

BIO MATRIX

NEWS



DEDICATED
TO MAKING
A DIFFERENCE

SUMMER 2023
VOLUME 18 | ISSUE 3

“ Nothing can dim the light that shines from within. — Maya Angelou ”

ABOUT BIOMATRIX

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

BioMatrix offers accredited, comprehensive specialty pharmacy and support services for a range of chronic health conditions. Our clinicians and support staff offer a tailored approach to every therapeutic category, improving

quality of life for patients and producing positive outcomes along the healthcare continuum.

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

MISSION + VISION

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

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

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

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

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

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

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

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

FINE PRINT

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Editors: Susan Moore and Justin Lindhorst

The purpose of BIOMATRIX NEWS is to provide information such as current news, upcoming events, educational matters, personal stories, and a variety of opinions and views on topics of interest to the bleeding disorders community. The information and opinions printed in this newsletter do not necessarily reflect the views and opinions of the partners, employees, or others associated with BIOMATRIX NEWS or that of BioMatrix.

Health-related topics found in BIOMATRIX NEWS are for informational use only and are not intended to take the place of treatment or medical advice provided by healthcare professionals or hemophilia treatment centers. Please consult with healthcare professionals when medical questions arise.

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A NOTE FROM THE EDITOR

We hope our latest issue of *BioMatrix News* finds our readers enjoying the long, warm days of summer! Many in our community spend their free time cooling off in a refreshing pool, cheering for their children during sporting events, tending to a garden, and/or getting together for outdoor cookouts with friends and family.

While you're at it though, be sure to carve out a bit of time for yourself. Cool off in an air-conditioned room, breathe deeply and enjoy the quiet. Even just a few minutes can do wonders to help lower stress, calm a busy mind, and reset a negative mood.

Enjoy a good read... This issue features a fascinating article, *The Royal Disease*, giving a historical account of

bleeding disorders in the European Royal families. We have come a long way in managing hemophilia!

Do you have children or young adults going to bleeding disorders camp this summer? Are you attending camp as an adult volunteer? We would love to hear from children and adults alike about what being involved in camp has meant to you. Please consider sending your stories to us. We would love to share them with our readers in a future issue! We also invite and encourage you to give us your feedback regarding *BioMatrix News*. Let us know your thoughts, ideas, and suggestions. Share your stories, send your photos! We would love to hear from you!

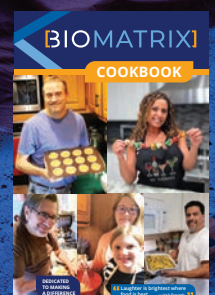
Maria Santucci Vetter
Editor-in-Chief, *BioMatrix News*
maria.vetter@biomatrixsprx.com

BIOMATRIX

Our cookbook brings together recipes from our family to yours!

Our Regional Care Coordinators have provided their very best recipes — from appetizers to entrees and desserts. To get your free cookbook, contact your Regional Care Coordinator or request online:

<https://mailchi.mp/biomatrixsprx/cookbook>



A EULOGY FOR MY FRIEND, MARK ANTELL

In Remembrance...

BY PAUL BRAYSHAW

It was hard to believe the news when Mark's daughter called to tell me about his accident and tragic death. After dodging so many proverbial bullets associated with his hemophilia health history, it is difficult to comprehend our greatest risk of all, a head trauma, was responsible for taking Mark's life. He had been out taking a walk and fell.

I had just seen Mark two days earlier at a local hemophilia gathering, and he seemed to be doing great. In one of the breakout sessions during that meeting, the speaker focused the discussion on adult men with bleeding disorders. Mark shared about his life and how treatment and care had changed. Everyone in the room was captivated by Mark's stories and there was profound respect among the group as they all knew Mark from his time on the Board of the Hemophilia Association of the Capitol Area, and his efforts on behalf of the bleeding disorders community.

While sharing his personal challenges and triumphs, Mark was very much at ease. I was excited to see Mark doing what he does best – being a patient advocate, speaking the truth and fighting for access to care. After experiencing complications that impacted his mobility with several months of recovery, Mark was finally getting back to good health. He and his longtime partner, Judy, had just returned from a three-month stay at their second home in Costa Rica where they enjoyed navigating the hilly terrain.

There are so many anecdotes I would like to share about my friendship with Mark, but one of the most consequential took place in September 2009. Mark and I were in a fight for our lives. We were both trying to figure out how to overcome hepatitis C (HCV), a disease transmitted thirty years ago from contaminated plasma derived therapies we used to treat our hemophilia. With little to lose and an unwillingness to let individuals and national advocacy groups take the lead or control our narrative, Mark and I devised a plan to gain access to investigational new drugs that showed promise for the treatment of HCV by filing a Citizen Petition to the FDA. The petition sought a public hearing to voice our concerns and to ensure people with hemophilia were not excluded from clinical trials.



MARK RUELL ANTELL

Nov 19, 1946 – Mar 29, 2023, Age 76

The petition was a huge success. Not only did we gain significant community exposure and support, but the FDA also held a hearing specifically for the bleeding disorders community and sought to eliminate bureaucratic barriers impacting patients who had little to no alternatives.

Mark and I were invited to the Gilead Headquarters in Foster City, California, where we met with senior researchers. We graciously demanded access to their combination HCV therapy. This regimen was so effective that patients in the trial studies were being cured in 8-12 weeks. With the support of the FDA and willingness of researchers at Gilead to help the bleeding disorders community, Mark and I were able to assist 125 people gain access to Gilead's lifesaving therapies.

This experience and many others like it were a testament to Mark's devotion to social justice for people who were impacted by situations beyond their control. Whether it was chronic illness, medical disaster or the health industrial complex, Mark was ready to challenge the status quo and fight for the rights of those who could not fight for themselves.

Mark was my dear friend and mentor for over twenty-five years. I will always remember the sincerity of our conversations in his apartment overlooking the Key Bridge and seeing Georgetown across the Potomac River. While reviewing his library of books or just paging through one of his magazine subscriptions, I could always learn something new and always felt better informed after our visits.

Our conversations about health, family life, or career helped guide me as we both pondered solutions to our shared challenges. I remain deeply saddened by Mark's sudden passing, but I remain humbled by the time we had together and through our efforts fighting to protect the community we shared.

Rest in Peace, Mark. You will be missed.

HOW ONE YOUNG MAN MADE A DIFFERENCE

World Hemophilia Day

BY SHELIA BILJES

World Hemophilia Day has been celebrated on April 17 every year since 1989 when it was started by the World Federation of Hemophilia (WFH). The date was chosen since it is the birthday of Frank Schnabel, the founder of WFH. The campaign is designed to increase the understanding and awareness of hemophilia and is celebrated by wearing the color red.

Each year, World Hemophilia Day highlights a different theme. The theme this year was *Access for All: Prevention of Bleeds as a Global Standard of Care*. The theme encourages bleeding disorder community members around the world to advocate at the local and national level. Global priorities include improving treatment access, controlling bleeds, and expanding coverage for prophylactic treatment.

On this special day, I have found that my biggest heroes come in tiny packages! Benjamin, a first grader diagnosed with severe hemophilia B, is an example of why I find this statement so true. He wanted to do something big on World Hemophilia Day to help spread awareness and education of hemophilia.

Benjamin encouraged everyone, students, teachers, and staff, to wear red on World Hemophilia Day. His mom, Stephanie, wrote an amazing description of hemophilia that was posted on the school's Facebook page along with the invitation to wear red. Benjamin's devoted big sister, Evelyn, a third grader at the same school, joined in spreading inspiration and education.

Every child who wore red received a pencil and a card that Benjamin and Evelyn worked for hours preparing. It was a big hit! Approximately 300 students showed their support by donning red attire!

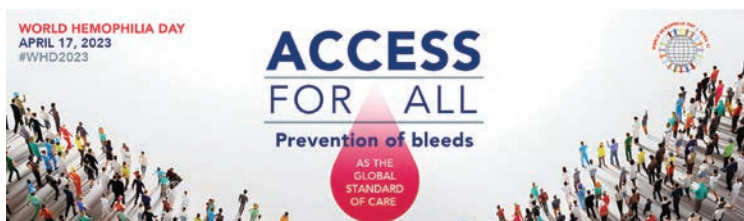
Benjamin invited me to the school to celebrate the event with his family, and I met Principal Kelli Corell. My pride for him is overwhelming! Congratulations to this fine young man on his impressive act to advocate, spread awareness, and share information about hemophilia!



Benjamin with Principal Kelli Corell, Shelia Biljes and Mom, Stephanie



Shelia Biljes with Benjamin and sister Evelyn



MY DECIDING FACTOR:

Making time for what matters most.

vonvendi
[von Willebrand factor
(Recombinant)]

Erica

VONVENDI Use: On-Demand & Surgery

- VONVENDI® is the **first and only treatment approved for routine use (prophylaxis)** in adults with severe Type 3 VWD who previously received on-demand therapy
- VONVENDI is **also approved for on-demand and surgical bleed management** in adults with all types of VWD
- VONVENDI **replaces VWF** (the main issue behind VWD), and **may be used with or without recombinant factor VIII** as instructed by your healthcare provider



Are you ready to ask about VONVENDI for your VWD? Visit [VONVENDI.com](https://www.vonvendi.com) to learn more, and talk to your healthcare provider.

VWD=von Willebrand disease; VWF=von Willebrand factor.

VONVENDI [von Willebrand factor (Recombinant)] Important Information

What is VONVENDI?

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- treat and control bleeding episodes
- prevent excessive bleeding during and after surgery
- reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy

Detailed Important Risk Information

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

How should I use VONVENDI?

Your first dose of VONVENDI for each bleeding episode may be administered with a recombinant factor VIII as instructed by your healthcare provider.

Your healthcare provider will instruct you whether additional doses of VONVENDI with or without recombinant factor VIII are needed.

What should I tell my healthcare provider before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.

- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

What else should I know about VONVENDI and von Willebrand Disease?

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop VONVENDI or factor VIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

What are the possible side effects of VONVENDI?

You can have an allergic reaction to VONVENDI.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with VONVENDI include: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate.

Tell your healthcare provider about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see the VONVENDI Consumer Brief Summary on the following page and talk to your healthcare provider.



Important facts about VONVENDI® [von Willebrand factor (Recombinant)]

This leaflet summarizes important information about VONVENDI. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.


vonvendi
**[von Willebrand factor
(Recombinant)]**

What is VONVENDI?

VONVENDI is a recombinant medicine used to replace low levels or not properly working von Willebrand factor in people with von Willebrand disease. Von Willebrand disease is an inherited bleeding disorder in which blood does not clot normally.

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- Treat and control bleeding episodes
- Prevent excessive bleeding during and after surgery
- Reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy.

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

What should I tell my doctor before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

What is the most important information I need to know about VONVENDI?

VONVENDI can cause blood clots particularly in patients with known risk factors for blood clots. Discuss this risk with your healthcare provider.

You can have allergic reactions to VONVENDI. Symptoms may include generalized itching; rash or hives; rapid swelling of the skin or mucous membranes; chest pain or tightness; tightness of the throat; low blood pressure; shock; drowsiness; nausea; vomiting; tingling, prickling, burning, or numbness of the skin; restlessness; wheezing and/or difficulty breathing; lightheadedness; dizziness; or fainting. If symptoms occur, stop using VONVENDI immediately and get emergency treatment right away.

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, they may stop VONVENDI or FVIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

What are the possible side effects of VONVENDI?

Side effects that have been reported with VONVENDI include: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate. These are not all the possible side effects with VONVENDI. You can ask your healthcare provider for information that is written for healthcare professionals.

Tell your healthcare provider about any side effects that bother you or do not go away.

What else should I know about VONVENDI and von Willebrand Disease?

Consult with your healthcare provider to make sure you are carefully monitored with blood tests to measure levels of von Willebrand factor and factor VIII so they are right for you.

You may infuse VONVENDI at a hemophilia treatment center (HTC), at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or HTC. Many people with von Willebrand disease learn to infuse VONVENDI by themselves or with the help of a family member.

Call your healthcare provider right away if your bleeding does not stop after taking VONVENDI.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use VONVENDI for a condition for which it is not prescribed. Do not share VONVENDI with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider or pharmacist about Vonvendi. The FDA approved product labeling can be found at https://www.shirecontent.com/PI/PDFs/VONVENDI_USA_ENG.pdf or call 1-877-TAKEDA-7 (1-877-825-3327).

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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US-VON-0657v1.0 04/22



NAVIGATING LIFE WITH HEMOPHILIA

BY DENISE RUIZ

My journey of living with hemophilia is much the same as, yet different than most in our community. Being adopted at just two weeks old, my parents would not have known the reasons behind my ailments and struggles.

As a somewhat clumsy child, I often found myself covered with bumps and bruises; scrapes and scratches always bled much longer than my peers. In puberty, I often had to stay home from school as my menstrual cycles were unbearable with pain and excessive bleeding.



Jon and Denise

My husband, Jon, and I married in 2004. In July 2006, our first child, Jacob, was born in Washington State. When Jacob was six months old, I took him in for a routine well-baby visit where he received a heel stick. Being in the military, my husband was gone for training as he was scheduled for deployment to Iraq the next month.

That night I put Jacob to bed as usual. When he woke in the early morning hours,

I found his crib bedding covered in blood. Of course, I freaked out – just 22 years old, by myself, with a bleeding baby. Unfortunately, my husband was not able to come home.

At the hospital, the wait for an answer was excruciating. The doctor asked if I had ever been tested for hemophilia. In fact, I had never even heard of it before that moment. Sure enough, Jacob was diagnosed with severe factor IX deficiency. Terror set in, and I immediately began researching what it meant. I was alone and terrified, and it was just the beginning.

Since my husband was going to be gone for a while, we felt it would be best that I move near my parents in California to have help with the baby. My husband ended up being in Iraq for 15 months. I was very fortunate and grateful to have the support of my family during that time.

The following year, it was decided Jacob would have a port placed so he could begin factor replacement three times a week, which I learned to administer at home. For someone with severe hemophilia, I feel Jacob has had a fairly fortunate childhood. With dedicated prophylaxis, he has experienced only a handful of joint bleeds and just one hospitalization due to a fall down a set of stairs.



When Jacob was diagnosed, I was tested as well and found to have 27% factor IX level. The reason for my own symptoms throughout my childhood became clear. I now treat as needed and certainly for any medical procedures.

When Jacob was 4-years old, we welcomed our daughter, Cora – the first of three girls. Ava and Emma followed. Cora is diagnosed with mild factor IX deficiency and is a carrier. Ava and Emma are not affected. My fifth and last pregnancy resulted in the birth of our crazy, comical, wild-child, Brody! At the time, we were stationed in Hawaii, and Brody was born in May, just weeks after COVID-19 paralyzed our country.

Almost from the start, Brody did not fare as well as his older brother. Toward the end of my pregnancy, I was 37 years old and required stress tests twice a week due to my “advanced” age. My daughter broke her arm the night before my appointment, and let’s just say the stress test didn’t go very well. Immediately, I was sent to the hospital and induced. Though the nurses told us it would still be hours before the baby’s arrival, I knew differently. My husband rushed to get to the hospital, arriving just 10 minutes before Brody was born.

Brody’s birth went well; however, a week later, he began developing bruises from the slightest touch, such as his car seat buckle or just being held. He seemed to bruise just by looking at him. Seeing my little boy constantly so black-and-blue was devastating. We wanted to have a port placed, but COVID made everything more difficult. At the time, only children diagnosed with cancer were given clearance to have ports placed.

At Brody’s six-month well-baby medical appointment, he received three vaccinations, two in one thigh and one in the other. One of his legs swelled almost to the point of developing compartment syndrome. I rushed him to the clinic and insisted he be hospitalized. After two hours and several failed attempts, clotting factor was finally administered via a PIC line. It took more than six weeks for the swelling to finally subside and get his leg back to normal. Although we are not sure whether this severe bleed was the instigator, Brody continues to have issues with his hips.

Finally in June of 2020, he was able to have his long overdue port placed. Brody arrived for his surgery covered in bumps, bruises, and even some hematomas. The procedure went well; in short order, most of his bumps and bruises were gone or greatly diminished. Elation and

a huge sense of relief settled in knowing I could administer his factor at home as I had been doing with Jacob for several years. Now four years later, Brody continues to do well with factor replacement and his port is holding steady. Jacob is 17 and self-infuses. His port was removed when he was eight years old.



Jacob and Brody

Being a military family, we have moved 17 times in the past 19 years. Currently living in the Washington DC area, we have lived in California, Texas, Washington State, Hawaii, Georgia, and Alabama, moving back and forth to some of the same states. Constantly moving a family already provides many trials and tribulations – throw in a bleeding disorder, and the challenges grow exponentially, especially when having to establish access to care with each move.



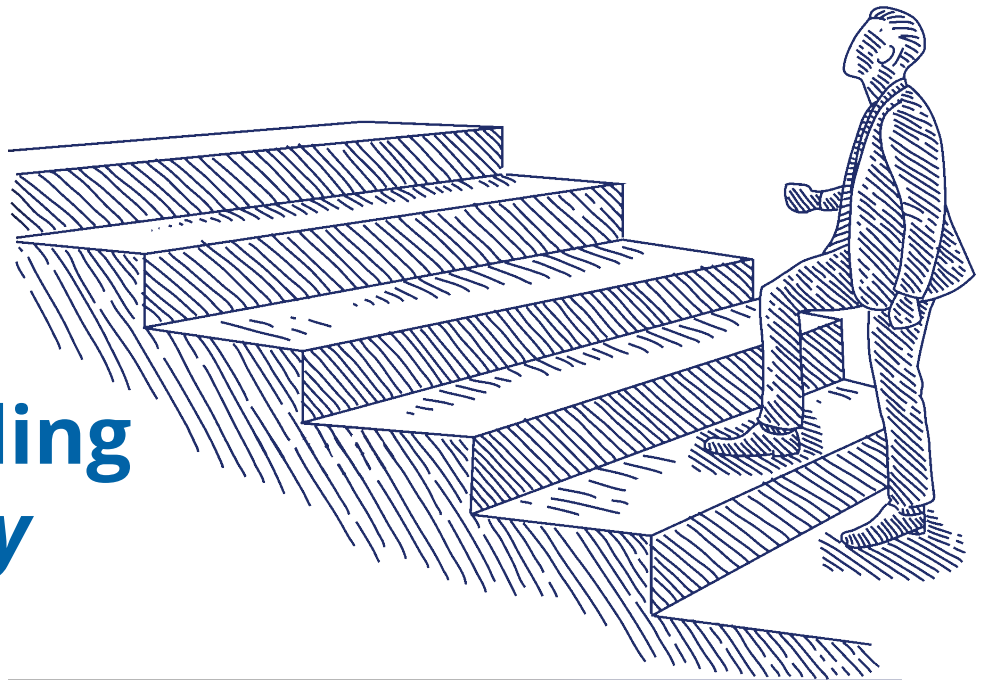
Halloween Fun!

I am truly thankful for many of the relationships and friendships we have been blessed to have over the years. I will always be grateful for the Hawaii Chapter, National Hemophilia Foundation for their support; for Ziggy Douglas, the chapter’s executive director who is no longer with us, for taking our family under his wing and for Donna Garner, BioMatrix Patient Care Coordinator, who has seen us through 17 years of moving and access-to-care hurdles. Donna has been our “constant” in all hours of the day and night, from when we lost the ONE bag that could NOT be lost (Jacob’s supply bag) and the countless times someone was hurt and needed extra factor sent ASAP, to just being our support and dear friend through it all.

My husband’s retirement is the light at the end of the moving tunnel. The plan is to leave the military in spring of 2024. We aren’t sure what the future will hold for us, but the message we would like to share is that we know being well-informed and having support is vital to survival in navigating the ever-changing world of living with a bleeding disorder.



Understanding Step Therapy Mandates



BY SHELBY SMOAK, PH.D.

About five years ago, I had my first dance with *Step Therapy*, also known as *Fail First*. I'm a 51-year-old with severe hemophilia and have chronic arthropathy. I'm also allergic to the current go-to medication used to treat hemophilia-induced arthropathy.

There is a scarcity of available products to treat this unique form of arthritis. Moreover, many other drug options have bleeding complications when used repeatedly, especially in the gastrointestinal (GI) tract. Thus, concern existed about how to navigate my risk factors against my need for relief from pain and tenderness, which until then had been primarily treated with acetaminophen, which, likewise, is also unsafe if used too frequently.

Due to my allergy, my physician wanted me to use the lowest dose possible of another medication for the therapy he chose. The drug's brand name was dispensed in 40 mg tablets, which pleased my physician, but the generic only came in 50 mg tablets, which he felt was too much. He also added his concern about the compound and binding ingredients in the generic and sided with the brand as being a safer choice. Reasonably then, he chose the brand version of the drug, wrote the script, and off I went to fill it.

Then Step Therapy began its two-step, jumping in to deny the brand drug. I must fill the generic and fail first on that, I was told by the pharmacist, who had the generic filled and ready to go. I left him holding the bag and called the insurer. On the phone with them, I remember distinctly saying, "You understand that failing this drug requires that I likely develop a GI bleed." The response was a bit of side-stepping: "The generic is a more cost-effective choice."

I returned to the pharmacy, filled the generic. My arthropathy improved. And so, things remained for about three months until blood appeared in my stool. At the

physician's advice, I immediately stopped the drug and began infusing morning and evening, which likely cost more than approving the brand drug to begin with. My physician was ready for a CAT scan and other tests if I continued to bleed, but thankfully, I recovered.

After several phone calls to the insurer, a letter and notes from my physician, and the return of my arthropathy due to delay in care, the brand drug was eventually approved. I took this medication without issue throughout the duration of that particular insurance policy.

This is my experience with Step Therapy and highlights its sister name of *Fail First Policy*. I have since had to have this argument with other insurers, and thus far, they have accepted my past evidence of failure and have approved the brand drug. However, I am sure this approval will end once I get too far out from that experience.

Many in our community experience Step Therapy programs, and while they are less frequently found in the factor-space, they do exist. I would expect, however, that many of our community may experience Step Therapy in the treatment of another ailment, as I did. Let's look at Step Therapy: What is it, how might it impact you, and what can you do to learn more about it?

WHAT IS STEP THERAPY?

Step Therapy is a type of prior authorization for drugs that prevents a patient from accessing treatments prescribed by their doctor and instead mandates a therapy as dictated by the insurance plan. In laymen terms, it means trying "less expensive" drug options before "stepping up" to a more costly drug therapy. Step Therapy plans could dictate that a patient begin treatment with a cost-effective drug before progressing to a more costly drug therapy if the initial treatment is proven ineffective. Some providers refer to this as a *Fail First* plan.

STEP THERAPY "FAIL FIRST"

Step Therapy, also known as Fail First policies prevent patients from accessing treatments prescribed by their doctor. It means trying "less expensive" drug options before "stepping up" to a more costly therapy.

HOW DOES STEP THERAPY IMPACT ME?

Step Therapy is more prevalent in commercial policies and may or may not impact you depending on your health plan. If your health plan implements Step Therapy, you may have to utilize other medications and, before getting coverage approval for a more expensive therapy, will have to document the ineffectiveness of the preferred, less expensive therapy. In some limited cases a doctor's intervention may allow an override of the Step Therapy program.

For many chronic and rare conditions, a less-expensive (often "generic") medication may not exist. In this scenario, a health plan may prioritize the most cost-effective medication as the starting step for treatment. In bleeding disorders, the health plan may dictate medication choices based on cost savings and may even deem some of the products as interchangeable.

Significant documentation is encouraged in order to appeal to use another medication. This can become problematic especially if you change to a new health plan which has instituted a Step Therapy program; despite perhaps a long history of using a particular factor product, the plan could dictate a medicine change.

For government programs such as Medicare and Medicaid, Step Therapy programs are less prevalent, but caution must be taken when selecting plans. Because Medicaid Advantage (MA) are managed by commercial payers, they may be more at risk of implementing Step Therapy programs, but the MA plans must adhere to Part B guidelines for factor medications and must ensure they do not disrupt ongoing Part B drug therapies for beneficiaries.

Under new policy guidelines, Step Therapy can only be applied to new prescriptions or administrations of Part B drugs for beneficiaries who are not actively receiving the affected medication. This means that no beneficiary currently receiving drugs under Part B will have to change their medication.

WHAT CAN BIOMATRIX DO TO HELP WITH A PROBLEM WITH STEP THERAPY?

If you're facing Step Therapy, our Patient Navigation team at BioMatrix can help you navigate the process. Please email bdpatientnav@biomatrixsprx.com, or go online to fill out our Patient Navigation form: bit.ly/bd-patientnavigation.

WHERE CAN I LEARN MORE ABOUT STEP THERAPY?

The Alliance for Patient Access has created a succinct overview for understanding Step Therapy, on YouTube: <https://www.youtube.com/watch?v=zg6mjEnUMv0>

THE COALITION FOR
HEMOPHILIA 

2023 MEETINGS ON THE ROAD!

FUN • ENGAGING • INTERACTIVE • NEW SPEAKERS

DATES & LOCATION:

- SEPT 16: AUSTIN, TX
- SEPT 23: CLEVELAND, OH
CONCORD, CA
- OCT 7: PHILADELPHIA, PA
- OCT 14: NEW ORLEANS, LA
- OCT 21: BOSTON, MA
- NOV 4: PHOENIX, AZ
MIAMI, FL
MILWAUKEE, WI



MEETINGS ARE FREE | PRE-REGISTRATION REQUIRED!

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For the first time in more than 70 years, the British monarchy crowned a new king. Prince Charles takes the place of his mother, Queen Elizabeth, who passed away at age 96 on September 8th, 2022. With Prince Charles' crowning ceremony taking place last May, we thought this would be a great time to revisit the Royal Family and how it was affected by hemophilia.

The Royal Disease

BY JUSTIN LINDHORST AND MARIA SANTUCCI VETTER

Queen Victoria

Until the reign of modern-day Queen Elizabeth, Queen Victoria had the longest reign of any female monarch in history. Her sovereignty entered a time that saw progress and growth in nearly every aspect of society. From industry and science to culture and politics, her rule ushered in an era that would later bear her name, Victoria. Taking the throne at age of eighteen and ruling for sixty-four years, Queen Victoria is perhaps one of the most iconic figures in the history of the British monarchy.



Queen Victoria
May 24, 1819 – Jan. 22, 1901
Age 81

Under Victoria, the British Empire rose to become a leading global power. One way the monarchy sought to secure political alliances came through strategic marriages between the ruling royal families. Queen Victoria became known as The Grandmother of Europe as some of her nine children and 42 grandchildren married into royal families across the continent. It was through these marriages that Victoria not only secured political clout, but such practice was also the cause for the passing of a condition the royal monarchy often tried to hide, hemophilia. As carrier of hemophilia, Queen Victoria inadvertently spread the condition from the United Kingdom to the royal houses of Germany, Spain, and Russia. The line of princes with hemophilia in Europe led to the bleeding disorder being coined as *The Royal Disease*.

Though they lived lavish courtly lifestyles, life for Victoria's descendants with hemophilia was not easy. At a time when doctors knew little about the condition, there was not much a family could do for their affected children. Though great care was taken to protect the princes, unfortunately, many did not live to see adulthood. The following is an account of *The Royal Disease* as found in some of the major ruling monarchies of Europe.

The United Kingdom

Prince Leopold, Duke of Albany

Leopold, Victoria's eighth of nine children, was born at Buckingham Palace. Of four sons, he was the only one with hemophilia. The condition caused Victoria much anxiety, prompting her to keep the prince close to her side. He was followed in permanent attendance by several physicians. Victoria thought it was unnecessary for him to leave the home and even encouraged him not to marry or have children.



Prince Leopold Duke of Albany
Apr 7, 1853 – Mar 28, 1884
Age 31

Unable to pursue a military career because of his condition, Leopold enrolled in the Christ Church, Oxford University, where he studied a wide variety of subjects. He earned an honorary law degree and became a patron of the arts and literature while serving as his mother's unofficial secretary.

Despite his mother's wishes, Leopold sought marriage and considered it his only hope for independence. His health condition caused some difficulty in finding a wife. After several rejections, Leopold eventually married Princess Helen of Waldeck and Pyrmont, a member of the German royal family. Though their marriage was brief, the couple was happy and gave birth to a daughter, Alice, Countess of Athlone, and a son, Charles Edward.



Princess Alice
Countess of Athlone
Feb 25, 1883 – Jan 3, 1981
Age 97

Due to joint pain associated with his hemophilia, the winter months were always difficult for Prince Leopold. In

Members of the Royal Family with Hemophilia and Carriers of Hemophilia

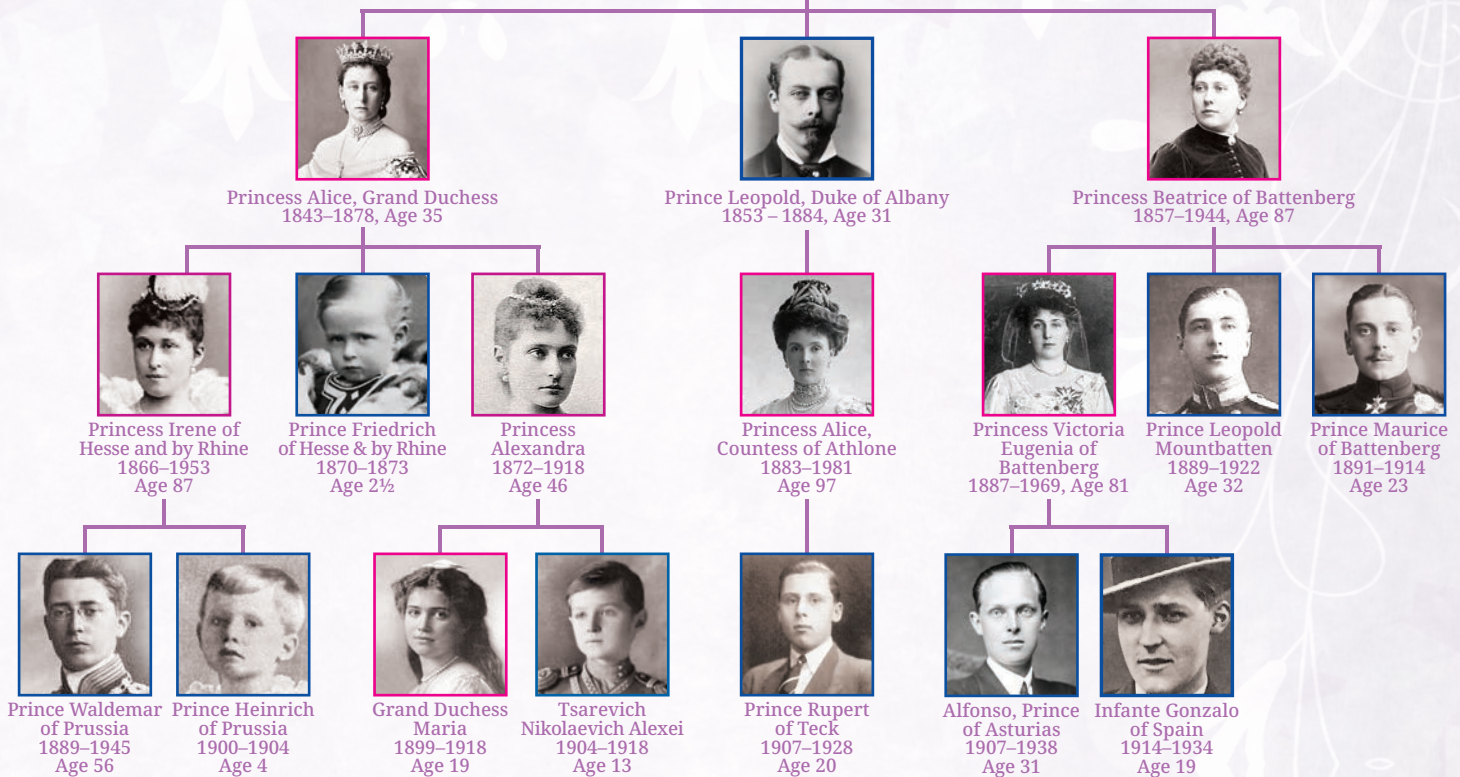
Chart does not include unaffected family members



Queen Victoria
1819–1901, Age 81

With Hemophilia

Carriers of Hemophilia



February 1884, while his wife was pregnant with their son, Leopold was encouraged by his physician to spend time in the warmer climate of Cannes, France. Just weeks later, while in Cannes, Prince Leopold suffered a fall, injuring his knee and hitting his head. He passed away early the next morning from a combination of a cerebral hemorrhage and a fatal mixture of pain medications.

Hemophilia in the royal family did not end with the princes most closely tied to the British Royal Family. Queen Victoria passed the hemophilia gene to two of her four daughters, both of whom gave birth to sons with the bleeding disorder, and one also had two daughters who were carriers.

Prince Rupert of Teck

Prince Rupert was the son of Prince Leopold's daughter, Princess Alice, Countess of Athlone. Like his grandfather, he had hemophilia. Rupert was a serious and studious young man and attended Eton and Trinity Colleges at Cambridge University. While traveling in Bellevue-sur-Saone, France, Rupert was in a car accident where he suffered a slight skull fracture. Prince Rupert passed away five days later, just a few days before his 21st birthday.



Prince Rupert of Teck
Apr 24, 1907 – Apr 15, 1928
Age 20

Germany

Hemophilia found its way to the German Empire with the marriages of Queen Victoria's daughters, Princess Beatrice of Battenberg and Princess Alice, Grand Duchess, to German suitors. Beatrice had two boys with the condition, Leopold and Maurice. Princess Alice had six children, including one son, Prince Frederick, with hemophilia and two daughters, Princess Irene and Princess Alice, who were carriers of hemophilia. Irene would go on to have two affected sons, Prince Waldemar and Prince Henry.



Princess Beatrice of Battenberg
Apr 14, 1857 – Oct 26, 1944
Age 87



Prince Leopold Mountbatten
May 21, 1889 – Apr 23, 1922
Age 32



Prince Maurice of Battenberg
Oct 3, 1891 – Oct 27, 1914
Age 23

Prince Leopold Mountbatten

Lord Leopold is the son of Princess Beatrice and Prince Henry of Battenberg. He served in the King's Royal Rifle Corps, where he attained the rank of Major. Leopold was also a member of the Knights of the Royal Victorian Order and the Knights Grand Cross of the Royal Victorian Order. At age 32, due to repeated bleeding episodes into his hip, Lord Leopold required surgery and passed away during the procedure.

Prince Maurice of Battenberg

Prince Maurice, Leopold's brother and the youngest son of Beatrice and Henry, was educated at Lockers Park Prep School. He went on to attend the well-known Wellington College. Like his brother, Maurice volunteered in the King's Royal Rifle Corps. As a Knight Commander of the Royal Victorian Order and a Lieutenant in the rifle corps, Maurice bravely served in World War I. At age 23, he was mortally wounded at the First Battle of Ypres in 1914 and died on the battlefield.

Prince Friedrich of Hesse

Prince Friedrich was born to Princess Alice, daughter of Queen Victoria. Grandson of the queen, Friedrich or 'Frittie' as the family often called him, was an active, cheerful child. He was diagnosed with hemophilia in February of 1873 after a cut on his ear bled for three days.



Prince Friedrich of Hesse & by Rhine
Oct 7, 1870 – May 29, 1873
Age 2 1/2



Princess Alice Grand Duchess
Apr 25, 1843 –
Dec 14, 1878, Age 35

Three months later while playing with his younger brother, Frittie climbed onto a chair in his mother's bedroom to get a better view from a window. After accidentally tipping the chair, he fell through the window. Though he survived the twenty-foot drop, he died hours later from a brain hemorrhage at the tender age of two. Princess Alice never recovered from her loss.

Prince Waldemar of Prussia

Princess Irene of Hess, the daughter of Princess Alice, Grand Duchess, had three children. The oldest and youngest were diagnosed with hemophilia. The family was devastated the "Royal Disease" had shown up in the ruling Prussian family with the birth of their first son, Prince Waldemar of Prussia. Although the condition caused Irene much anxiety, Prince Waldemar lived into his fifties, unlike many of his relatives. He married Princess Calixa of Lippe-Biesterfeld in August 1919, and even though they had a happy marriage, they decided against having children,



Prince Waldemar of Prussia
Mar 20 1889 – May 2, 1945
Age 56

Waldemar lived to see a time when treatment for hemophilia saw some improvement. Doctors discovered that an infusion of blood from a healthy patient could help stop the bleeding in people with hemophilia. As such, Waldemar received blood transfusions to control his bleeding episodes. During World War II, he and his wife fled the Russian advance and arrived injured and exhausted in Tutzing, Bavaria, where Waldemar received his last blood transfusion. Not long after arriving in the city, the American Army took control of the area and sent all available medical resources to treat the concentration camp victims. At a medical clinic, but without access to blood transfusions, Waldemar bled internally and passed away.



Prince Henry of Prussia and Princess Irene with sons, Waldemar, Heinrich (center) and Sigismund (unaffected)



Princess Irene of Hesse & by Rhine
Jul 11, 1866 – Nov 11, 1953
Age 87



Prince Heinrich of Prussia
Jan 9, 1900 –
Feb 26, 1904, Age 4

Prince Heinrich of Prussia

Also born to Princess Irene of Hesse, Prince Heinrich was the youngest brother of Prince Waldemar, and also diagnosed with hemophilia. Heinrich climbed up on a table and fell. Although the fall itself was not all that far, the young boy had fallen headfirst. Just four years old, Heinrich died the following day from the resulting brain hemorrhage. The entire family was shattered.

Russia

Princess Alice, Grand Duchess, had another daughter, Alexandra of Hesse, who married Tsar Nicholas II Romanov of Russia. They would go on to have five children – one of whom would come to be considered the most famous of all the royals affected by hemophilia. Tsarevich Nikolaevich Alexei of Russia was the great-grandson of Queen Victoria.



Princess Alexandra of Hesse
Jun 6, 1872 – Jul 17, 1918
Age 46

Tsarevich Nikolaevich Alexei

After having four daughters, it was an extremely joyous occasion for the Romanovs when Alexei was born. Being the first son, Alexei was in line to become the next Tsar and leader of the Russian Empire. As the only male heir to the throne, the family was distraught when after the umbilical cord was cut, his navel continued to bleed for hours, indicating the young prince had hemophilia.



Tsarevich Nikolaevich Alexei
Aug 12, 1904 – Jul 17, 1918, Age 13

Alexei was very spoiled, prone to mischief, had a temper and was often difficult to control. An extremely active child, he was prohibited from playing too roughly and from activities as riding a bike, playing tennis or horseback riding. He was lonely but for his sisters as he wasn't often allowed to play with other children. Two Imperial Navy sailors were appointed to watch over and keep him out of trouble, but they were not always able to do so.

As the center of attention in his family, when Alexei felt well, the entire house was happy. When he suffered a bleeding episode, everyone suffered with him. He was prone to spending weeks in bed in severe pain and had suffered many near-death bleeding episodes. Yet, Alexei grew to become a much better-behaved, good-natured, considerate and sensitive young teen.

So severe was Alexei's hemophilia, Alexandra and Nicholas

devoted much of their time and energy to seeing that he was taken care of. They came to rely on the services of Grigori Rasputin, a Russian mystic and self-proclaimed holy man, who was able to help Alexei through his painful bleeding episodes. No one knows exactly how Rasputin was able to mend the young Tsarevich's bleeding episodes. It is speculated he prevented physicians and caretakers from manipulating Alexei's body too much and used a combination of hypnosis, herbs, or as some believed, "supernatural healing powers" to ease the boy's pain.

Alexei's hemophilia often took his parent's attention away from governing. Their reliance and close connections with Rasputin spurred much gossip and discontent. The country was already plagued with political and social unrest. A series of bloody revolutions took place that would ultimately put the communist Bolsheviks in power. Arrested in the Russian Revolution of 1917, Alexei and his family were forced to live as captives.



The Romanov Family
Czar Nicholas II with his wife, Alexandra (top right) and their children (from left) Olga, Maria, Anastasia, Tsarevich Alexei and Tatiana

In July of 1918, the family was tragically and systematically executed by the Bolsheviks to ensure a counter-revolution could not rally around the former rulers of Russia. Alexei and his family were eventually canonized as "passion bearers" in the Russian Orthodox Church Abroad.

The remains of Alexei and one of his sisters, believed to be Maria (although it *might* have been Anastasia), were discovered in 2007. DNA tests conducted in 2009 revealed that in addition to confirming the factor IX deficiency diagnosis, Maria was a carrier. This correlates with a report that at 15-years old, Maria bled excessively when having her tonsils removed. It is unknown if any of the other sisters were carriers since their remains were incinerated.



Grand Duchess Maria
Jun 26, 1899 – Jul 17, 1918, Age 19
Grand Duchess Anastasia
Jun 18, 1901 – Jul 17, 1918, Age 17

Spain

Hemophilia would find its way into the ruling royal Spanish family by Victoria Eugenie of Battenberg, the daughter of Princess Beatrice and granddaughter of Queen Victoria. Victoria Eugenie became the Queen of Spain when she married King Alfonso XIII. Including the heir to the throne, two of their seven children were diagnosed with hemophilia. It was reported that the marriage was unhappy with the king never forgiving his wife for bringing hemophilia into the royal bloodline, and they later separated.



Princess Victoria Eugenia of Battenberg
Oct 24, 1887 – Apr 15, 1969
Age 81

Alfonso, Prince of Asturias

Queen Victoria's great grandson, Alfonso was born to Victoria Eugenie of Battenberg and her husband King Alfonso XIII. As their first-born son, Alfonso was the heir-apparent to the throne of Spain. It was discovered he had hemophilia at the time of his circumcision. Alfonso and his younger brother, Infante Gonzalo, were fitted with special jackets that were made to help prevent bleeding episodes.



Alfonso, Prince of Asturias
May 10, 1907 – Sept. 6, 1938
Age 31

commoner having met her at a hospital in Switzerland where he was being treated for his hemophilia. He would later divorce, marry another commoner and divorce again. Alfonso did not have children with either wife.

At age 31, while being driven by a friend in Miami, Florida, the car swerved to avoid a truck and crashed into a telephone booth. Although his injuries were thought to be minor at the time, he suffered fatal internal bleeding and passed away. Initially buried in Miami, Alfonso was re-entombed in 1995 at The Pantheon of the Princes in El Escorial, Spain.

Infante Gonzalo of Spain

Another great-grandson of Queen Victoria, Infante Gonzalo was the youngest child of King Alfonso and Queen Eugenie. The final name in his title included "Mauricio" in honor of Prince Mauricio, his uncle with hemophilia who had been killed in World War I. During his life, it was not widely known that Gonzalo had hemophilia. Though he suffered hemophilia-related health issues, he was an avid sportsman, attended the Catholic University of Leuven to study engineering and held rank as a private in the Spanish Army.



Infante Gonzalo of Spain
Oct. 24, 1914 – Aug. 13, 1934
Age 19

In 1934 while spending the summer holiday in Austria with family, Gonzalo was out for a ride with his sister. To avoid hitting a cyclist, his sister swerved and crashed into a wall. Like his brother, Alfonso, who would perish in a car accident four years later, Gonzalo suffered no visible injuries right after the accident; however, hours later, it was discovered he was experiencing a severe abdominal bleed. Gonzalo passed away just two days later at age 19.



One day, Olga, Tsarevich Alexei's sister, found the ten-year old prince gazing up at the sky. When she asked what he was doing, he replied, "I like to think and wonder...I enjoy the sun and the beauty of summer as long as I can. Who knows whether one of these days I shall be prevented from doing it." The royal princes born with *The Royal Disease* faced struggles largely unknown to our bleeding disorders community today.

Though the ruling monarchies of Europe often attempted to minimize the appearance of hemophilia in their families to the public, privately, great measures were taken to learn about and treat the bleeding disorder. They commissioned the finest physicians of the time to attend to their children. Increased attention from doctors brought about awareness and new literature regarding hemophilia.

The late 1800s saw a huge increase in the number of publications focused on hemophilia, shedding light and paving the way for future physicians to advance treatment. Though their struggles were great, the status of the princes with hemophilia helped drive research and bring attention to The Royal Disease. Since the death of Prince Alfonso in 1938, there remain no living descendants with hemophilia or known carriers in the royal family.

It is speculated that treatment for hemophilia would not have advanced as quickly were it not for the royal princes who suffered from the condition. Their stories are compelling and prompt us, as young Alexei, to think and wonder...



Symposium 2023

April 13-16

Orlando, Florida

Renaissance Orlando at SeaWorld

BY DAVE BURGESSON, DIRECTOR DB SALES SOUTH

Hemophilia Federation of America's 2023 Symposium took place under the sunny blue skies of Orlando!

The purpose of this annual gathering is to bring together the many constituencies of the bleeding disorders community for networking and education. Specialty pharmacies, manufacturers and non-profit organizations were available in the exhibit hall for all to visit and learn about the latest news regarding services, treatments, and support offerings. The host hotel, Renaissance Orlando at SeaWorld®, was what Goldilocks would like – just right. It was neither too small nor too large. The exhibit hall was full without being crowded, with sessions and meals just a short walk away.

Symposium offerings included programs for everyone in the community with rap sessions that shared suggestions and solutions when facing challenges, opportunities to learn about future therapy options, and information presented on manufacturers' featured products, just to name a few. Particularly poignant and tender was HFA's Celebration of Life to remember those community members who are no longer with us.

The BioMatrix booth team consisting of the Florida Regional Care Coordinators (RCCs) with an assist from some of our out-of-state coworkers. They were kept very busy handing out cooking-themed promo items - spatulas, cutting boards and the much-in-demand BioMatrix Employee Cookbook all while answering questions about our pharmacy services, our Patient Navigation Program, and our numerous educational sessions. If you

or someone you know needs help with any barrier to care, please visit our website (bit.ly/bd-patientnavigation) and request the completely confidential

assistance of our Patient Navigators. They have been guiding community members through challenging circumstances with insurance and connecting folks with resources to solve difficult financial situations with great success for years.

The booth was kept lively by Terry Rice, BioMatrix's Director of Education. Terry ran our exciting *Jeopardy* game testing the knowledge of guys-versus-gals on "all things about food." Players returned to the booth again and again to try their hand at scoring more points for their squad! The guys squeaked out a victory with 400 points over the gals at this year's competition. Visitors really enjoy participating and being challenged, while others just like watching others try to beat the board.

And if HFA's gathering wasn't already enough, the final night event was held at SeaWorld! Just a short bus ride away, dinner was served in a private area, followed by access to the entire park. Many attendees took advantage of this opportunity to socialize and enjoy the park's exhibits and rides in family and friend groups.

Past. Present. Future.

Yes, indeed, there was something for everyone!



ONE FISH... TWO FISH... ELEVEN FISH

BY SHELBY SMOAK, PH.D.

May 19-21 on the Atlantic shores of Delaware, adult men with hemophilia gathered—again—to share time together on a men’s weekend retreat. The event was hosted by Country Boy Fishing and was sponsored by Octapharma, Medexus, and BioMatrix.



The weather was beautiful but chilly, the sky bright as participants arrived from nearby Maryland, New Jersey, Pennsylvania, and Virginia, with a few guys making the trip from North Carolina. After arriving, the men reconnected with friends and gained new bonds with an ice-breaker event. The Atlantic Sands Hotel on Rehoboth Beach then served up their chef-inspired meals, which we all agreed far surpassed ordinary hotel menus and rivaled top-rated restaurants.

Medexus speaker Christian Harris got his vogue going and styled the group with fashion knowledge, ironing technique, and button sewing. While this may be far from what many imagine as a “men’s retreat,” the laughter, jeering, and rowdy embrace of domesticity stamped it as men-approved!

Afterwards, the night grew long as men shared stories of their lives, their families, and their hemophilia. Guys with guitars (me being one of them) provided a festive backdrop as rough and ready rock licks were tossed about.

Saturday brought rain, but the boat drew anchor and

slipped into Delaware Bay. The guys fished here... They fished there... They fished everywhere... Zero fish.

“I can’t make ‘em bite,” the captain of The Angler crowed from atop the helm. The boat pitched and yawed. The men stared at the rain, the invisible hook in the sea, the pewter sky.



The Angler churned to another spot. The lines went out. The men waited...

"FISH ON!" was yelled, and heads turned to see our very own Terry Rice clambering from his seat and gripping his rod with a mighty squeeze. He yanked, pulled, turned the reel as if Moby Dick were on the other end. Eventually, the 2-pound shellcracker, the size of a palm, swung into view. Terry held it up. The men on the boat laughed.

"FISH ON!" another shouted. And another. One fish, two fish, eleven fish were caught before we had to pull anchor. It was never about the fish. The boat and the sea drew out the friendship and tugged at the stories of hemophilia which were sent up with wind.

Back at the hotel, the men freshened up and then joined for the BioMatrix program "Singing to Heal," which I led. They learned about the healing power of music, its positive impacts on health, and its importance in my own journey of healing. I then joined two other guitar players and led the group who beat buckets, tapped tambourines, or shook egg shakers along with cover and original songs. The consensus at the end was that with a few more practices this group could be ready to take our act on the road, our own veritable Hemophilia Stomp.

Saturday evening, Octapharma sponsored sessions presented by Dr. Claudio Sandoval and Mike Zolotnisky, PT, DPT. Dr. Sandoval's talk, *Hemophilia Treatment: The Importance of Adherence and Bone Mineralization*, explained the significance of therapy adherence, but then explored the myriad forces that serve to undermine it. We talked about infusions and doses and gained insight from one another on how to be better patients. Next, Mike Z. rolled up everyone's arm sleeves and pant legs and rolled out his Kinesio-tape. Elbows, shoulders, knees, and toes..., I mean ankles, were produced for Mike Z. to demonstrate taping techniques. He cut strips here, put strips there, crossed over strips everywhere.

As the night grew dark, some gave into it while others sought the verve of a late-night beach town where conversation still flowed freely, and we chatted up the moon.

By Sunday morning, all of us were revived—the balm of an emotionally uplifting weekend having done its work. Handshakes, hugs, and farewells were passed around. The



clutch of hemophilia may have brought us together, but it was the hug of shared experiences that carry us forward.

Many, many thanks are deserved for Brandon Young and County Boy Fishing for creating this weekend and a space for healing to happen. And a similar thank you goes out to our sponsor partners Grant Belsham at Medexus, and Paul Brayshaw and Peter Marciano at Octapharma. Rich Vogel, Terry Rice, and I at BioMatrix joined to sponsor and help this event set sail!



BIOMATRIX] ON THE Move!

Our Regional Care Coordinators and Education Team have been out in the bleeding disorders community live and in-person! In 2023, we will continue to offer on-line sessions with a wide and expanding variety of educational topics and fun activities to choose from. Interested in scheduling a session for your group of any size either in-person or virtually? Please contact your Regional Care Coordinator or message the Education Team at: education@biomatrixsprx.com.



Pool Sharks! Chinedu, Phil, Matthew, Todd, Luke, Shelby and Wint

MARYLAND

Terry Stone

It's always a great day when men can break away from their daily grind and hang out with friends and billiards. Thanks to the Hemophilia Association of the Capital Area (HACA), the guys met for a **Men's Dinner** in Bethesda, Maryland's Rock Bottom Brewery March 11th to enjoy quality time together NOT doing Saturday chores.

The guys were happy to replace those duties with some hearty beer sampling, games of pool, and great food. If that wasn't enough, BioMatrix Education Specialist Shelby Smoak, Ph.D., engaged the guys with *Financing a Chronic Illness*, an interactive talk about overcoming insurance obstacles, including changes to expect in this current year and strategies to avoid medical debt. It has been said in jest that there are two things to count on in this life... death and taxes. Well, this can easily be updated for most to death, taxes, and medical/insurance debt, with the latter being what the bleeding disorder community talks and advocates about. Thanks to Shelby for keeping that continuing conversation fresh and current.

It was awesome having a group of men with different histories and experiences engaging and sharing, from legacy bleeding disorder patients who have navigated many insurance obstacles over time to dads with school-aged children to the youngest of the group who was 21 and just getting started on his own adult path. Great conversation and a day of not doing chores was enjoyed by all!



Matthew: Sharp eyes, steady hands

Chinedu: Sinks the winning shot

Phil: It's all about the angle

CONNECTICUT

Richard Vogel

The 2023 New England Hemophilia Association **Consumer Medical Symposium** was held March 25th-26th at the Hartford Marriott Downtown in Connecticut with a welcome reception and presentation by Novo Nordisk. Since the program was jam-packed with information, community members were up bright and early for breakfast and a stroll through the exhibit hall.

Keynote speaker Stephen Maguire gave a high-level presentation *Making the Most of What You Have*. While some circumstances in life are well beyond our control, like having a bleeding disorder, how we respond to those circumstances ultimately helps determine our path to happiness. Current NEHA board member and retired pediatric hematologist, Dr. Cathy Rosenfield explained how the body is a remarkable machine in *The Magic (Biology) of Blood Clotting (Hemostasis)*.

Deciding which breakout session to attend was difficult: *Search for a Cure: Understanding Treatment Options for Hemophilia in the Modern Era* was presented by Dr. Stephanie Prozora, Pediatric Medical Director, Yale Hemostasis and Hemophilia Program. Dr. Prozora gave a brief history of hemophilia therapies, current treatment options for hemophilia A and B, including standard and extended half-life factor replacement therapy, non-factor therapies, and gene therapy were all discussed. *Treatment of von Willebrand Disease & Rare Bleeding Disorder Treatment* by Dr. Laura McKay, Director, Hemostasis & Thrombosis Program at CT Children's reviewed treatment options and considerations for von Willebrand disease and rare bleeding disorders.

Afternoon rap sessions gave consumers a forum to openly discuss the challenges they face today. *Transitioning to Independence* was geared toward parents of pre-teens and teenagers; *Insurance* helped explain how to understand and navigate insurance plan barriers; *Aging* addressed issues encountered as one grows older; *Caregivers of Younger Kids*; *Other Health Issues/Comorbidities* offered a forum to discuss additional health issues.

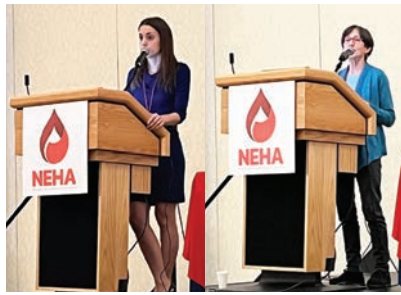
The last session of the day, *Promoting Positive Coping*, focused on using cognitive behavioral

therapy and proactive coping strategies to manage stress and anxiety.

The final evening ended with dinner, arcade games, and family karaoke, wrapping up with a *New England Organizational Update*.

Nancy Messina, NEHA Board President, and Saurabh Vaidya and Dennis Mackey from the Connecticut Hemophilia Society (CHS) announced that CHS will now be part of the NEHA family.

Thank you to all involved in providing this highly informative educational event to the community.



Speakers Dr. Prozora and Dr. Rosenfeld

VIRGINIA

Michelle Stielper and Terry Stone

Where better to mingle among your people and gain knowledge from resident experts than at a college, right? A place of higher learning where

you feel like you belong. Once again, the Hemophilia Association of the Capital Area (HACA) held its **Annual Education Day** at Northern Virginia Community College in Annandale. Through the doors of the Ernst Cultural Center, HACA members came together for a day of education, enlightenment, and togetherness Saturday, March 25th.

There were so many reasons that made this meeting a must this year. Special contributor, HTC Hematologist Dr. Gary Kupfer, presented two topics. His keynote presentation was on *Emerging Therapies*, and then he teamed up with Kristen Parker, RN, BSN, Clinical Program Coordinator from Children's Hospital HTC to present and moderate a conversation about *What Does the Future Look Like for My Child*, a wonderful interactive event with parents sharing and having the opportunity to ask questions of the medical professionals. Additional programs included *Aging with Hemophilia*, *How to be a Savvy Community Member*. As adults enjoyed and learned, the older kids had big fun with the team from Camp Holiday Trails, while the littles hung out with the hired professional nannies. Here's to another great event – thanks, HACA!



Reunited and it feels so good! RCC Terry Stone (center) and her mentor mommas, Nina and Linda!

NEW JERSEY

Richard Vogel and Carolina Luna

Members of the bleeding disorders community made their way to the America Dream Mall in East Rutherford March 26th for Hemophilia Association of New Jersey's (HANJ) **Community Connections** event, a day of education, comradery and a lot of fun!

During a continental breakfast, attendees were able to gather information and ask questions of the exhibitors. After opening remarks by Executive Director Stephanie Lapidow, the first education seminar got underway. Tyra Holland, RN BSN MBA, Patient Resource Navigator for CSL Behring covered the topic of gene therapy. There is currently only one FDA-approved gene therapy for hemophilia called Hemgenix®, which is indicated for Factor IX deficient patients. Tyra explained how gene therapy works and the goals of their product.



The second session was presented by Dr. Rajan, Associate Professor of Medicine, Div. of Hematology & Oncology at Vanderbilt University. His topic was *Discovering the Possibility of Higher Factor Levels for Longer*.

After lunch families were treated to an afternoon at Dreamworks Water Park, making an exciting Sunday afternoon. Many thanks to HANJ for bringing this all together!



RCCs Richard Vogel and Carolina Luna with community members, Carlo and Julio (center)

FLORIDA

Peggy Klingmann and Marcy Foertsch

BioMatrix and Takeda brought an engaging **Evening of Education**, conversation, and fun to community members March 28th at Maggiano's Little Italy Restaurant in Tampa. The program began with *What Moves You*, presented by Morgan Cook, Community Education Specialist for Takeda. Morgan encouraged fitness and nutrition for people with chronic bleeding disorders and emphasized a holistic approach to healthcare. Morgan's message highlighted that there is

more to treating a bleeding disorder than medicine. She was a terrific speaker with a deep knowledge of the topic.



All Good! Kevin, Heather, Josiah, and Cortland

BioMatrix followed with five rousing rounds of TV and film *Medicine Trivia*. Players had to dig deep in their knowledge of medical TV from questions about *Doogie Houser* and *Grey's Anatomy* to movies like *John Q.* and *Love & Other Drugs*. It was a perfect evening that highlighted the benefits of balance of life and health and having fun and enjoying a delicious meal all the while. We thank Takeda and Morgan, and especially our Tampa community members for joining and sharing the evening.

CALIFORNIA

John Martinez

Spring has begun with a renewed focus on empowering individuals to take responsibility for their care and learning the skills needed to bring about the positive health outcomes we all desire. The Hemophilia Foundation of Northern California (HFNC) heard the Humboldt County community request for self-infusion training and scheduled a **Self-Care Educational Dinner** March 30th. Partnering with Takeda, HFNC reached out to BioMatrix to provide the training. In a private room at the Sea Grill restaurant in Eureka, families arrived and immediately engaged in rekindling friendships and meeting new friends.



Following Takeda's delivery of Patrick Wagner's interactive program on hemophilia, BioMatrix's Rania Salem, RN, provided the hands-on infusion training. Though some attendees have decades of experience, many had never successfully self-infused. After reviewing the basic process, Rania began an individualized course of instruction. One by one, each of the participants who had never self-infused began to gain confidence. By the end of the evening, every participant who attempted self-infusion was successful! Community members and HFNC requested more training be scheduled as they knew other families in the area and throughout northern California who could benefit from the lesson. Many thanks to HFNC and Takeda for bringing us all together!

ILLINOIS

Eva Kraemer

We know therapies have come a long way when we can host a bleeding disorders **Educational Dinner and Program** with axe throwing as the entertainment! BioMatrix, Octapharma, Medexus and HEMA Biologics got together and hosted a March 30th event at Axeplosion Lounge in Orland Park. A tasty BBQ meal was catered to enjoy so everyone could munch away while awaiting their turn to throw an axe.

BioMatrix Education Specialist Shelby Smoak, Ph.D. facilitated a lively conversation about the importance of advocating for oneself and knowing where resources and support can be found when help is needed. BioMatrix is committed to the Illinois community and creating this kind of networking and support. Many thanks to our partners for providing this evening with fun, laughter and improved throwing skills!



Shelby Smoak, John Thorson (Octapharma), Alan, Dave Todd (Medexus), Sarah, Chris Becchetti (HEMA Biologics), RCC Eva Kraemer, Thomas, Kelly, Alvaro, Jonathan, Hector, Maria and Johanna (front)

OHIO

Shelia Biljes

Peter Cottontail detoured from the trail to make an appearance and enjoy a special **Dinner with the Easter Bunny** event sponsored by BioMatrix and Bayer with families of the Central Ohio Chapter of NHF April 5th. As guests arrived at Brio Italian Restaurant in Polaris, children were encouraged to participate in a game to learn about factor infusion supplies hidden in plastic rabbits. Mr. Cottontail's entrance surprised the little ones, and although excited, each child waited patiently for their turn to visit and take a special photo with him. Many of the grown-ups also posed for photos!

Bayer presented an update on their product, Jivi®, before introducing their guest advocate speaker, Rex Harold, who shared his amazing story and engaged in conversation with the families. During the presentations, children were invited to color pictures for a contest and create a special picture frame for their bunny photos, printed on the spot.

After winners were selected, an amusing round of *What's in Your Phone?* followed providing a ton of laughter, and a chance for the adults to win yummy Easter chocolates. The kids had been anxiously awaiting the final *Egg Scramble* game. They were arranged in two lines with a pile of filled plastic eggs in the middle. Excitement was soaring and patience dwindled as they had to wait to be told when to reach in and grab eggs. As the children opened their eggs, the evening came to an end.

See you next year, Mr. Cottontail!



Garrett, Ethan, and Becca with Shelia



Stephen, Jermain, Coleen and Allie



Jeanine and Wendy

Jermain

Lucas

Isabella

Adam and Jaycee

Jack, Travis, Katie, Tara & Mary

OHIO

Shelia Biljes

Warmer weather and spring fever have finally arrived in Northern Ohio! BioMatrix partnered with Bayer April 6th to host **Dinner with the Easter Bunny**, an awesome spring evening event with families of Northern Ohio Hemophilia Foundation in the Cleveland area.

Gathering at the Brew Garden in Strongsville, Bayer speaker Wendy Perkins presented fundamentals of hemophilia and infusing. Family shared their experiences and tips for setting up the perfect infusion site in their home and overcoming some infusion obstacles with the little ones. Children engaged in games, coloring, crafts, the ever-so-popular, Egg Scramble, and of course, the long-awaited visit and photo with Mr. Cottontail!

Getting together and learning from one another is always a delightful time!



Coloring contest winner, Matthew!



Carmelo, Chardea, Chantel, Elaina, Carter and their mom, Tiffany



Kristen and Melba



Mary, Marie, Chan and Joe



Selina



Bob and Charlene



Brylin



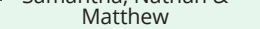
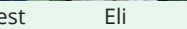
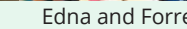
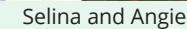
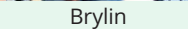
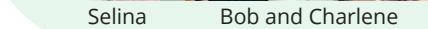
Selina and Angie



Edna and Forrest



Samantha, Nathan & Matthew



TENNESSEE

David Tignor

On your mark! Get set! Go! The Tennessee Hemophilia & Bleeding Disorders Foundation (THBDF) held their **5th Annual Blazin' for Bleeders 5k Run/Fun Walk** at Gateway Island in Murfreesboro April 8th. Although it was moderately cold outside with drizzle and light rain, it did not deter dedicated participants from competing and supporting this important fundraiser.



Jimmie



Justin



Hunter

After the race/walk, awards were given to the top participants in their age group and photos were taken. BioMatrix sponsored breakfast and coffee for everyone. We look forward to supporting this THBDF community fundraising event again next year!



MILD MATTERS

Disparities in the diagnosis and care of people with mild bleeding disorders are evident in both males and females. **We're working to change that.**
hemophiliafed.org

hemophiliafed.org/mild-matters/



VERMONT

Richard Vogel

New England Hemophilia Association's (NEHA) inaugural **Men's Retreat** kicked off April 21st at the Stratton Mountain Resort with a welcome dinner and entertainment. We "Ran Away with the Circus" with Michael Jay Garner of Beyond Recreation who shared his circus juggling and balancing skills that took him around the world, touring with Cirque du Soleil and Britney Spears. Michael is also a medical clown, cheering up sick children.



Taking Aim

After Saturday's breakfast, it was time for breakout sessions. BioMatrix Education Specialist Shelby Smoak, Ph.D., presented *Singing to Heal*. This interactive discussion is about music, the brain and tapping into the healing power of music. In the afternoon we paired in teams to throw axes (yes, you read that right). With my limited throwing skills, I was lucky to partner up with a young dad who did his best to provide points for our team.

In the evening, we shared a meal and another interesting activity as Michael Jay Garner released our inner Indiana Jones with *The Art of Whip Making & Cracking*. Everyone had the opportunity to make their own whip and learned how to crack it! Since no one ended up in the hospital with our activities, we continued to bond well into the evening while shooting pool, hot tubbing, watching the hockey and basketball playoffs or listening to a late-night jam session led by Shelby Smoak.

Sunday morning sessions focused on dating or aging with a bleeding disorder. Afterward, Executive Director Rich Pezzillo gave closing remarks, and we all said our goodbyes, leaving behind Stratton Mountain but taking home lasting connections and looking ahead to the next men's retreat.

NEW JERSEY

Richard Vogel and Carolina Luna

As warmer weather arrived in New Jersey, community members gathered at Bloomfield's Bella Napoli Ristorante for a **Fireside Chat** with delicious food and informative education. On this particular evening, BioMatrix partnered with Genentech to answer the question, "What does it mean when a bispecific antibody mimics the function of FVIIIa?" Joanne Gallego, RN, MSN, ANP, OCN from Genentech discussed the benefits and answered questions about Hemlibra®. Patient Ambassador Steven L. shared his story of how Hemlibra® has enhanced his quality of life.

BioMatrix Education Specialist Shelby Smoak, Ph.D. led us in a *Hillbeat on the Road* conversation covering many updates in the bleeding disorders community. A variety of topics were discussed



Issaiah, Janet, Sidney and Trevor

including Medicaid redetermination letters. If you are on Medicaid and receive a letter from your state, be prompt and concise in completing and submitting the requested information. BioMatrix's Patient Navigation program was also discussed. This program is for community members who experience challenges related to insurance coverage, difficulties accessing prescribed therapy, financial burdens due to medical care, and employment and school-related issues. This program is open to all members of the bleeding disorders community regardless of specialty pharmacy affiliation.

A successful program is when folks linger after the presentations, talking, asking questions, and laughing. We got the hint it was time to leave when the restaurant started putting away the chairs.

VIRGINIA

Terry Stone

It's the season for fun, friends, and waterfront views! The Virginia Hemophilia Foundation (VHF) gathered members from across the state at the Hilton Norfolk for a weekend of learning and laughter May 6th-7th for their **Annual Education Day** followed by a **Community Event at the Virginia Zoo** on Sunday.



Camp Holiday Director Caitlin Carroll, MSW, along with 2023 Counselors Matt and Toni ready to create some pre-camp magic

The meeting kicked off with an engaging presentation from Christian Harris, a community member and Ambassador for Medexus. He shared the professional path that led him to a career in fashion which has been filled with travel around the world and has landed him a job at Nike on the west coast. He spoke about his experiences as a "camp kid" and how those deep and meaningful relationships made such a difference in his life.

Other topics included the latest therapies, advocacy, and research, and gave recognition to the recipients of the Lyman Fisher Scholarships. VHF kids were kept busy with their own programming thanks to Camp Holiday Trails and tie-dyed their little hearts out making custom tees.

At Sunday's Zoo event, there were animal encounters, tons of food, and the cool tunes of DJ Shelby Smoak! Afterward, families had the rest of the day to explore the zoo and all its residents. Many thanks to VHF for their continued support and educational events!

OHIO

Shelia Biljes

Spring has sprung! We chose a wonderful day, May 9th, in northern Ohio to celebrate our beautiful mothers and sisters in the bleeding disorders community. BioMatrix and Genentech sponsored our **Celebrating Moms Luncheon** in the tearoom at Clementine's Restaurant in Olmsted Falls. Genentech Patient Ambassador Maria from Waco, Texas,



Amber, Kristen, Connie and Melba



OraLee and Tiffany Charlene and Allyson

shared her story of struggles and joys while raising a son with severe hemophilia. Everyone laughed, cried, and shared along with her.

A round of *What's in your Purse?* brought more giggles and fun prizes and we concluded with a trivia quiz based on Genentech's presentation. The oldest and youngest mother of the group were each recognized with a colorful floral bouquet. BioMatrix honors all our community mothers. Hats off to you for the amazing job you do!

FLORIDA

Marcy Foertsch and Peggy Klingmann

BioMatrix joined with Genentech May 11th for an **Evening of Education** with friendly competitive rounds of trivia. Community members gathered with us at Tibby's New Orleans Kitchen in Brandon. Genentech's Territory Manager with Christie Vidal-Straub led a presentation on Hemlibra® as everyone enjoyed their dinner. Then it was time for *BioMatrix Trivia* featuring bleeding disorders-related topics. Everyone was a winner, gaining knowledge and looking forward to the next BioMatrix program! Many thanks to Genentech for partnering with us!



Enjoying the evening! Mike, Rebecca, Emily, TJ and Lynne.

NEW MEXICO

Felix Jacquez Garcia

BioMatrix teamed up with Bayer and Medexus to host a **Community Dinner** May 16th for members of Sangre De Oro Inc., Bleeding Disorders Foundation of New Mexico. We opted for the relaxed setting of Tomasita's Restaurant in Albuquerque. Before dinner was served, Steve Calderon, Medexus Hemophilia Territory Manager, and Felipe Greven, Bayer Hemophilia Community Executive, made brief introductions. Congratulations to Nolan who won the BioMatrix door prize! We appreciate everyone taking the time to join us and we hope to see you at our next event!



Angelica, Bernadette, Jennie & Jesus



Gary and Nolan



Katalina, Anna and Isaia



AnnMarie and Felicia

OHIO

Shelia Biljes

Northern Ohio Hemophilia Foundation (NOHF) hosted its **Family Educational Program** May 17th at Spins Bowling in Independence. On this unexpectedly chilly evening, the bowling alley was a great place to be for an evening of fun! Foundation Program Manager Randi Clites gave an advocacy and legislative update and led a discussion on what to be expecting from our state legislature in the upcoming year and how to get more involved. Industry sponsors were also on hand to share information about their products and services. We were fortified with a dinner of tasty pizza, wings and meatballs - just what was needed to energize us for knocking down high pin numbers. Video and arcade games were also available for those who chose not to bowl. Many thanks to NOHF for bringing us together for this noisy event!



Matthew lets it roll!



Keiden ready to throw a strike!



Julien checks out the games



La'sha is a Warrior Woman!

KENTUCKY

Justin Lindhorst and Rania Salem

Families gathered at the beautiful Cedar Ridge Camp in Louisville May 19th-21st to participate in the Kentucky Hemophilia Foundation's (KHF) **Third Annual Family Camp Program**. Family camp provides opportunities for parents and caregivers to partake in the same camp magic kids experience during traditional summer camp. In addition to lots of fun and games, families enjoyed bleeding disorders-focused educational programming provided by the camp nurse and a highly interactive photography program conducted by BioMatrix Education Specialist John Martinez. From campfires to canoeing, archery, crafts, and a fantastic Luau-style barbecue, families disconnected from everyday life and connected with fellow members of the community. Hats off to the Kentucky Hemophilia Foundation for another successful camp program and shout out to volunteers for their ongoing support of KHF.



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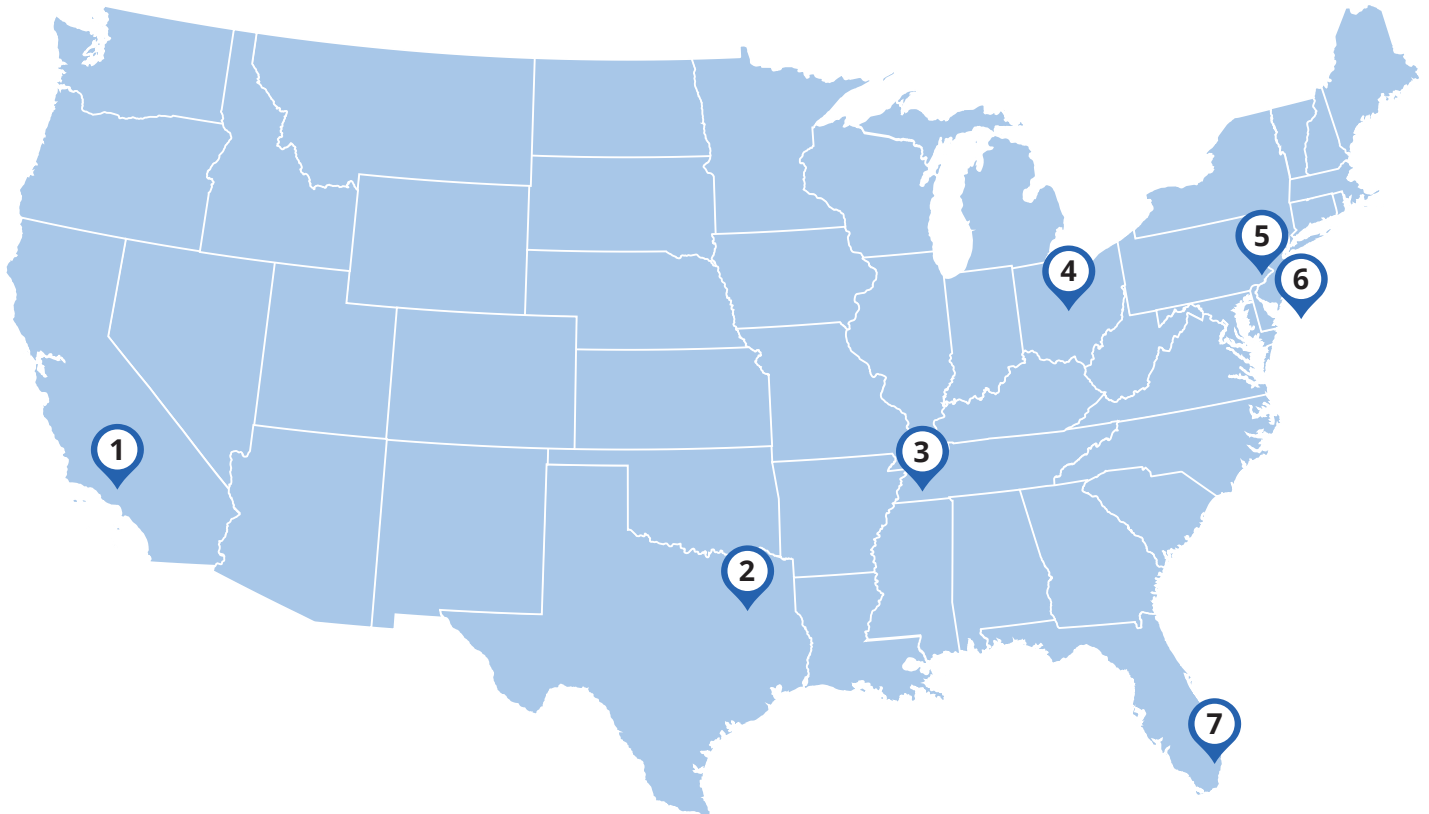
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Pharmacy Locations

1. Canoga Park, California
2. Tyler, Texas
3. Bartlett, Tennessee
4. Dublin, Ohio

5. Garnet Valley, Pennsylvania
6. Totowa, New Jersey
7. Plantation, Florida



**BEST AND
BRIGHTEST
COMPANIES**
TO WORK FOR
IN THE NATION
2019, 2020, 2021, 2022