in January 2017. This 10-participant clinical trial consists of two cohorts: low dose and high dose. Data published March 2018 demonstrated factor IX activity increased to levels classified as mild hemophilia in 6 patients and moderate hemophilia in 4 patients. Eight of 9 participants previously on prophylaxis have since discontinued their routine infusions of factor.

While improvement of disease severity was observed in all participants, uniQure is working towards advancing their gene therapy product. In October 2017, AMT-060 was updated with FIX-Padua variant amid plans to initiate a pivotal study with enhanced AMT-061 in 2018. AMT-061 will be included under the existing *Breakthrough Therapy* designation for AMT-060 and is expected to begin phase 3 studies in 3rd quarter of 2018. According to a Bloomberg report, uniQure expects to be first to market with a treatment for hemophilia B as early as 2020.[5]

New data presented by uniQure at the American Society of Gene and Cell Therapy (ASGCT) annual meeting May 19, 2018, suggest their AAV5 gene therapy may be suitable for at least 97% of patients. Three of 10 participants in phase 1/2 trial who tested positive for pre-existing antibodies to the AAV5 vector still responded positively to the gene therapy treatment. Therapeutic transgene expression was established in all 3 patients with no immune response. Furthermore, the patient with the highest anti-AAV5 neutralizing antibodies presented the greatest mean factor IX activity in his dose cohort. In a press release after the meeting, Chief Scientific Officer Sander van Deventer, MD, PhD, stated, "These important data presented at ASGCT bolster our confidence that AAV5 gene therapies can provide successful liver transduction in all or nearly all patients."[6]

SANGAMO THERAPEUTICS

SB-525/Alta Study in collaboration with Pfizer (Hemophilia A) --PHASE 1/2 CLINICAL TRIAL
SB-FIX/FIXtendz (Hemophilia B) – PHASE 1/2 CLINICAL TRIAL

SB-525/Alta Study in collaboration with Pfizer (Hemophilia A) uses an AAV2/6 vector containing a human B-domain deleted factor VIII gene contrived from an insect manufacturing platform. In May 2017, the FDA granted *Fast Track* status to SB-525. The following month, the first patient received a vector infusion of SB-525. As of the date of this article submission, although exact dosing has not been revealed, enrollment to the first two cohorts has been completed. Four patients received vector infusion of SB-525 with plans to dose the next patient soon.

While this clinical trial is behind several others, expectations for SB-525 are high. Sangamo Vice President and Chief Medical Officer, Edward Conner, shared during a first-quarter conference, "The literature

and experts in the field have stated that factor levels above 12% of normal are sufficient to prevent bleeding. Our target for factor levels in the blood are to be well above this 12% threshold, but less than 150% of normal as levels above 150% of normal may present risk of thrombosis." Clinical data from the first 2 cohorts is expected in late summer 2018.

SB-FIX/Fixtenz (Hemophilia B) is different than other gene therapy trials in that it uses an in-vivo gene editing approach (Zinc Finger Nucleus technology). This study, which began November 2016, consists of 3 separate cohorts: low, middle and high dose. To date, a total of 3 patients have received a single dose treatment of SB-FIX. Challenges in finding individuals to participate in this clinical trial has led Sangamo Therapeutics to expand the trial into the European market and in February 2018, United Kingdom's Medicines and Healthcare Products Regulatory Agency (MHRA) granted clinical trial authorization (CTA) for enrollment of subjects into the ongoing phase 1/2 clinical trial. While 4 sites are open and actively screening for eligible patients in the US, Sangamo Europe is working to activate sites in the UK with hopes of enrolling patients by year-end. Once preliminary safety and efficacy is demonstrated in adults, adolescents (ages 12-17) in the United Kingdom may begin to be enrolled.

ZINC FINGER NUCLEUS

Engineered nuclei are what researchers used to edit genomes (complete set of DNA). One type of engineered nucleus is the zinc finger nucleus (ZFN), which consists of proteins called zinc fingers with an attached enzyme at the end of the chain. Zinc fingers recognize and bind to specific triplets of DNA bases and the enzyme then cuts the DNA with precision at certain recognized sequences.

SHIRE

SHP-654 (BAX 888) PHASE 1 CLINICAL TRIAL

New to the playing field is Shire's gene therapy program. After receiving *Orphan Drug* status from the FDA October 2017, Shire opened its program March 2018. SHP-654 uses an AAV8 vector containing a human B-domain deleted factor VIII gene contrived from a mammalian manufacturing platform. Patients are currently being recruited.

IN CONCLUSION...

By 2020, the first gene therapy for hemophilia is expected to hit the market with additional gene therapies soon following. This paradigm shift from "living with a bleeding disorder" to "living without a bleeding disorder" is going to forever alter the lives of individuals with hemophilia. Going back to my son's experience of feeling like Superman after reaching a high factor level, I wonder how a single dose of gene therapy will change his life. Given a successful treatment, his factor levels should be in the normal range, thus eliminating the need for ongoing factor replacement therapy, but how will gene therapy change his perspective? How will it impact his lifestyle? As we focus on the science behind these clinical trials in anticipation of a single dose curative treatment, a vision of the future emerges that is different from our current experiences where the all-too familiar effects of hemophilia will simply no longer apply.

GENE THERAPY POINTS TO CONSIDER

There are differences in vectors being used in clinical trials. Some are using a mammalian manufacturing platform while others use an insect system. Although insect cell lines have better production capacity enabling more efficient manufacturing, it's unknown whether immunogenicity or expression of the gene can be affected.

Vector dosing varies between clinical trials. BioMarin uses a higher dose in its program, which according to a Bloomberg Intelligence report, may result in their product being more costly than Spark's, which uses a lower dose. Also stated in reference to their higher dosing, "There may be a tradeoff in efficacy and safety given higher levels of factor VIII can cause blood clotting. This must be carefully watched for in Phase III trials."[7]

Safety and efficacy are still paramount. Elevation of liver enzymes should be carefully monitored as this can interfere with the efficacy of treatment.

Immune response to gene therapy is still a concern. Researchers are aggressively seeking ways to ensure tolerance to future gene therapies; however, testing for an immune response has not been standardized across all clinical trials. This can lead to varying results beyond clinical study differences.

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PATIENT JOURNEY:
FROM SYMPTOMS TO SOLUTIONS

BY JUSTIN LINDHORST
Regional Care Coordinator, US Health Group

Von Willebrand disease (vWD) is the most common bleeding disorder. It is estimated that up to 1% of the US population has vWD, and many remain undiagnosed. There are three main types of vWD, and people with the condition either don't have enough von Willebrand factor (vWF) or the vWF they do have doesn't work properly. Many individuals go undiagnosed for years. Learning to recognize signs of abnormal bleeding is important to help affected patients receive diagnosis and treatment sooner. This article explores the experiences of three patients and their story leading up to a diagnosis.

TAMMY

My bleeding symptoms started at a young age. I had my first menstrual cycle at 8½ years old and also always had a lot of bruising. Horrible looking bruises would pop up with no recollection of bumping or hitting myself. I thought it was just a normal part of my life. My bleeding and bruising patterns were something I accepted without too much question.

The bleeding episodes became more severe the older I got. When I began having children, the bleeding really intensified.

I have 4 beautiful children, and with each birth, I experienced excessive bleeding. There were many indications that something was wrong - continued periods during the first few months of pregnancy, excessive bleeding during and for weeks following childbirth, lots of pain, cramping, and just feeling very tired.

During this time, I knew something had to be wrong, but my clinicians didn't seem to be on the same page. Eventually, my gynecologist suggested a hysterectomy and I burst into tears. I just was not ready for such a permanent solution.

A year after having my 4th child, the bleeding continued to intensify. I reluctantly agreed to the surgery, so at 33 years old, I had a hysterectomy. My doctor still did not pick up on anything being abnormal and suggested no further testing.

It was not until my third child was around 11 years old that we finally received some answers. She began having excessive, daily nosebleeds. My daughter's doctor suggested she may have von WIllebrand Disease and sent us to a pediatrician at a local hospital. One-by-one we were each tested, and the results showed we were all affected with vWD type 1 moderate.

After our diagnosis, I became very involved with the bleeding disorders community. Over the years I've served in a number of capacities: many years on the planning committee for the Great Plains Women's Retreat, years of education and advocacy work, volunteering on the Victory for Women task force and serving as President, then Treasurer for the Hemophilia Foundation of Arkansas.

My latest advocacy and awareness was *Running Red*, our first annual 1k walk/5k run fundraiser in March 2018. I am known for saying "Knowledge is Power." Advocacy is my heartbeat!

CHEYENNE

Nosebleeds were the norm for me as long as I can remember. My parents say they started when I was only 10 months old. Throughout my childhood, the nosebleeds became progressively worse and I learned to handle them as just a normal part of my life. Finally my ear, nose, and throat doctor decided on cauterization of the affected blood vessels in my nose.

However, even after the procedure, the problems persisted and I was referred to Hershey Medical Center. It was there I was finally diagnosed with von Willebrand Disease at the age of 15.

After having lived with the problem for so long, I felt better knowing there was a reason behind the bleeding. I felt so much better knowing my condition had a name with resources, medication, and support to control something I had for so long just accepted. With a diagnosis, I was able to put a plan in place with my medical team to finally control my bleeds.

At that point, I felt compelled to get involved with the bleeding disorders community. I knew I wanted to advocate and make a difference for others facing similar challenges. It should not have taken so long for me to be diagnosed, and I wanted to help make sure others did not have to go through the same troubles.

Connecting with the bleeding disorder community is one of the biggest blessings in my life. I'm currently involved with the Eastern Pennsylvania Chapter of NHF. I believe it is important to become advocates for ourselves and for the community so we can educate others and raise awareness about bleeding disorders.

TIFFANY

(As told by her mother)

Our story began with a loose tooth. My daughter Tiffany had one that was dangling, so I went ahead and pulled it out. After that, her gums just would not stop bleeding. As the bleeding continued, we eventually decided to take her to the emergency room. I felt so panicked and worried I had somehow done something wrong. Although the team at the hospital took great care of Tiffany that day, when we left, we still had no idea she had von Willebrand Disease.

A few years passed with Tiffany experiencing continual problems. She had joint pains and lots of easy bruising - some of the bruises lasted for months. There was some history of vWD on my mother's side, so when Tiffany was around 12 years old, I asked her doctor to test her. When the results came back as positive, I was heartbroken. We learned Tiffany would have to infuse medication to control bleeding episodes.

Many thoughts were flashing through my mind, and as if coping with my daughter's diagnosis was not enough, I'm terrified of needles!

In time, we realized that having a valid diagnosis was a good thing; knowing what we were up against helped us to work together to avoid and control bleeds. Tiffany very quickly learned to self-infuse. I was so proud!

Admittedly, Tiffany is a somewhat clumsy child. She is constantly falling or bumping into something. Learning to self-infuse has helped empower Tiffany to take care of her condition when something comes up, and despite her clumsy nature, has minimized her bleeding episodes. Tiffany is now living a "normal life" and vWD does not limit her activities.

THE COALITION FOR HEMOPHILIA B

2018 SYMPOSIUM IN REVIEW

BY TERRY STONE
Regional Care Coordinator
US Health Group

It is - without a doubt - one of the best family reunions on the planet! Beautiful "B" people from across the country gathered in Ponte Vedra Beach, Florida at the Sawgrass Marriott Golf Resort March 22-25th for the 12th Annual Coalition for Hemophilia B Symposium. This family reunion may not have people that look like one another, but the smiles are all the same! They are connected by a uniqueness in their blood that makes them a different kind of blood brother and sister, and that's just fine with them. One big, unique, happy family!

Prior to the weekend educational events, golfers hit the greens and brought their "A" game to raise funds for two of the Coalition's programs: *Let'sPlayNine* and *BCares*. Hats off to the early birds who came in ahead of the symposium for tee time on the famous greens of the legendary TPC Sawgrass course for a true PGA tour experience.

There was a flurry of activities Friday as early-arrivals were naturally welcoming many friends and families coming for a weekend of laughs and learning. The afternoon began with a meet-and-greet luncheon followed by the separation of genders so each could have time to attend sessions unique to their needs, followed by an inspiring talk from Shelby Smoak, PhD, Community Advocate and Educational Specialist, US Health Group, on *Getting Hip to Hep C* and a session on *Nutrition and Wellness* from Dr. William Patsakos. The evening wrapped with a family event filled with games and goodies!

For those up with the Saturday morning sunshine, Paul Brayshaw teamed with Dr. Tammuella Chrisentery-Singleton to facilitate Novo Nordisk's *"B" Yourself Breakfast* entitled, *High Factor Levels and You*. After a warm welcome from Dr. David Clark, members listened to an inspiring update from Dr. Christopher Walsh, HTC Director at Mt Sinai, New York.

Other valuable topics throughout the day included: *Pain Management: Where Are We Going?*; *New Diagnosis, New Normal: A Mom's Perspective*; *Standards of Care in the ER*; *The Healing Power of the Drum: Merging of Art and Science*; *Benefits of Music Therapy*, along with personal stories and *Sunset Tai Chi*. A wonderful dinner followed with a fantastic show with music courtesy of many talented B's including *Iliandi* with Spencer Duggan and his fiancée, Ili Ana Fernandez, and *The Bleeders* with Wayne, Kevin, Rick, Elizabeth, Phil and Shelby at the mic! It was a Band-tastic evening - who knew we harbored such talent - from vocals to drums to guitar to the keyboard! This group needs an agent!

Sunday morning included a final wrap-up and many good-byes! Matrix Health Group was happy to be a sponsor for this event along with many organizations who supported and participated during this education and networking weekend. Thanks to all the generous sponsors, community members, and to Kim Phelan and her team for making the magic happen once again!

LetsPlayNine Golf Tournament

BY FELIX GARCIA
Regional Care Coordinator, US Health Group

Have you heard about the 2nd annual ***LetsPlayNine Golf Tournament*** Formally called the "Fore Life" tournament, this benefit raises monies for two of The Coalition for Hemophilia B programs: ***LetsPlayNine***, an initiative striving to help members of the hemophilia community gain access to the game of golf and the opportunity to engage in a healthy sport and, ***BCares***, a patient assistance program to financially help members of the bleeding disorders community in times when paying bills or affording food becomes difficult. Many came out to join fellow hemophilia brother and PGA touring pro Perry Parker at TPC Sawgrass Golf Course for a training clinic and tournament March 22nd.

Set on 65 acres, this laid-back golf resort is 2.7 miles from Ponte Vedra Beach in sunny Florida. Although it meant an extra day away from our work and home lives, it was great to enjoy the abundant sunshine and raise money on a TPC Golf course!

Many of those participating are members of the hemophilia B community and industry representatives. What was additionally impressive was the number of golfers who came out just to raise money for a worthy cause. With just about every team filled and a beautiful day ahead of us, we were destined to have a great time... and that we did!

As he is known to do, Perry Parker along with Jared Schimmels, gave a very helpful training clinic before we teed off. Without their help, I'm not sure I would've had enough golf balls to get through the course. When the scores were tallied, my team fell short of a win, but we still felt great! The Coalition raised much-needed funds and more people became aware of hemophilia B.

Also serving as an opener for the CHB Annual Symposium on the followed day, it proved to be a tremendous event! Hats off to tournament co-chairs, Wayne Cook and Jim VanSant, the dedicated staff and all the wonderful volunteers of The Coalition for Hemophilia B!

BCares
THE COALITION FOR HEMOPHILIA B
PATIENT ASSISTANCE PROGRAM

LETSPLAYNINE

MATRIX ON THE MOVE

CALIFORNIA

Even rainy weather couldn't keep community members from attending ***Family Education Day*** hosted by Hemophilia Association of San Diego County (HASDC) at the San Diego Zoo! Everyone arrived March 17th in good spirits and ready to take in the informative sessions while enjoying a tasty meal together. Just as lunch was wrapping up, the sun broke through the clouds, giving everyone the opportunity to walk through the zoo and visit all the amazing animals! Thank you to HASDC for another wonderful event!

NEW YORK

It's been a tough March on the east coast with 4 nor'easters, so it was a nice break for the Bleeding Disorders Association of Northeastern New York community to get together March 22nd for ***Education, Food and Fun***. Sponsored by CSL Behring and Matrix Health Group, the group met at The Standard in Albany. Over dinner, Dezarae Tate, Hemophilia Nurse Coordinator at the South Texas Hemophilia Treatment Center in San Antonio discussed Idelvion, CSL Behring's extended life product for Factor IX. She was very engaging and explained how the product works in an easy to understand manner.

Our inspirational patient speaker was John Vieke of Indiana. He told us how through hard work and determination, he persisted to pursue his life dream of becoming a police officer though having severe hemophilia B. He earned his bachelor's degree in Criminal Justice and despite being told not to pursue a law enforcement career because of his medical condition he persevered and was finally was offered a place on the police force. The take away was we should never take no for an answer, nor let anyone interfere with our dreams.

The group then took a 3-minute walk over to *Escape the Mystery Room* for some fun. If you've never participated in an escape room adventure, you should try it - it's a lot of fun! Matrix Health Group reserved 3 rooms, *Zombie Apocalypse*, *Sherlock's Library* and *Secret Agent*. Each team had 50 minutes to work together to find clues, solve puzzles, and decipher hidden codes to escape the zombies. It was a blast!

OHIO

Excitement filled the air as Matrix Health Group co-sponsored this year's ***Family Circus*** with Bayer March 24th at the Canton Memorial Civic Center. With 142 guests in attendance, we packed the party room wearing matching Matrix Health Group t-shirts displaying a moment in everyone's spectacular life.

Bayer sponsored a great taco bar dinner and while everyone got his or her fill, Kelly Gonzalez, Educational Specialist with US Health Group, presented *The Family Circus* program. The discussion was geared towards family dynamics. Kelly offered pointers on parenting and marriage tips to keep the family running smoothly.

Clowns Whizzer and Blake were on hand and visited each table to give lessons on balloon bending. Everyone made a balloon animal to take home. After dinner, we proceeded to the arena and found our seats. Even though the clowns kept trying to steal the show, the elephants seemed to be everyone's favorite! The show also featured a motorcycle on a wire, trapeze aerialists, trampoline-jumping clowns, and of course, lions and a white tiger.

It's always fun to sit and enjoy the evening together. It's even more fun to watch the excitement on the children's faces. Once the evening was over, the children were not quite ready to settle down. It's safe to say each family had fun remembering the details of the night during the ride home!

FLORIDA

April 7th kicked off the ***7th Annual Gator Clot Trot Walk and 5K*** hosted by Hemophilia Foundation of Greater Florida (HFGF) at Gainesville's Depot Park. Throughout the event, everyone visited with sponsors' booths and enjoyed refreshments and snacks. Walkers and runners were cheered on by deejay Joe Sena of Aairius DJ Entertainment, the University of Florida's Cheer Team and mascot Alberta and the 501st Star Wars Legion. All participants received a beautiful medal, with trophies going to the winners of various contests. This successful and popular event raised almost $30,000 for programs for the Florida bleeding disorders community! A job well done!

Alberta, the UF mascot brings out a big smile from Sam.

OHIO

As ladybugs return to Ohio's long-awaited spring weather, Matrix Health Group teamed up with Shire for an amazing ***Family Evening***. It was a full house at the Santo Soussa Restaurant in Medina April 12th. The evening began with a presentation by Sue Kovatz-Bell, RN, Senior Clinical Specialist at Shire on *Rixubis True ID*. Up next a young man with hemophilia, Jordan Timura presented, *I've Got This a Shire* True ID Program biography.

Following a delicious dinner of authentic Italian courses, 11 year-old Daniela Delgato from Connecticut told her story of struggling with von Willebrand's and how she chooses to focus her life on making others happy. This young lady's passion is decorating beautiful cakes for other kids living with serious medical conditions. For our group, Daniela chose a ladybug design for the example and shared an interesting fact about ladybugs. When threatened, ladybugs protect themselves by playing dead and releasing a drop of bad smelling blood from their legs to ward off predators. Daniela offered assistance as everyone decorated his or her cupcake. Some chose to vary their design, but most of the cupcakes turned out exactly like Daniela's ladybug example. It was such a fun evening and Daniela stole everyone's hearts! Thanks to Shire for partnering with us to bring this event to the community and big thank you to Daniela for sharing her talent!

Happy smiles from Jordan and Daniela!

MATRIX ON THE MOVE

IDAHO

A beautiful day, a comfortable setting and a common bond brought women together from the Idaho bleeding disorders community. April 14th at the Boise Hyatt Hotel, affected women and mothers, wives and caregivers of bleeding disorder patients gathered for a ***Victory for Women*** event. Friendly faces of the Boise Idaho Chapter of NHF graciously greeted the women upon their arrival and industry representatives were happy and eager to answer questions about their products and services.

Robin and baby Island sneak a picture!

Throughout the day, various sessions were presented specifically designed for the ladies, who were also treated to relaxation techniques, self care coaching and much more. Lunch, bonding, goody bags and lots of laughter allowed our community's amazing women a moment in time to focus on themselves. Thank you to the Chapter and industry participants for recognizing the importance of Victory for Women and organizing this event!

ILLINOIS

It was an evening of Oscar-esque proportions as the Illinois bleeding disorder community walked the red carpet in support of Bleeding Disorder Alliance Illinois (BDAI). The ***29th Annual Gala, Night of 20 Thousand Stars*** was hosted by BDAI April 14th at Itasca County Club. Glitz and glamour packed the hall as the community circulated to bid on spectacular silent auction items. Live auction items included Hamilton tickets for two, sailing excursion on the Celeste Ann out of DuSable Harbor, and tickets to the home of the Cubs, complete with in-field box seats and dinner at Chicago's State Restaurant, just to name a few. Bob Robinson and the staff at BDAI provided a magnificent evening in support of children and adults with bleeding disorders!

Gala Goers !
Greg, Jen, Jim, Joi, Mia (the dog), and Sue

MAINE

The Coalition for Hemophilia B's ***New England Family Meeting on the Road*** April 14th was a dedicated time to spend with other New England factor 9 families and the event was a fantastic success. Taking place at the Westin Portland Harborview Hotel, many had not previously attended a hemophilia B-only event. The customized programming was welcoming, relevant and helped the families make deeper connections as a subset of the larger bleeding disorders community. The highlight of the event was Michael Zolotnitsky's physical therapy presentation, which demonstrated how to properly use kinesio tape to support different parts of the body. Thank you to the Coalition for providing *Meetings on the Road* to patients across the country!

Michael demonstrates proper taping.

ARIZONA

Taking place April 14th-15th at Sloan Park in Mesa, the spring training facility for the Chicago Cubs, the Arizona Hemophilia Association (AHA) hosted its annual, widely acclaimed ***My Nana's Best Salsa Challenge***. Drawing over 1000 attendees both from the bleeding disorder community as well as the general Arizona population to partake in what is certainly the social event of the year! Teams of competitors worked right on the spot utilizing fresh ingredients to make delicious salsa for one of three categories – *Hot*, *Mild* and *Anything Goes*!

Throughout the day, attendees sampled salsas from participants before voting for their favorite one. Amazing

salsas, amazing fun, and an amazing amount of funds raised to benefit the AHA!

FLORIDA

The Foundation of Hope and Life USA hosted their ***5th Annual "Light of the World" Candlelight*** event April 15th at the Rusty Pelican in Miami. In addition to providing an opportunity for the bleeding disorders community to join, the event honors and remembers those from our community no longer with us. Executive Director, Ana Calero led the presentation with touching videos and music. Attendees shared in a feast of delicious food and had an opportunity to visit representatives at industry booths. We at Matrix Health Group are pleased to be part of this honorable event.

Representatives from Bayer and Novo Nordisk, Rene and Jesus visit the Matrix Health Group booth.

NEVADA

Maureen draws the winners!

Although there are many things to gamble on in Vegas, the NHF Nevada Chapter's ***Golf Gets in Your Blood*** golf tournament April 26th was not one of them! This event was a sure win as it brought together community members, chapter personnel, volunteers and supportive industry members, who all have a common goal of raising money to support the Nevada bleeding disorder community.

Located on the western edge of beautiful Las Vegas valley, the Red Rock Country Club provided fantastic views for the fun-filled day! Various activities included driving against the pro, a Texas Hold 'em hole and, of course, the Send-a-Kid-to-Camp hole. Funds raised throughout the event benefit programs such as camp, financial assistance and educational sessions. Thank you to everyone involved who helped make this event such a success!

LOUISIANA

Members of the Louisiana Hemophilia Foundation gathered April 16th-17th to raise awareness during ***Louisiana Capitol Day***. During the first evening we went over important information pertaining to Louisiana laws, state bills and covered Medicaid/Medicare. We discussed the importance of connecting with our state lawmakers to share our stories and concerns. NHF's Brendan Hayes and HFA's Deema Tarazi led the presentation. Bright and early the next morning, we had breakfast and were then on our way to the Baton Rouge Capitol Building for a series of scheduled meetings.

Our first meeting was with State Senator Dan 'Blade' Morrish (District 25) and Chairman of the Committee of Education. He welcomed us and listened intently as our young advocates told personal stories on their day-to-day life with hemophilia and answered his questions. The youngest of our group, 5 year-old Ashton, shared a story of when he fell off his bike and had to infuse. In that moment, the young voice of a sweet child was able to raise awareness for the hemophilia community and made an impression on Senator Morrish. After the meeting and pictures were taken, Senator Morrish called Ashton over and gave him his Senator pin! Ashton was so full of energy and excitement - what a great moment!

Our next meeting was with President pro tempore, Senator Gerald Long (District 31). Senator Long seemed to really connect with our group and was moved by our young advocates. He walked our group to the Senate floor and shared interesting history and told us a bit

Brent, Senator Dan Morrish, Joshua, Benjamin with Ashton (front).

about how things work when the Senate is in sessions.

As the meeting came to an end, we gave him a red tie signifying awareness of bleeding disorders, which he much appreciated. Two more meetings, first with Representative Phillip R. DeVillier (District 41) and then with Senator Wesley T. Bishop (District 4) concluded our visits. As we continue our mission to raise awareness, we hope our legislators will remember us as they make decisions affecting our community. We wrapped up our day on the Hill by sharing a late lunch on the capital lawn under beautiful shade tree where we praised our young advocates on their courage!

CALIFORNIA

The Central California Hemophilia Foundation celebrated ***World Hemophilia Day*** at La Sierra Community Center in Carmichael April 17th. Over 100 participants were greeted with a red tie in support of NHF's Red Tie Campaign. Rodney Dickson, Advocate for Shire spoke on the importance of *Advocacy for the Bleeding Disorder Community*.

Nick and Elizabeth (center) with their children, Ryan, Nicholas, Nadia, Julius, Alexis and Isabel.

The highlight of the evening was everyone sharing their stories, speaking about how their life was impacted by the exceptional support of the community. A wonderful buffet was served with Factor Support Network providing a dessert of delectable cupcakes featuring a World Hemophilia Day design. Thank you Central California Hemophilia Foundation for reminding us of the importance of community!

Tina and son, Ryan

Delfia, Evelyn and Cesar.

MAINE

Just a few short years ago, 4 families from the Hemophilia Alliance of Maine (HAM) came together to honor people affected by hemophilia across the globe in a ***World Hemophilia Day Celebration***. The enthusiastic growth and participation has been dynamic ever since! April 17th saw more than 70 members of HAM celebrate the evening with a dinner at the Sea Dog Brewing Company in Bangor.

HAM ran 3 simultaneous sessions providing group support and programming for children age 8 and under, 'tweens and teens, and adults. While the youngest set was treated to a reading station, games and fort building, Cassandra Starks presented *Reconnecting the Body and Mind Through Fitness*, a fantastic program for our older youth group. For adults, Kelly Gonzalez, Educational Specialist with US Health Group, presented *Putting on the Mask*, a self-care guide for caregivers of those with bleeding disorders.

One grateful mom expressed, "For me, I think a lot came to light - we sometimes get so wrapped up with the woes of hemophilia. We need to keep in mind how far we have come, treatment, education and the resources we have available. We also need to remind ourselves that as caregivers we aren't giving 100% to our affected loved ones if we aren't also caring for ourselves. We are so grateful to have HAM for these connections and education to remind us we aren't alone. It is comforting." HAM remains committed to broad outreach to bring more members in. By this time next year, perhaps attendance will have tripled again!

CALIFORNIA

It was a perfect spring morning in the Port of San Pedro! You could sense the excitement in the air as community members waited for the moment they could finally board a boat to gorgeous Catalina Island Friday, April 20th. Organized by The Latino Hemophilia Foundation, ***Hispanic Heritage Event Catalina Camp*** has become a favorite event attracting members from all over the US, Mexico, and this year, from as far as Egypt.

Jorge, baby Oliver and Lucia.

Carolina and Matias.

Everyone enjoys the day!

After warm greetings, a delicious lunch was served, and before you knew it, the time had arrived to embark the boat and begin the unforgettable camping weekend!

MICHIGAN

It's that time of the year again, ***Springfest 2018***! Hosted by Hemophilia Foundation of Michigan (HFM) April 20-22nd at Ann Arbor Ypsilanti Marriott at Eagle Crest, this is the state's biggest bleeding disorders event of the year. Bringing in more than 600 community members, the weekend included fun activities, seminars for learning and national speakers who raise awareness in all issues related to bleeding disorders.

We stood ready with smiles and information for our visitors. Thanks to everyone that stopped by. We had a lot of laughs and enjoyed the time we had together! A big round of applause to HFM for hosting another important and successful event!

ILLINOIS

Christine and Damon!

Bleeding Disorder Alliance Illinois (BDAI) hosted its annual ***Statewide Education and Fun Weekend*** April 21st-22nd at the Northfield Inn Suites in Springfield. After a welcome from Executive Director Bob Robinson, Connie Montgomery from The National Hemophilia Foundation (NHF) kicked off the weekend with a passionate presentation about diversity and the importance of how individual strengths and perspectives can create a robust and vibrant community.

Kollet Koulianos, also from NHF, updated everyone on insurance reform in Illinois and why some pharmacy benefit managers are no longer counting copay assistance towards one's deductible. Dr. Jonathan C. Roberts of Bleeding and Clotting Disorders Institute discussed what's on the horizon in the product pipeline. Breakout sessions included *Mastering Social Media*, *Relationships and Treatment* discussing the rights and responsibilities of educated consumers; *Journey of Factor: A Deeper Dive* covered how factor works in the clotting process; *The Art of Speaking Up* discussed how to educate others on 504s, IEPs, childcare, workplace, social life, dating and sports; The *HERO Study* identified and evaluated 1,200 psychosocial issues and their impacts on people with hemophilia worldwide; and *The Science of Hemophilia A: A Changing Landscape*.

Families enjoyed dinner, but there was no time to spare as everyone headed to a nearby bowling alley to strike up friendly competition and good conversation. The weekend was solid and Matrix Health Group was pleased to be part of the mix.

LOUISIANA

Family Fun Day at the Park was just that! About 200 members of the Louisiana Hemophilia Foundation (LHF) gathered April 22nd for a beautiful day at Camp Istrouma in Greenwell Springs, also home of bleeding disorders Camp Globeclotters. We gathered in the main hall for a warm welcome by LHF's Executive Director Erica Simpson. Subodh Pethe presented the event's educational program, *Being Prepared for Travel*. He explained the items you may need when traveling, including important letters and documents, and provided links where travelers can search for the nearest hemophilia treatment centers.

Everyone then met at the dining hall to visit industry sponsors while patiently awaiting the first round of food. Burgers, hotdogs, chips and drinks got us started as we waited to throw down some crawfish! It was really cool to watch Cajun ala Carte Catering stir the 2, 4' x 4' boiling pots with 600 pounds of crawfish.

When the feast was ready, happy faces returned with large trays full of glowing red crawfish, a true Cajun fest! Activities ensued after lunch with canoeing, rock climbing, swimming, Gaga ball and water slide fun, with some relaxing in rockers at the dining hall patio, staying cool with ice cream and popsicles. Write this one down as another successful event in LHF books!

Haylee takes in the view.

Heather and Brock with their children Madox and Jaxon

MATRIX ON THE MOVE

VIRGINIA

How better to celebrate the arrival of warm spring days and cool gentle breezes than to gather with friends and family along the James River for the Virginia Hemophilia Foundation's (VHF) ***Hope Blooms Spring Fundraiser***? Held April 22nd at The Boathouse at Rockett's Landing in Richmond, this landmark event continues to bloom with the hope of raising funds to support bleeding disorders' Camp Youngblood and other enjoyable events that community members look forward to throughout the year.

Auction items are an event highlight!

This event is always a great time, and is supported by a dedicated following of community members, friends and locals. Normally, the amazing gift baskets are the highlight of the goodies available by silent auction, but this year, attendees were excited to bid on some top shelf prizes and the competition was YouTube worthy as the professional auctioneer and his team helped raise not only the excitement, but the bids too.

Every year gets harder than the year before to keep making this event even better. Yet, somehow they do it. Congratulations to VHF on another fabulously fun event. You made our spirits fulfilled, and our wallets a little lighter by a whopping $35,000, but it's all good, for a good cause, that is!

WASHINGTON DC

BioMatrix was honored to sponsor members of the Hemophilia Association of the Capital Area (HACA) to attend the poignant theatrical production of ***Roz and Ray***, written by Karen Hartman, presented at the Theater J, April 22nd. The story describes the complex relationship between pediatric hematologist, Roz, and Ray, the father of twin sons with hemophilia during the era of contaminated clotting factor therapies (1976-1987).

The performance was an emotionally moving and dynamic portrayal of the complicated and dynamic relationships patients and families had, and continue to have, with their providers who help them deal with all aspects of living with a bleeding disorder. From serious injuries to constant worry and anxiety, Roz and Ray dove deep into the circumstances patients live with. In the dramatic depiction of the devastating historical events, Dr. Roz Kagan became very close to her patients as she had watched them grow and thrive, and then become very sick with many losing their lives to a "mystery bug."

Following the performance, a panel discussion was held with Dr. Naomi Luban, a pediatric hematologist at Children's National Medical Center during the years of the tainted blood crisis. She was accompanied by Ms. Linda Price, the mother of a child with hemophilia who had personal experience navigating hemophilia during those trying times.

The dramatic depiction of the devastating historical event was an emotional experience that created a great amount of awareness of the bleeding disorders community history. The play is being shown in many cities across the country and creating an enormous amount of public awareness regarding the community's past, and the complexity of bleeding disorders. BioMatrix is so grateful to have played a part in bringing this story to our local community members through a partnership with HACA.

PENNSYLVANIA

The beautiful Normandy Farms in Blue Bell was the place to be as 170 elegant women gathered for ***Run for the Roses – The 39th Annual Luncheon and Fashion Show*** hosted by the Eastern Pennsylvania Chapter NHF April 28th. BOC Productions and their models promoted designs by one of Philadelphia's premier dress stores, Berta Sawyer Fashions. This year's guest speaker was Jeff Cole, Investigative Reporter for Fox 29 News. Jeff had everyone on the edge of their seats with stories he covered over the years.

Pat, Vickie and Jessica smile for the cameras!

Gorgeous junior models from the bleeding disorders community were the first to hit the runway, followed by the professional models of BOC Productions.

In addition to previewing the collection of trendy fashions, an array of door prizes and raffle items were featured including a spa day for 2, a 43" Toshiba Smart TV, a 32GB gold iPad, and a horse-drawn carriage ride, just to name a few. The Fashion Show Committee, along with Executive Director Curt Krouse did an amazing job and we all eagerly look forward to the 40th Annual Show!

PENNSYLVANIA

Vickie, Tom and Tommy Jr. make their way through the exhibit hall.

By far one of the best-attended events hosted by Eastern Pennsylvania Chapter NHF, ***Annual Community Dinner*** took place May 1st at Hilton Hotel City Avenue in Philadelphia. In addition to exploring the exhibit hall, over 400 people eagerly listened to programming covering community comments and concerns, medical research updates and bleeding disorders advocacy efforts. This event also provides a perfect opportunity to meet newly diagnosed families and reconnect with old friends as well! Thank you to Executive Director Curt Krouse and his staff for hosting this wonderful event!

OHIO

The first weekend of May hosted the world-renowned Kentucky Derby, but was also the weekend for Northern Ohio Hemophilia Foundation to host its own version of ***Run for the Roses***. Donning extravagant wide-brimmed hats, over 200 guests gathered at the Ballroom in downtown Cleveland May 4th for an exhilarating evening of food, drinks and horse racing on the big screen!

This event, otherwise known as the ***Annual Black and Blue Ball - Night at the Races***, is a popular fundraising event for the foundation. Exciting auction items were available to bid on including items such as tickets to Hamilton, Aladdin, a Big-10 basketball game, a variety of wine baskets, Coach and Michael Kors handbags, a handmade quilt and an array of other sought-after items. Community member Forrest Stone, an upcoming artist from the Cleveland Art Institute, donated 3 beautiful paintings. One of them was auctioned for an amazing $300! During the silent bidding, another community member, Zach Oatley skillfully played the cello. Shortly after dinner, Miya Timura, a college student and volunteer, played *Call to Post* on the

Bebe, Miya and Richard.

Miya - pretty in blue.

trumpet. It was time to bet and cheer for favorite horses. And down the stretch they came! Six races raised over $60,000! Thanks to NOHF for a triple crown evening!

DELAWARE

Brandywine Valley Hemophilia Chapter members were treated to an evening of ***Education and Fun*** by Matrix Health Group and Bioverativ May 4th! Our event began at Wilmington's Big Fish Grill, where Danielle Mueller Durham, Bioverativ Community Relations and Education Manager, presented *Braving Change*. While enjoying food and the interactive program, everyone was so interested and into it, the program went a bit longer than planned. Now that's a great agenda!

Next, we headed across the street to Frawley Stadium to watch the Wilmington Blue Rocks take on the Frederick Keys. The skies opened and cooled things off, but that did not dampen the spirits of all in attendance.

Highlights of the evening included the adorable Monkey Rodeo - yes, a monkey wearing chaps riding a collie,

Gail and Robert enjoy the game!

MATRIX ON THE MOVE

Gail and Danielle.

Mr. Celery greets the fans!

and of course, Mr. Celery who comes onto the field when the Blue Rocks score. Rumor has it Mr. Celery is Brandywine Valley Hemophilia Chapter President, Gail Nuvak's favorite part of the game! However, the very best part of the evening was sitting together with chapter members, taking in the evening and having a blast. Delaware may be a small state, but the chapter and their members have huge hearts! We look forward to co-sponsoring this event again soon!

CONNECTICUT

April showers bring May flowers and this year the flowers were in bloom as the Connecticut Hemophilia Society held their annual fundraiser ***Comedy Night and Spring Social***. The weekend started with laughs at The Skyline Restaurant in Windsor Locks May 5th. Of the three comedians, my favorite, and the crowds as well, was Jay London.

His signature line is "You might recognize me,

Bloodbrothers Matt and Max.

Ropes Course

I'm the fourth guy from the left on the evolutionary chart," referring to his slouching posture and unkempt appearance.

The next day, we made our way southeast to Bridgeport where the ***Spring Social*** was held at the Discovery Museum and Planetarium, an interactive science museum. The museum provides dynamic, hands-on experiences designed to encourage young learners to ask questions and solve problems. Perfect for our young members of the bleeding disorder community, of which there were plenty in attendance! After an educational program, members enjoyed pizza, ice cream and snacks before trying their skills on the outdoor ropes course.

NEW MEXICO

Balloon Fiesta Park in Albuquerque was the place to be for Cinco de Mayo to support the Sangre de Oro ***Unite for Bleeding Disorders Walk and C.I.N.C.O. Event***! The morning began with volunteers setting up tents, tables, chairs and signage. Matrix Health Group was there not only showing support with their sponsorship and a booth, but by helping with the set up, working the dunk booth, and being part of the clean up crew. "All In" was the theme of the day!

As attendees made their way in, Sangre de Oro did a great job (thanks to some wireless mics) of thanking industry vendors for their continued support, as well as highlighting several local businesses that went all out to support the not only the walk, but the C.I.N.C.O. Event. Sangre de Oro also held their inaugural ***Community Interactive Networking Collaborative Outreach Program***. This program reaches out to the general public to bring awareness to bleeding disorders. Bravo to Sangre de Oro's walk committee for getting local radio publicity before and during the event.

So what actually happened that day... well, besides walking? Over 300 people showed up to enjoy pizza, hotdogs, burgers, tacos, shaved ice and great games, like inflatable obstacle course, bungee dunk challenge, and the sibling rivalry favorite, Gladiator Joust, and the dunk booth that didn't rest all day. Big 98.5 radio station provided tickets to Albuquerque Isotopes AAA baseball game, which incentivized players to keep dunking the volunteers. With all this fun, we can't leave out mentioning the great entertainment provided by *Triple X*, and no Cinco De Mayo celebration would be complete without mariachis and folkloric dancers. This was a complete celebration!

TENNESSEE

Ashleigh Jameson

Every year my brother-in-law, Greg Jameson, hosts a race on behalf of my stepson (or *bonus son*, as I like to call him), Karson, who has severe hemophilia A. Known as the ***Be A Factor 5K***, the race is held at Loudon High School in Loudon, Tennessee. This year, it took place May 5th.

It began in 2012 initially with the thought to help Karson directly. The more Greg learned about bleeding disorders and the role Tennessee Hemophilia and Bleeding Disorders Foundation played in the assistance, education and support for families, the more he understood he needed to help the foundation in *honor* of Karson, specifically to raise funds for Camp Freedom, which Karson has attended since he turned 7.

Camp Freedom has been just that for Karson; Freedom. With his diagnosis, Karson is unable to be away from medical assistance for longer than a day or two, making it difficult to be away from us. Camp Freedom gave him the ability to spend a whole week with friends who have similar medical needs. With nurses on site, kids are able to enjoy their time knowing they don't have to go home for an infusion. At 7 years-old, Karson even learned how to self-infuse, which was huge! Last year when we picked him up, he was actually sad and missing his camp friends terribly.

Be A Factor 5K is extremely important and dear to the hearts of our family. Each year, we are provided with more generous donors and people who want to volunteer and/or participate. It is truly an honor to help children experience bleeding disorders camp and help raise awareness. On behalf of Karson and the Jameson Family, we are so thankful for Greg and the support of the hemophilia community and are so looking forward to next year's race! Come join us!

FLORIDA

Sunday, May 6th was the ***8th Annual UNITE for Bleeding Disorders Walk at Jungle Island*** in Miami hosted by the Florida Hemophilia Association. BioMatrix employees came to walk and show support, from those who have attended five or more consecutive years, to those joining for the first time.

Newcomer Zinnia Santiago expressed her enthusiasm, "My family and I were excited to join and support Team BioMatrix. It was wonderful to witness the community come together to raise awareness and funds to benefit children and families affected by debilitating bleeding disorders. We're looking forward to continuing our support in the future."

The Walk helped raise more than $85,000 and brought together individuals affected by bleeding disorders, their families, friends and supporters. BioMatrix was proud to support the cause, while enjoying an amazing day at Jungle Island.

MATRIX ON THE MOVE

VIRGINIA

You don't have to be in the English Countryside to mingle with locals in a beautiful mansion while sipping wine and tasting fine culinary treats. If an outing of this nature strikes your fancy, then grab your checkbook and join us next time! The Hemophilia Association of the Capital Area's ***Annual Spring in the Mansion*** was held on a delightful Sunday afternoon, May 6th, at the Stone Mansion. A historic home and true treasure nestled within the grounds of a Fairfax County Park in Alexandria.

It was an afternoon of friendship, casual conversation and enjoying an opportunity of merriment and togetherness while supporting a worthy cause. We chatted away as our local favorite musical duo *Iliandi*, played beautifully in the backdrop offering up sweet melodies.

Old friends, Sharon and Patty!

This year's gathering offered many wonderful silent auction and drawing prizes that were so great that we had a rather spirited prize auction with people casually looking over their shoulder to see if they were still in the running for their favorite gift! Congratulations to Executive Director Brenda Bordelon and Assistant Stephanie Jackson for all of their hard work that truly made this afternoon of charity and merriment one that will not soon be forgotten.

TENNESSEE

An ***Educational Dinner*** was hosted May 10th by CSL Behring and Matrix Health Group at Coletta's Restaurant in Memphis. Attendees enjoyed a casual dinner with lots of conversation and laughter! At the end of the meal, Milybet Montijo-Cepeda, M.S.Ed. and hemophilia mom, spoke on overcoming adversity in a program titled *Have Resilience: You are Not Alone*.

Fantastic speaker, Milybet Cepeda.

Maria, Zak, Gabi and Rosie smile for the camera!

At the beginning of her talk, Milybet explained she would do a little salsa dance and that when she did, the audience was to yell out, "Resilience!" Milybet shared her personal testimony from when she was a child and maturing into adulthood. Whenever a difficult time of her life was brought up, she would break out her salsa moves and the audience exuberantly yelled "Resilience!" Her talk was heartfelt, inspiring and fun! With a shared commonality, we came away knowing adversity can be overcome because we are resilient!

NEW JERSEY

Community, pharmaceutical and specialty pharmacy came together May 11th to honor CSL Behring CEO and Managing Director, Paul Perreault, at the Hemophilia Association of New Jersey's ***38th Annual Humanitarian Award and Testimonial Dinner Dance***.

A dapper Sal Rafanelli attends the celebration!

At Fiddler's Elbow Country Club in Bedminster, the evening began with hors d'oeuvres and cocktails, and soon progressed to the award ceremony, dinner and dancing. With more than 30 years' experience in the global healthcare industry, Paul ended his award acceptance speech with, "As an industry, we must be a reliable and engaged partner in understanding and overcoming barriers to access." He was then presented with the Steuben Eagle. Around the world there is no greater symbol of achievement and accomplishment than this magnificently carved statue standing proudly as a sign of outstanding success.

CALIFORNIA

The Hemophilia Foundation of Southern California (HFSC) held their ***Family Information Day*** at Knott's Berry Farm Hotel in Buena Park May 11th-12th. Speakers and topics were carefully chosen. Glenn Pierce MD, PhD, of the World Hemophilia Federation, gave a very interesting update on gene therapy, Marvin Enriquez,

Jada and Fiach

MA, spoke about the importance of building independence in our children, and attorney and actor Shaka Smith offered a powerful motivational speech about living with hemophilia and the challenges he personally faced.

And then it was time to explore Knott's Berry Farm! A remarkable and happy weekend! Thank you to HFSC for coordinating this fantastic event!

VIRGINIA

There was excitement in the air when the HACA youth learned that THE ARTIST has returned! I can think of no better way of encouraging members to come out and participate in the Hemophilia Association of the Capital Area's (HACA) ***Annual Meeting*** May 12th than to know while they are networking and learning updates that matter, their kids are getting creative with Chinedu Felix Osuchukwu creating beautiful art. The Ernst Culture Center in Annandale was where the magic happened and what a great event it was!

The day started with a blank canvas - oh, the possibilities! With each presenter and every topic, a picture emerged and it was a work of art. It was one of a group of people, united by blood, learning about school advocacy, saving joints, understanding Medicare, facing transitions, disclosure 101, and the all too common trifecta of pain, anxiety and depression.

The HACA youth were busy creating their own masterpieces as Chinedu Felix Osuchukwu guided them in their art exploration. He taught them to find what inspires them and then transfer those feelings to their canvas. The kids were excited to see their teacher featured in the current issue of the Matrix Health Group News and asked him to sign their copy. Teens painted too, then had time to "Get Real" with Linda Pollhammer, Nurse Educator for Pfizer as she led a chat on issues that affect them.

Overall it was an enriching day for all who attended. Matrix Health Group was delighted to join other industry sponsors and support HACA's meeting as we learned together and welcomed a new Board of Directors to lead the HACA family through another great year of success.

MARYLAND

You don't have to ask any HFM family twice! They know what that coveted invitation to the Hemophilia Foundation of Maryland's ***Annual Family Weekend*** means. They are going to learn the latest industry news that matters. They are going to see old friends and make new ones. Their kids are going to be cared for and treated like the princes and princesses they are. There is going to be pampering, parties and grilling going on.

Family Weekend Goers!

All eyes might have been on the royal wedding, but HFM families had a royal time all their own May 18th-20th at the Hyatt Resort in Cambridge. An immensely popular and growing event, chapter leadership decided to scale back the event to a dedicated number of families so the weekend could return to a more quaint and nurturing atmosphere. Families were invited based on recommendations from the area HTCs, and focused on new families, inhibitor families and those in need of respite. There were new families in attendance who were welcomed with open arms and were so excited to connect with other families.

The programming allowed time for learning as a group, while allowing time for Mars (Dukes) and Venus (Duchesses) to take time away from one another and participate in activities with their own kind. Spa time for the ladies, grilling and fishing stories of grand catches for the gentlemen.

After a busy day of learning, families were treated to a talent show starring the HFM kiddos, followed by a carnival night. The DJ rocked the tunes while everyone under 5 feet tall bounced and slid, and played games to earn tickets for prizes. Matrix Health Group was happy to support this coveted event with a GIANT Plinko game, and even though it was taller than most of the kids, they loved it!

MATRIX ON THE MOVE

FLORIDA

The annual Hemophilia Foundation of Greater Florida's ***Super Hero Fun Walk*** took place May 19th - a full-of-sunshine day at Al Lopez Park in Tampa. Walkers sported outfits reflecting their favorite super heroes and many brought canine companions to raise support and awareness for bleeding disorders. Funds raised help send kids to camp and assist with urgent financial needs of families within the bleeding disorders community.

Industry supporters came together to sponsor the event - BioMatrix was happy to provide the Gatorade for thirsty walkers! This year's effort boasted 180 attendees, making up 19 teams and volunteers. The chapter reported raising over $60,000 – a whopping 32% MORE than their goal! Way to go!

MAINE

Hemophilia Alliance of Maine (HAM) broke new ground for the bleeding disorders community at its ***Annual Meeting*** in Orono at the Black Bear Inn. HAM ran an afternoon program May 19th educating its members directly from industry representatives with parameters. The unique agenda was an opportunity for pharmaceutical companies and specialty pharmacies to draw time slots and speak briefly to the group about their products and services. Knowledgeable speakers presented details about a broad array of factor products, savings programs, educational opportunities, scholarships and services with a Q & A after each presentation.

Maryann May, Executive Director of the Connecticut Hemophilia Society, presented the keynote address, sharing her history and connections to the bleeding disorders community. She stressed the importance of advocacy and making a difference. Maryann left us with the powerful message: "Don't just follow the footsteps, BE THE FOOTSTEPS."

Another speaker took us on a journey of growing up with hemophilia in the 1950s and 1960s when the life expectancy for a person with severe hemophilia

Medical information was cutting into little Kaden's nap time!

was 20 years old. He explained various therapies available through the years and shared his personal experience as a community leader and advocate.

Meanwhile in the room next door, children celebrated the arts, including painting and videography sessions, while older youth attended a first aid/CPR certification class. It was another flawless and informative event for the consumers of Maine. Thank you, HAM!

OHIO

With an oink, oink, here and an oink, oink there...E.I.E.I.O! The Northern Ohio Hemophilia Foundation (NOHF) hosted their very first annual ***Family Picnic*** May 19th at Lake Metroparks Farmpark in Kirtland. The morning began with threatening skies, but luckily the sun came out in time for everyone's arrival at the main pavilion. Matrix Health Group, along with other sponsors, offered goodies that included hand sanitizers and sunscreen. After having time to visit the industry booths, Randi Clites, Advocacy and Program Manager, presented information on programs offered by the chapter and walked everyone thru the steps to get their kids involved in a summer camp.

Alaina gives us her biggest smile!

The Headless Horseman and his beautiful horse.

Lunch vouchers were given to families and then they were off to enjoy the day. Lake Metroparks Farmpark is an interactive working farm where folks are welcomed to milk cows, watch active beehives, visit gardens and participate in hydroponics. Stagecoach rides were available and a large variety of horse breeds were on display for the horse fest event. Though he was a sight, no one seemed afraid of the headless horseman – plus, the horse he was riding was beautiful!

It turned out to be the perfect day with so much to see and do. We look forward to this new annual event – thank you NOHF!

NEW JERSEY

Community members made their way to Pines Manor in Edison May 31st for Hemophilia Association of New Jersey's (HANJ) ***Annual Meeting***. During a delicious buffet dinner and coffee/dessert breaks, attendees gathered information from a variety of industry exhibitors who were set up in the same ballroom where the meeting took place. The evening's keynote speaker was Christopher Walsh, MD, PhD, Associate Professor of the Department of Medicine at Mount Sinai School of Medicine and Director of the Mount Sinai Hemophilia Center in New York City. He presented *Hemophilia in 2018*, discussing current treatment therapies and what's on the horizon, including gene therapy.

Larry Guiheen

Dr. Christopher Walsh

A big part of HANJ's annual meeting is the award ceremony. Among the awards given is the *Dr. L. Michael Kuhn Memorial Award* given in recognition of deep compassion for those afflicted by hemophilia. This year's deserving recipient was Larry Guiheen, Chief Commercial Officer at Kedrion Biopharma, Inc. Larry has been giving hope and encouragement to the bleeding disorders community for many years. The evening wrapped up with the announcement of scholarship awards to individuals pursuing higher education. These young people are the future of our community, along with the new therapies discussed by Dr. Walsh. Many thanks to HANJ for hosting this fabulous event!

OHIO

It was a long cold winter in Ohio, but warm weather has arrived! Matrix Health Group partnered with the Northern Ohio Hemophilia Foundation and CSL Behring May 31st for a ***Summer Safety and Traveling Tips*** event held at WhirlyBall Laser Sport in Bedford Heights. NOHF Programs Director Dawn Evans gave opening remarks and offered details for the *Gears for Good* bike run and the annual fundraiser walk.

Officer John Vieke

Gwen and John

Starr and Hanna

Over salads and pizza, Kelly Gonzalez, Educational Specialist with US Health Group, spoke on traveling with factor and what to expect at airports. She also spoke about proactively finding hospitals on your insurance plan and insurance notifications of travel. John Vieke, CSL Behring Common Factor 9 Advocate Speaker and police academy instructor, was up next. He covered issues such as bike safety, curfew and swimming and hiking safety. The children were excited to ask him questions about having hemophilia and being a police officer.

Bob is ready to play!

Lilly needs a strike!

MATRIX ON THE MOVE

Lashay and Kimberly have bumper car fun!

Following the education, it was time to play! While some chose laser tag and bowling, others gave WhirlyBall a try. Played in bumper cars on an electric basketball court, the whirlyball is passed with a racket from car to car to gain points when the ball hits the net. Each match lasts 12 minutes and results in much laughter and screaming to your teammates to pass the ball. So much fun for children and adults alike! With over 50 in attendance, it was a great night to kick off summer vacation!

PENNSYLVANIA

June 1st was an evening of learning and fun as members of the Western Pennsylvania Chapter of NHF gathered at Fun Fore All Family Fun Park in Cranberry. With more than 50 guests in attendance, Matrix partnered with CSL to present ***Summer Safety and Traveling Tips***. Kelly Gonzalez, Educational Specialist with US Health Group, presented *Travel Safety* and shared tips on traveling with a bleeding disorder. John Vieke, CSL Common Factor speaker, shared his personal story of having hemophilia and being a police officer. John did not allow his bleeding disorder to stand between him and his childhood dream. John wrapped up his presentation by offering parent tips on keeping their kids safe in the summer months ahead.

Ryker was thrilled to meet everyone!

Chapter director, Allison Yazer, wrapped things up and sent everyone off to enjoy the park. The evening included unlimited mini-golf, go-karts, bumper boats, rock wall, batting cages and an indoor arcade. By the end of the evening, the kids as well as the parents were exhausted, but happy!

SOUTH CAROLINA

Helping **E**mbrace **L**ife's **L**earning **O**pportunities or better known as the annual ***H.E.L.L.O. Conference*** was hosted by Hemophilia of South Carolina June 1st-2nd at Embassy Suites Golf and Conference Center in Greenville. Approximately 200 members of the bleeding disorders community attended this illustrious opportunity of learning and networking. Keynote speaker, Patrick Lynch, award-winning actor and person with hemophilia, opened the event. He encouraged everyone to keep moving forward and power through life's challenges.

A variety of educational sessions followed including very engaging topics on gene therapy, vWD, nutrition, managing depression and tackling transitions from tots to teens. Many thanks to the chapter for hosting this wonderful opportunity!

MICHIGAN

Previously hosted at a bowling alley, a positive change was made when Hemophilia Foundation of Michigan(HFM) decided to change the location for the ***Western Michigan Community Night*** to Craig's Cruisers Family Fun Center in Grand Rapids. Following a pizza dinner, 66 attendees were treated to an educational session on the importance of good dental care presented by Christy Clark, a dental hygienist from Devos Children's Hospital Coagulation Disorders Program. She discussed when pretreatment of factor is necessary and for which procedures, and included details on how long and how often we should brush our teeth.

After receiving a new toothbrush, everyone was free to take full advantage of the fun things to do at Craig's Cruisers! From go-karts, bumper boats and bumper cars, frog hopper and miniature golf to laser tag, ropes course, cruiser coaster, ninja course, trampoline park and dodge ball, there was something for everyone! We wish to thank HFM for bringing the community together for another community night!

VIRGINIA

The Virginia Hemophilia Foundation's (VHF) ***Annual Education Meeting*** travels around the state year-to-year. This year's meeting brought members to a city rich in history that is documented back to the founding of America. Newport News was named for Christopher Newport, captain of the Susan Constant, which was the lead ship of the three-ship fleet that carried the Jamestown settlers to the New World in 1607. Turns out it was a perfect location to host this year's meeting, as VHF is a leader in education and advocacy and continues to make their own history with a robust agenda June 8th-9th, at the Marriott Newport News.

Matrix Health Group sponsored Kelly Gonzalez, Educational Specialist with US Health Group, who presented a nationally popular program, *Putting on Your Mask First*, a cautionary talk of self-help that offers a powerful message to all caretakers. It was also great to have HTC nurse practitioner, Courtney Carr, discuss *Pain Management* from the view of a clinician. Along with other timely topics, a family dinner, kids painting and movie time at the theatre next door, everyone had special time and lessons to take with them.

VHF teen member, Matt, enjoying Teen Track programs and catching up with friends!

VHF continues to do a great job bringing together its members from all across the state to educate, advocate and help families network and enjoy time together, which is one of the best things they can do because united we are stronger...for our day-to-day life and beyond.

NEW JERSEY

In the 10 years since Erin and Dino Cirelli started this walk, the weather has been hot and sunny and the East Hanover community has come in full force. While the weather this year was overcast, the community still responded in big numbers for the ***10th Annual Hemophilia Walk-a-Thon*** at Lurker Park in East Hanover June 10th. Looking out at a sea of pink tie-dyed T-shirts filling the park for this family friendly event, I was reminded of Woodstock once the music and dance teams started. While we waited for the walk to start, community members enjoyed food, bounce houses, face painting and games galore. After the Cirelli family thanked the sponsors and township, and talked about what the money raised goes to, it was time to kick off the walk.

"To the Batmobile - let's go. Da da da da da da da da Batman!" Who better to lead the masses in the fight against hemophilia than Batman? KAPOW to spontaneous bleeding! BAM to joint damage! What makes this walk unique is that Erin and Dino Cirelli host this event year-after-year by themselves, with help from family, friends and local community. Another unique aspect is that all the monies raised goes to the Nicolas Cirelli Family Research Fund and every penny funds an NHF Judith Graham Pool fellowship. This year's pennies added up to over $90,000 - an amazing feat! With this dedication to research, the Cirelli family is ensuring we get quality hematologists dedicated to working in the hemophilia community for years to come.

UPCOMING EVENTS

AUGUST 3-5, 2018 OHIO
FAMOHIO, famohio.org
Family Annual Meeting State of Ohio "Hit it Out of the Park!"
Columbus Marriott Northwest
Dublin

AUGUST 3-5, 2018 TEXAS
Lone Star Chapter of the NHF
713-686-6100
lonestarhemophilia.org
Texas Central Hemophilia Found.
972-386-3865
texcen.org
TX Bleeding Disorders Conference
Marriott Rivercenter
San Antonio

AUG. 3-5, 2018 WEST VIRGINIA
West Virginia Chapter of NHF
681-212-9255, wvnhf.org
Family Camp
Cedar Lakes Conference Center
Ripley

AUG. 11, 2018 FLORIDA
Foundation Hope & Life USA
786-534-2900
www.fhlusa.org
Back to School Day
Doral Receptions Hall; Miami

AUG. 12, 2018 VIRGINIA
Hemophilia Assoc. of the Capital Area
703-352-7641
hacacares.org
Family Picnic and Walk Kickoff
Water Mine Water Park
Reston

AUG. 16, 2018 TENNESSEE
Tennessee Hemophilia & Bleeding Disorder Foundation
888-703-3269, thbdf.org
Pitchin' for Caleb Cornhole Tournament
Centennial Park
Crossville

AUG. 19, 2018 NORTH CAROLINA
Hemophilia of North Carolina
800-990-5557
www.hemophilia-nc.org
Family Day Out
Tanglewood Park and Aquatic Center – Shelter #1
Clemmons

AUG. 25, 2018 KANSAS
Midwest Hemophilia Association
816-479-5900
midwesthemophilia.org
Unite for Bleeding Disorders Walk
Shawnee Mission Park
Shawnee

AUG. 25, 2018 NEVADA
Nevada Chapter NFH
702-564-4368, hfnv.org
Southern NV Women's Retreat
Hilton Garden Inn
Henderson

AUG. 27, 2018 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Board of Directors Annual Meeting
Holiday Inn William Tell
Countyside

SEPT. 7- 9, 2018 CALIFORNIA
Hemophilia Foundations of
Southern CA, 626-765-6656
Northern CA, 510-658-3324
Central CA, 916-448-0370
Hemophilia Association of San Diego County, 619-325-3570
familiadesangre.org
Familia de Sangre
Marriott Oakland City Center
Oakland

SEPT. 8-9, 2018 VIRGINIA
Hemophilia Association of the Capital Area
703-352-7641, hacacares.org
Women's Retreat
Meadowkirk
Middleburg

SEPT. 9, 2018 NEW YORK
New York City Hemophilia Chapter
212-382-2974
nyhemophilia.org
Back to School Day
New York Marriott Downtown; NYC

SEPT. 11, 2018 PENNSYLVANIA
Eastern Pennsylvania Chapter NHF
484-445-4282
www.hemophiliasupport.org
Golf Classic
RiverCrest Golf Club; Phoenixville

SEPT. 15, 2018 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495; bdai.org
Hemophilia Walk
Lincoln Park; Chicago

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

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

TIME FOR FUN!

ANSWERS TO PUZZLES ON PAGE 43

WORD CHALLENGE

1.) T 2.) R 3.) A
4.) F 5.) C 6.) O

"FACTOR"

SEPT. 15, 2018 MAINE
Hemophilia Alliance of Maine
207-631-7550, mainehemophilia.org
Hike4HAM
Mount Battie; Camden

SEPT. 15, 2018 NEVADA
Nevada Chapter NFH
702-564-4368, hfnv.org
Unite For Bleeding Disorders Walk
Floyd Lamb State Park; Las Vegas

SEPT. 15, 2018 TENNESSEE
TN Hemophilia & Bleeding Disorder Foundation
888-703-3269, thbdf.org
Blazin' for Bleeders Walk, 5k, & 10k
Two Rivers Park; Nashville

SEPT. 15-16, 2018 KANSAS
Midwest Hemophilia Association
816-479-5900
midwesthemophilia.org
Family Education Weekend
Overland Park Marriott

SEPT. 15-16, 2018 VIRGINIA
Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Family Retreat Weekend
Great Wolf Lodge
Williamsburg

SEPT. 21-23, 2018 MASSACHUSETTS
New England Hemophilia Assoc.
781-326-7645
newenglandhemophilia.org
Women's Retreat
Essex Woods; Essex

SEPT. 22, 2018 NEVADA
Nevada Chapter NFH
702-564-4368; hfnv.org
Unite For Bleeding Disorders Walk
Bartley Ranch State Park; Reno

NATIONAL EVENT!

70th NHF Bleeding Disorders Conference ORLANDO • 2018

OCT. 11-13, 2018

FLORIDA

National Hemophilia Foundation
212-328-3700
hemophilia.org

70th ANNUAL BLEEDING DISORDERS CONFERENCE!

Orlando World Center Marriott

SEPT. 23, 2018 NEVADA
Nevada Chapter NHF
702-564-4368, hfnv.org
Nevada Women With Bleeding Disorders Conference
Hilton Garden Inn; Elko

SEPT. 29, 2018 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Celebrating Hispanic Heritage
National Museum of Mexican Art
Chicago

SEPT. 29, 2018 VIRGINIA/DC
Hemophilia Association of the Capital Area, 703-352-764
hacacares.org
Fall Festival and Walk
Lake Accotink Park; Springfield

OCT. 7, 2018 OHIO
Southwest Ohio Hemophilia Foundation
937-298-8000
swohiohemophilia.org
Annual Fall Outing
Young's Jersey Dairy Farm
Yellow Springs

OCT. 7, 2018 PENNSYLVANIA
Eastern PA Chapter NHF
484-445-4282
hemophiliasupport.org
Trick or Treat Trot 5K Run/Walk
Philadelphia Zoo

OCT. 19, 2018 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Autumn Wine Auction and Dinner
Columbia Yacht Club
Chicago

OCT. 20, 2018 WEST VIRGINIA
West Virginia Chapter of NHF
681-212-9255
wvnhf.org
Hemophilia Walk
Hazel Ruby-McQuain Park
Morgantown

OCT. 27, 2018 VIRGINIA
Virginia Hemophilia Foundation
804-740-8643
vahemophilia.org
Trick or Trot 5K Monster Dash
Robious Landing Park
Midlothian

OCT. 28, 2018 PENNSYLVANIA
Eastern PA Chapter of NHF
484-445-4282
hemophiliasupport.org
Adventures in Learning
Warehouse Hotel at the Nook
Manheim

I LOVE SWIMMING...

I JUST DIDN'T KNOW IT AT FIRST!

BY NATHAN BELL
Community Member

There are a couple reasons I became interested in swimming. One was that I couldn't play other sports because I have hemophilia.

For example, I played basketball, but kept getting elbow bleeds, so I had to stop. My mother was a swimmer and was very good at it. She would tell me stories about how she and her teammates were undefeated for many years and she inspired me to try it. It has been four years since I began swimming and I love it!

My coach and most of my teammates know I have hemophilia. During practice, if I feel anything weird or not right, I get out of the pool and let my coach know something is wrong. Then I call my mom and she comes to pick me up. As with any injury, I go home and factor up right away.

It was not easy when I started swimming. I had to work hard during practice. Once I started putting in my best effort, it began to pay off during swim meets. Swimming is divided into age groups. When I was in the 9/10 age group, I started making regional and state times. I got my first regional time in the 50-yard backstroke, then my first state time in the 200-yard IM (individual medley). I continued to get state times until I aged up to the 11/12 age group.

Now that I am in the 11/12 age group, the competition is way harder. Winter Regional was the first 11/12 regional I went to and only had 2 eligible times. My hard work paid off at last summer's regional; I had 12 regional times, but still didn't make it to state. My goals for next season are to improve all of my times and techniques, and get some state times.

Swimming is an excellent sport to do if you have hemophilia. I have never gotten hurt in the pool, but have injured myself outside the pool, and it has affected my swimming. For example, right before regionals, I broke my toe and had to miss a week of practice. It really impacted my summer swim events. So no matter what sport you're in, you must make sure to take care of yourself while you are playing the sport, and even outside of it.

If you are going to start competitive swimming, it won't be easy in the beginning, and it is not a sport you can miss a few practices. If it's something you want to do, you can do it if you put your mind to it. I would recommend anyone with hemophilia to start swimming. It is a fun and safe sport you can do for a lifetime.

TIME FOR FUN!

WORD CHALLENGE!

Follow the clues in the lines below to find the right letter answer.

Then, unscramble the letters to find out what someone with a bleeding disorder like hemophilia or von Willebrand might need if they are experiencing a bleeding episode.

Answers are on page 40!

What letter am I?

1.) I am in TOURNIQUET and in ELEVATE, but not in NEEDLE. 1.) _____

2.) I am in SYRINGE and in PORT, but not in BANDAGE. 2.) _____

3.) I am in PROPHYLAXIS and in TAPE, but not in PROTEIN. 3.) _____

4.) I am in INFUSE and in BUTTERFLY, but not in GAUZE. 4.) _____

5.) I am in COMPRESSION and in ICE, but not in VON WILLEBRAND. 5.) _____

6.) I am in HEMOPHILIA and in infusion LOG, but not in BLEED. 6.) _____

_____ _____ _____ _____ _____ _____

For many kids with bleeding disorders, clotting _ _ _ _ _ _ is the key ingredient for stopping a bleeding episode or preventing one from occurring!

Sudoku!

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

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

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

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fb.com/matrixhealthgroup

DEDICATED TO MAKING A DIFFERENCE

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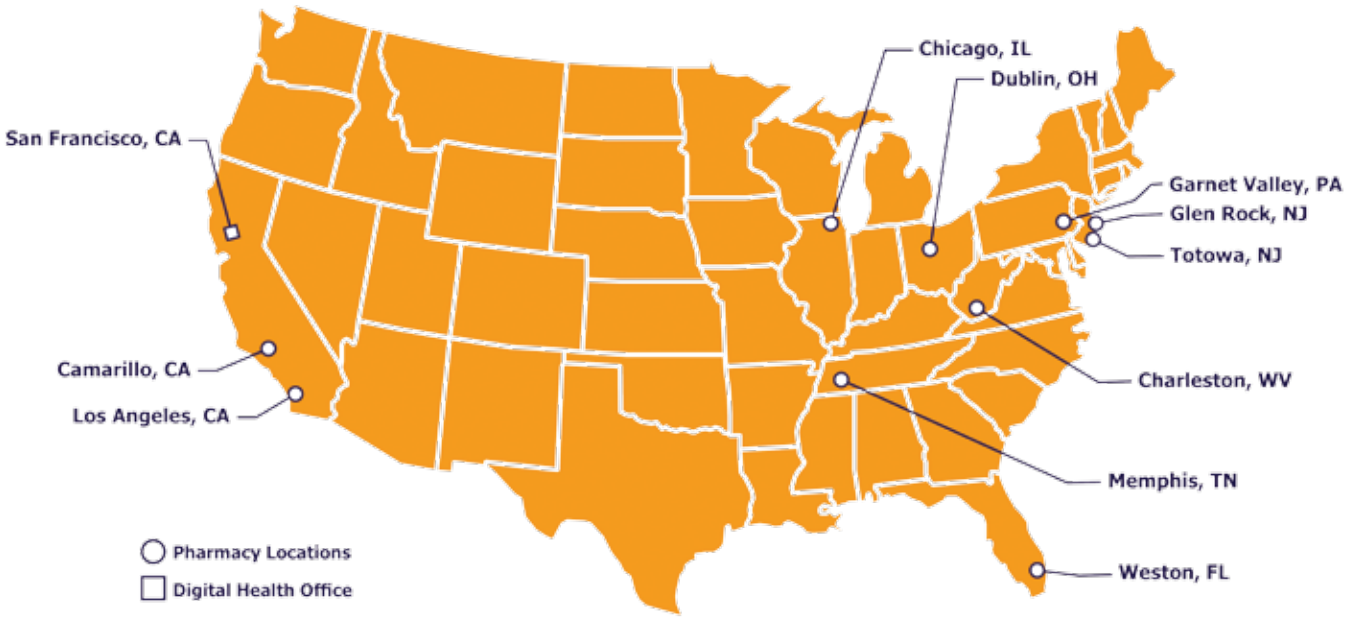
BIOMATRIX FAMILY OF COMPANIES

Matrix Health · FACTORRx Support Network · Medex BioCare · BiologicTx · Elwyn Pharmacy Group · Decillion