BIOMATRIX

NEWS

DEDICATED TO MAKING A DIFFERENCE

FALL 2022
VOLUME 17 | ISSUE 4

> **Cherish youth but trust old age.**
> — Native American Indian Pueblo Proverb

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ABOUT [BIOMATRIX]

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

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

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

MISSION + VISION

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

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

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

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

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

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

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

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

FINE PRINT

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

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

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

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A NOTE FROM THE EDITOR

Dear Readers:

Are we really at the tail end of 2022? Is this possible? I'm sure many of you are thinking the same thing! As we get older, time seems to pass more quickly. It feels like yesterday I had four little kids at my ankles – they are now all grown up, living their own lives, and have settled hundreds of miles away. I can still hear their little voices in my quiet house.

Not that long ago the outlook for those living with a bleeding disorder was much different than today. Before the 1960s, life expectancy was very low for patients with a severe bleeding disorder. Then, just as things were looking up, the 1980s and the "hemophilia holocaust" saw some of our darkest days. Many previous generations in the bleeding disorder community grew up unsure if they would make it to their golden years.

In just a short amount of time, so much has changed. Safe, effective treatment options and a robust pipeline of new therapies paint a bright future for the bleeding disorders community. Patients are living long, happy lives and as such must contend with the same aging issues as the general public. In this issue of BioMatrix News, we focus our attention on the topic of *Aging with Hemophilia*. We have been privileged to hear from a few of our "veteran" community members who share their experiences with growing older. Their collective unwavering message is one of continued perseverance, gratitude and hope for the future.

Take time to enjoy the tranquility of fall before the busy holiday season rushes in!

Maria Santucci Vetter
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I'm Still Standing

BY TERRY RICE

According to a 2010 American Society of Hematology article titled, *The Aging Patient with Hemophilia Complications, Comorbidities, and Management Issues,* the median life expectancy for persons with hemophilia in the early 20th century was 11 years.

That was my expected lifespan when I was born in 1962. However, with the rapid improvement of hemostatic therapies throughout the 60s and 70s, life expectancy increased to 55-63 years with severe cases on the lower end of this range. By the early 1980s with 73% of people with hemophilia using plasma-derived factor concentrate replacement therapy, life expectancy had increased to nearly 68 years old. Great news for us!

Factor concentrate proliferated through the 1970s, and treatment delays greatly diminished as more and more patients embraced the ease of home infusion, which was quickly becoming the gold standard of care. Then the ominous 1980s were ushered in, and with them, the gains in life expectancy took a sharp drop to an average of 40 years. This, of course, was the result of the HIV and hepatitis C transmission through the very same miracle factor products that initially increased our longevity.

The manufacturing process for clotting factor combined thousands of donations into a single pool from which various therapeutics, including hemophilia factors, were produced. At the time, these processes did not include the same purification and viral inactivation steps currently used to safeguard blood donations.

Hepatitis was known to be a risk for those using factor products. In mid–1981, the CDC began to receive reports of rare illnesses that were soon labeled under the umbrella of acquired immune deficiency syndrome or AIDS, later found to be caused by the HIV retrovirus. The first reports of otherwise healthy hemophiliacs being affected began in mid–1982. And so began the recognition of the blood-borne pathogen that had been spreading through the hemophilia community like wildfire.

The results of the 1980s is now history. Estimates are that at least 50% of all people with hemophilia and 80% of those with severe disease were lost. I mention this because I am likely the oldest surviving person with severe hemophilia, HIV and hep C in my home state of Maine. And I'm only 60 years old.

In 1986, when my HIV diagnosis was confirmed, my doctor told me, "You should really think about what you're going to do with the time you have left," which statistically was about 4 or 5 years. This was a sobering reality for someone in their mid-20s. I had worked hard to graduate magna cum laude from college and intended to pursue medical school. But that sobering news and the resulting end of a long-term personal relationship sent me into a spiral of depression.

Dark thoughts occupied my mind for years. I began to drink heavily since there was no reason to preserve my liver. "For what?," I would ask myself! Many of my peers had surrendered their hopes and dreams in life just as I had to adjust to our new reality. Throughout the decades I've watched so many friends from my youthful years at camp and clinic visits experience the most traumatic gut-wrenching emotional, physical and financial assault possible on their humanity. Simply horrible deaths that in part were preventable. The majority of my generation became members of the "Triple H Club" — hemophilia, hepatitis, and HIV. The fact that I survived is remarkable but has carried its own burden and weighed heavy on my mental health.

Those who experience and survive a catastrophic event where most everyone perishes can't avoid the survivor's guilt that accompanies one's escape. Why was I spared this death? It reminds me of a line from the movie *Unforgiven* where just before William Mooney (Clint Eastwood) shoots the sheriff (Gene Hackman), the sheriff says, "I don't deserve to die this way." Mooney replies, "Deserves got nothin' to do with it." I survived simply by luck of the genetic draw. It's true that "deserving" had nothing to do with it, but it still has taken an explicit toll on my spiritual and psychological wellbeing.

As years passed and I outlived my doctor's bleak prognosis, my focus shifted from medicine to real estate and to advocacy. Real estate helped me earn a living, while advocacy allowed me to find and share answers in search of some semblance of accountability for the 'hemophilia holocaust', as coined in the early 1990s by the advocacy organization, The Peer Association.

The age demographic existing today reveals the fallout of the 1980s. Comparing the 2000 US Census figures to the 2009 CDC Universal Data Set, 32% of the general population versus just 15% of the hemophilia population was 45 and older. 10% of the general population versus 2% of the hemophilia population was 65 and older, more specifically only 1% with severe disease. Roughly estimated, in 2010 there were approximately 230 severe hemophiliacs 65 or over. That number is not statistically large enough to make conclusions with a high degree of confidence as to what may be unique health challenges for elderly people with hemophilia.

In a way, those of us aging with hemophilia are in uncharted territory. We will likely experience all the same pathologies as those of our non-hemophilia-affected elderly peers, though, I expect some of these health issues will be more acute and have earlier onsets. For example:

- We are not immune to and can experience DVTs, strokes and heart attacks. Hemophilia patients will likely need anticoagulants, which may alter how therapies are used.
- Joint and muscle damage from previous bleeding episodes, along with natural-aging forms of arthritis and osteoporosis may lead to an increased risk of falls. With intracranial hemorrhage being the third leading cause of death (after HIV and hep C) among those with hemophilia, the risk of falling must be avoided.
- Aging people with hemophilia may have an increased risk of developing cancers related to HIV and hep C.
- For those with severe factor XIII deficiency, there appears to be an increased incidence of developing inhibitors with advanced age.
- Failing eyesight may push aging people with hemophilia to re-evaluate their self infusion plans and may lead to treating less often.
- Hypertension is another emerging concern for aging persons with hemophilia.

At 60, I have now experienced ailments associated with aging such as arthritis (more than just hemolytic arthropathy), hypercholesterolemia, disk degeneration of L3-L4 requiring fusion, fatigue, some imbalance issues, osteopenia, depression, presbyopia, and the real sad malady, cranial alopecia (hair loss!) to name a few.

With all the "medical bullets" sent my way over time, I'm doing relatively well for being part of the 1% of aged persons with severe hemophilia. I take enough pills now to fill one medium size weekly pill container, but I can see an "AM" and a "PM" weekly pill container in my future!

My situation may sound familiar to you if you too are over 60. My medical care now is primarily handled through my internal medicine physician and supplemented by specialists – Hemophilia Treatment Center clinicians, infectious disease doctor, orthopedist, optometrist, and the occasional gastroenterologist and urologist. My hematology team was once the center of my health wheel, but now serves as just one of its spokes.

Being born with hemophilia today is a much safer, healthier, and enlightened time to take on its challenges. As for my fellow geriatric brothers and sisters with hemophilia, you are one of a small group to have made it. For us to eventually mirror the general aging demographic, as a community, we will need to take more responsibility in finding and coordinating from experts outside of the HTCs when appropriate, adhering to prescribed care plans and being tireless advocates. Then, fortunately, just like everyone else, we will grow old and experience the same issues of the aging American – a concept completely unthinkable six decades ago when I was born.

Reference:

Philipp, Claire. "Aging Patient with Hemophilia: Complications, Comorbidities, and Management Issues." American Society of Hematology, 4 Dec. 2010, https://ashpublications.org/hematology/article/2010/1/191/96370/The-Aging-Patient-with-Hemophilia-Complications.

Growing Older WITH A BLEEDING DISORDER

BY ANGELA LAMBING, MSN, ANP, GNP

Who would have thought that now, in this day and age, we can talk about aging with a bleeding disorder? Many of our current senior persons with hemophilia can certainly remind us of what it was like in the early stages of their life when the life expectancy was barely into the 20s and the risk of early death due to an acute bleeding episode was highly possible.

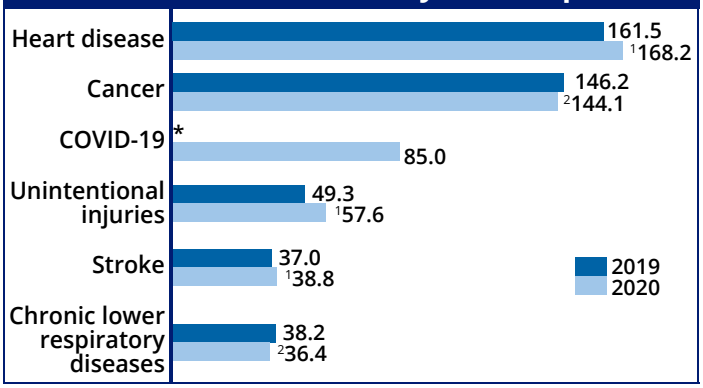
Since the development of safe prophylactic treatment and Hemophilia Treatment Centers that provide expert care, the proof is now here. People with bleeding disorders (PWBD) are living longer – into their 60s, 70s, and 80s – due to the expert care they have received. So as people grow older, what are the guidelines for healthy aging? Let's review steps to maintain a healthy aging lifestyle based on national guidelines.

"Healthy aging is the process of slowing down, physically and cognitively, while resiliently adapting and compensating in order to optimally function and participate in all areas of one's life – physical, cognitive, social, and spiritual."[1]

The current longevity of the average male in the United States (U.S.) based on CDC 2020 data is 74.2 years, and 79.9 years for females.[2] "Advances in the care of persons with hemophilia have progressively improved life expectancy, almost to the level observed in the general population".[3] This is fantastic news, but many persons with bleeding disorders may not be prepared. Let's review what can be done to maintain good health as you age.

Table 1 outlines the current causes of mortality in the general population of the United States. Heart disease, cancer and chronic lower respiratory disease were typically the top 3 causes of death; however, in just the last couple of years, COVID-19 deaths have replaced the number 3 spot over respiratory diseases.

Table 1.[2] Causes of Mortality in US Population



Heart disease remains the leading cause of death for men and women of all cultures with a reported 659,000 persons in the U.S. and an additional 805,000 people suffering a heart attack every year.[4] As PWBD age and more data is collected, these same risks are evident. In earlier studies, it was thought PWBD had less risk of cardiovascular disease, but this is no longer the case. A 2011 Mayo Clinic study identified that hemophilia patients were at risk for cardiovascular disease comparable to the general population.[5]

In several studies, hypertension was found to be more evident in PWBD.[5-10] Risk factors include smoking, limited physical activity, high cholesterol, obesity, diabetes, uncontrolled hypertension and family history of hypertension.

Risk factors can be reduced by a) exercising regularly, within your limitations; b) not smoking or quitting smoking; c) routinely having cholesterol evaluated and taking steps to reduce levels when able; d) eating a healthy diet and maintaining optimal weight; e) maintaining normal blood sugar; f) regularly monitoring blood pressure and taking medication to control blood pressure if necessary.

As aging occurs, everyone has the potential to develop cancer. Based on the CDC 2020 data, lung cancer (23%) was the leading cause of cancer deaths, followed by colon and rectum (9%), pancreas (8%), female breast (7%), prostate (5%), and liver and intrahepatic bile duct (5%) in the U.S. general population.[11] Additionally, one in five people in the U.S. will develop skin cancer, most often related to sun exposure.[12]

In reviewing ATHN (American Thrombosis Hemostasis Network) 2014 data, liver cancer was a documented risk in persons with hemophilia due to many of our senior gentlemen who were exposed to hepatitis C many years ago. Untreated hepatitis C increases the risk of liver failure and liver cancer. Hence, getting treatment for it remains essential. Current treatment options are now better than ever with a shorter treatment time, fewer side effects, and over 95% success rate in obtaining a negative viral load. Successful treatment can reduce the risk of liver cancer by 75%.[16] Long-term studies are still in progress to determine the long-term effectiveness rate of the current therapies.

In the U.S., prostate cancer is relatively rare in men under 40; however, after age 65, the risk increases exponentially with advancing age.[14] Talk to your primary provider regarding when to start an annual rectal digital exam screening for prostate cancer, typically beginning by age 50.[15] If there is a family history of prostate cancer, sooner may be recommended. Benign prostate hypertrophy (BPH) means the prostate enlarges over time with aging, which may cause problems with urination. Reach out to your provider if you have symptoms including frequent trips to the bathroom to empty your bladder, a change in the urinary stream such as difficulty starting, a weak flow, or stopping and starting the flow, or not feeling empty once you have finished urination.

Regular health maintenance is imperative as the years march forward. As aging advances, it becomes essential to have a primary care provider or a geriatrician to coordinate your services with your Hemophilia Treatment Center (HTC) or hematologist. Your primary provider is a gatekeeper to general health and wellbeing, while your hematology team is the expert in your bleeding disorder and will guide you to minimize bleeding risk.

REDUCE RISK OF CANCER BY:

- **Not smoking**
- **Eating a healthy diet rich in fruits and vegetables and limiting processed meats**
- **Maintaining optimal weight and exercising regularly**
- **Limiting alcohol**
- **Protecting from ultraviolet (UV) rays by avoiding prolonged, unprotected time in the sun and tanning salons, using sunscreen and covering exposed areas (with clothing, a wide-brimmed hat, etc.)**
- **Engaging in safe sex to avoid HIV and HPV**
- **Avoiding infections that may contribute to cancer by getting vaccinated for hepatitis B and HPV**
- **Having yearly physical exams with appropriate age-related screenings**

Table 2.[13] Health Maintenance for Older Adults	
Blood pressure	Yearly
Colon cancer screening	Fecal test: yearly Stool-DNA fit test: 1-3 years: Colonoscopy: every 5 years or as directed
Breast cancer screening	Mammogram every 2 years
Smoking use/cessation	Yearly
Depression screening	Yearly
Vision/hearing screening	Yearly
Abuse screening	Yearly
Hepatitis C screening	Yearly
Vitamin D, calcium levels	Yearly
Diabetes: Blood sugar	Yearly
Cholesterol screening	Yearly
Obesity (BMI>30)	Yearly
Osteoporosis screening	As needed
Cognitive screening	Yearly
Fall risk assessment	Yearly
Medical/legal/financial care planning	Yearly
Sexually transmitted disease	At-risk persons as needed
Skin Cancer screening	Yearly
Prostate screening	PSA periodic; Age 55-69 yearly rectal digital exam
Dental care/screening	Yearly
Abd aortic aneurysm screening	Abd US; 1x for smokers
Vaccinations	
Influenza (flu)	Yearly
Pneumonia	Age 60 x 1
Tetanus/Diphtheria	Every 10 years
Shingles	Age 60 x 1
COVID-19	As directed

Additional steps to healthy aging include getting enough sleep, maintaining social connections and exercising your brain. There are many activities you can do to exercise your brain, not limited to: building puzzles, reading, learning a new skill, teaching a skill, playing cards, and playing or listening to music, just to name a few. The possibilities are endless.

Also important is staying connected to friends and family members, as social interactions are necessary for maintaining mental health. In the current climate, even staying connected by telephone or other digital means is essential.

Maintaining optimal eyesight with regular vision screening is critical. Having good vision is beneficial for PWBD to be able to self-infuse promptly and accurately when treating a bleeding episode. Good dental care and regular dental checkups are essential throughout our lives as oral disease is an indicator of general health. Periodontal disease is a risk factor for diabetes, cardiovascular disease, endocarditis, systemic infections, and bacterial pneumonia.[17,18]

Table 2 provides the recommendations for health maintenance and should be completed yearly or as indicated. Your primary care provider can coordinate services with your HTC provider to reduce and help prevent any potential bleeding issues with these recommendations. Keep up to date on your vaccinations as a strategic part of maintaining health with age. Remember the vaccinations required in the first year of life? Now there are important vaccinations for older folks to retain health as well.

Another area PWBD should think about is safety in the home. Arthritic joints that may accompany having a bleeding disorder can affect mobility leading many aging adults to downsize to a smaller, easier-to-maintain home without stairs. Reduce the risk of falling by repairing or removing loose carpets and rugs, installing safety bars and no-slip strips in the bathroom, adding handrails where needed, using nightlights throughout the home, and keeping areas clear of décor or items on the floor to be able to move about more freely.

Planning for the future also includes taking steps to identify and document advance directives related to your health and finances. Take steps to meet with a financial planner to optimize your retirement as you head in that direction. It is important to identify and document a Power of Attorney (POA) for financial and health directives in addition to completing a Living Will. Planning for unforeseeable situations will help you and your loved ones to be better prepared.

As you age with your bleeding disorder, engage in research studies so the data collected can continue to be used to improve your lifestyle as you age. Embrace the opportunity to reach your senior years in the best way possible - something that was elusive to many with bleeding disorders just 30-40 years ago. And most of all, welcome to your senior years!

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AGING GRACEFULLY

BY BOB MURDOCK

One of the most ironic comments a doctor has ever made to me was about five years ago. She said, "Good news – bad news. The good news is hemophilia has become a very manageable and treatable disease. Most likely, you are not going to die from a bleeding episode and will live a normal life span. Bad news, now that you're going to live a longer life, you will most likely die from a heart attack, cancer, stroke, etc. - medical issues that affect most adults." My response was, "So basically nothing has really changed."

I feel blessed to be a part of my generation of hemophiliacs because we have witnessed an incredible amount of progress in the treatment of our bleeding disorder. Advances we were never sure we'd see are here. As a result of living longer, I have developed moderate/high blood pressure and had an AFib event for which I now take daily medications.

I also never thought I'd see the day I would have to modify my diet because a cardiologist told me to eat healthier, exercise and stay active. The diet part stinks because I had to cut back eating the things I truly enjoy. I've had to learn the term *everything in moderation*. I used to eat whatever I felt like and went happily on my way.

All that said, I feel very fortunate to have lived long enough to have these issues to deal with. I am able to live a relatively pain-free life and can do most of the things people my age can do. All is good in my world!

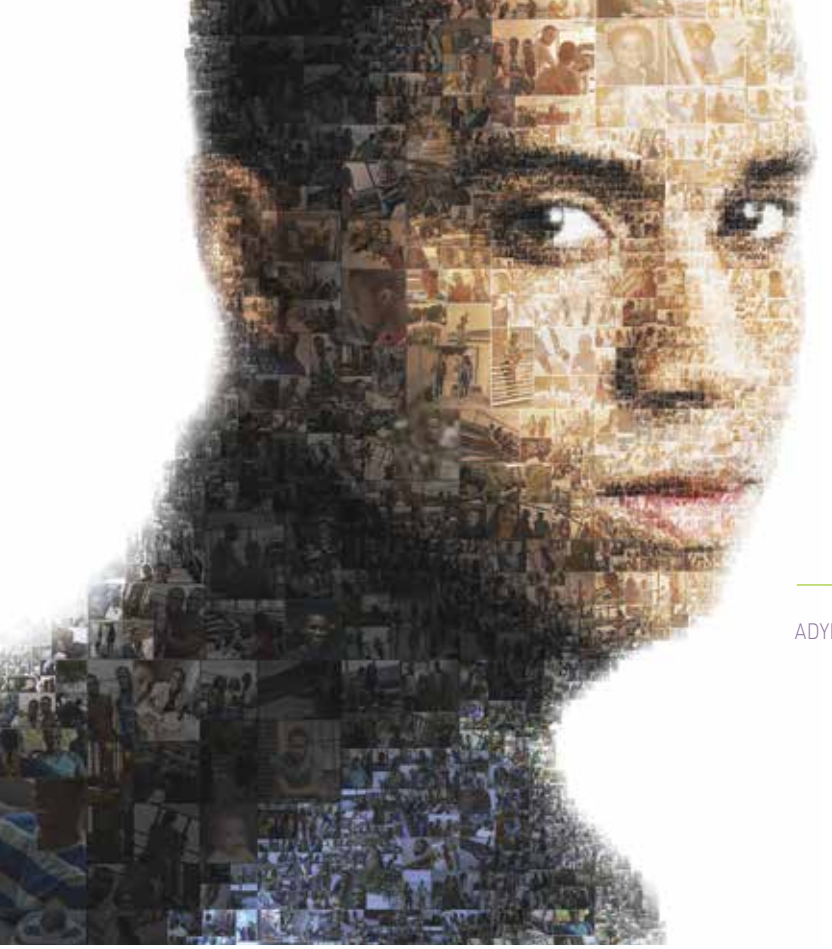
1974, age 15
Band Performance

1977,18 y/o
HS Graduation

1979, age 20
New Year's Eve Performance

2014, age 55
British Invasion Concert

Cheers!



No actual patients depicted.

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]
REAL LIFE. REAL BLEED PROTECTION.*

HEMOPHILIA A IS A PIECE OF THEM.

NOT ALL OF THEM.

ADYNOVATE® has a simple, twice-weekly dosing schedule on the same 2 days every week that can help personalize treatment, so your patients have more time to spend doing the other things that also make them who they are.[1,2]

*In clinical trials, ADYNOVATE demonstrated the ability to help patients prevent bleeding episodes using a prophylaxis regimen.

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ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds[2]

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)[2]

- **Children Under 12 Years**: This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment
  - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median† overall ABR‡ of 2.0
  - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis
- **Adolescents and Adults 12 Years and Older**: This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR‡ between the prophylaxis and on-demand treatment groups[2]
  - 95% reduction in median overall ABR [41.5 median ABR with on-demand (17 patients) vs 1.9 median ABR with prophylaxis (120 patients)]
  - 0 bleeds in 40% (40 out of 101 per-protocol§ patients) during 6 months on twice-weekly prophylaxis

†Median is defined as the middle number in a list of numbers arranged in numerical order.
‡ABR=annualized bleed rate, the number of bleeds that occur over a year
§Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

ADYNOVATE Important Information

Indications and Limitation of Use

ADYNOVATE is a human antihemophilic factor indicated in children and adults with hemophilia A (congenital factor VIII deficiency) for:

- On-demand treatment and control of bleeding episodes
- Perioperative management
- Routine prophylaxis to reduce the frequency of bleeding episodes

ADYNOVATE is not indicated for the treatment of von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

CONTRAINDICATIONS

Prior anaphylactic reaction to ADYNOVATE, to the parent molecule (ADVATE® [Antihemophilic Factor (Recombinant)]), mouse or hamster protein, or excipients of ADYNOVATE (e.g. Tris, mannitol, trehalose, glutathione, and/or polysorbate 80).

WARNINGS & PRECAUTIONS

Hypersensitivity Reactions

Hypersensitivity reactions are possible with ADYNOVATE. Allergic-type hypersensitivity reactions, including anaphylaxis, have been reported with other recombinant antihemophilic factor VIII products, including the parent molecule, ADVATE. Early signs of hypersensitivity reactions that can progress to anaphylaxis may include angioedema, chest tightness, dyspnea, wheezing, urticaria, and pruritus. Immediately discontinue administration and initiate appropriate treatment if hypersensitivity reactions occur.

WARNINGS & PRECAUTIONS (continued)

Neutralizing Antibodies

Formation of neutralizing antibodies (inhibitors) to factor VIII can occur following administration of ADYNOVATE. Monitor patients regularly for the development of factor VIII inhibitors by appropriate clinical observations and laboratory tests. Perform an assay that measures factor VIII inhibitor concentration if the plasma factor VIII level fails to increase as expected, or if bleeding is not controlled with expected dose.

ADVERSE REACTIONS

The most common adverse reactions (≥1% of subjects) reported in the clinical studies were headache, diarrhea, rash, nausea, dizziness and urticaria.

Please see the following page for the Brief Summary of the ADYNOVATE Full Prescribing Information.

For Full Prescribing Information, visit www.adynovatepro.com.

References: 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. *Haemophilia*. 2014;20(5):607-615. **2.** ADYNOVATE Prescribing Information.

Takeda

ADYNOVATE [Antihemophilic Factor (Recombinant) PEGylated] **Rx Only**
Lyophilized Powder for Reconstitution for Intravenous Injection
BRIEF SUMMARY: Consult the Full Prescribing Information for complete product information.

INDICATIONS AND USAGE

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ADYNOVATE is contraindicated in patients who have had prior anaphylactic reaction to ADYNOVATE, to the parent molecule (ADVATE), mouse or hamster protein, or excipients of ADYNOVATE (e.g. Tris, mannitol, trehalose, glutathione, and/or polysorbate 80).

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Formation of neutralizing antibodies (inhibitors) to factor VIII can occur following administration of ADYNOVATE. Monitor patients regularly for the development of factor VIII inhibitors by appropriate clinical observations and laboratory tests. Perform an assay that measures factor VIII inhibitor concentration if the plasma factor VIII level fails to increase as expected, or if bleeding is not controlled with expected dose.

Monitoring Laboratory Tests

- Monitor plasma factor VIII activity by performing a validated one-stage clotting assay to confirm the adequate factor VIII levels have been achieved and maintained.
- Monitor for the development of factor VIII inhibitors. Perform the Bethesda inhibitor assay to determine if factor VIII inhibitor is present. If expected factor VIII activity plasma levels are not attained, or if bleeding is not controlled with the expected dose of ADYNOVATE, use Bethesda Units (BU) to determine inhibitor levels.

ADVERSE REACTIONS

The most common adverse reactions (≥1% of subjects) reported in the clinical studies were headache, diarrhea, rash, nausea, dizziness and urticaria.

Clinical Trials Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in clinical trials of another drug and may not reflect the rates observed in practice.

The safety of ADYNOVATE was evaluated in 365 previously treated patients (PTPs) and previously untreated patients (PUPs) with severe hemophilia A (factor VIII less than 1% of normal), who received at least one dose of ADYNOVATE in 6 completed multi-center, prospective, open label clinical studies and 1 ongoing clinical study. The total number of infusions within the safety database is 74487. Following are the adverse reactions reported during clinical studies.

Adverse reactions reported for ADYNOVATE as shown by Percent of Subjects, Number of subjects (%, n) (N=365). Reported adverse reactions are listed by MedDRA Preferred Term. Diarrhea (6.8%, n=25), Nausea (2.2%, n=8), Ocular Hyperaemia (0.8%, n=3), Hypersensitivity[a] (0.5%, n=2), Headache (11.2%, n=41), Dizziness (1.9%, n=7), Rash (2.7%, n=10), Urticaria (1.9%, n=7), Drug Eruption (0.3%, n=1), Flushing (0.27%, n=1), Eosinophil Count Increased (0.5%, n=2), Infusion Related Reaction (0.5%, n=2).

[a] The event of hypersensitivity was a mild transient non-serious rash, occurring in one 2-year old patient who had developed a previous rash while on ADYNOVATE.

Two cases of acute pancreatitis, with no precipitating cause identified in one case, were reported in adults during an extension study of the clinical trial which evaluated 216 subjects. Administration of ADYNOVATE continued and both cases resolved.

Immunogenicity

Clinical trial subjects were monitored for neutralizing (inhibitory) antibodies to FVIII. Of the 6 completed clinical trials in previously treated patients (PTPs), in the randomized controlled trial comparing different dosing regimens of ADYNOVATE, one previously treated patient developed a transient low titer FVIII inhibitor at 0.6 BU while receiving more frequent dosing with ADYNOVATE. In a continuation study with ADYNOVATE, one patient developed a transient low titer (0.6 BU) FVIII inhibitor. Repeat testing did not confirm the presence of inhibitor. Both of these subjects continued treatment without change in the dose of ADYNOVATE.

Immunogenicity also was evaluated by measuring the development of binding IgG and IgM antibodies against factor VIII, PEGylated (PEG)-factor VIII, PEG and Chinese hamster ovary (CHO) protein using validated ELISA assays.

Persistent treatment-emergent binding antibodies against FVIII, PEG-FVIII or PEG were not detected. Out of 365 subjects, thirty-six subjects in total showed pre-existing antibodies to factor VIII (n=5), PEG-factor VIII (n=31) and/or PEG (n=6) prior to the first exposure to ADYNOVATE. Twenty-four subjects who tested negative at screening developed transient antibodies against factor VIII (n=10), PEG-FVIII (n=16) and/or PEG (n=3) at one or two consecutive study visits. Antibodies were transient and not detectable at subsequent visits. Two subjects showed positive results for binding antibodies at study completion or at the time of data cutoff. Binding antibodies that were detected prior to exposure to ADYNOVATE, that transiently developed during the trial or were still detectable at study completion or data cutoff could not be correlated to any impaired treatment efficacy or altered PK parameters. There was no causal relationship between observed adverse events and binding antibodies except in one subject where a causal relationship cannot be ruled out based on available data. No subject had pre-existing or treatment-emergent antibodies to CHO protein.

From an ongoing study in previously untreated patients <6 years with severe hemophilia A, 9 cases of FVIII inhibitor development associated with treatment with ADYNOVATE were reported.

The detection of antibodies that are reactive to factor VIII is highly dependent on many factors, including: the sensitivity and specificity of the assay, sample handling, timing of sample collection, concomitant medications and underlying disease. For these reasons, comparison of the incidence of antibodies to ADYNOVATE with the incidence of antibodies to other products may be misleading.

USE IN SPECIFIC POPULATIONS

Pregnancy: Risk Summary

There are no data with ADYNOVATE use in pregnant women to inform a drug-associated risk. Animal reproduction studies have not been conducted with ADYNOVATE. It is unknown whether ADYNOVATE can cause fetal harm when administered to a pregnant woman or can affect reproduction capacity. In the U.S. general population, the estimated background risk of major birth defect and miscarriage in clinically recognized pregnancies is 2-4% and 15-20%, respectively.

Lactation: Risk Summary

There is no information regarding the presence of ADYNOVATE in human milk, the effect on the breastfed infant, or the effects on milk production. The developmental and health benefits of breastfeeding should be considered along with the mother's clinical need for ADYNOVATE and any potential adverse effects on the breastfed infant from ADYNOVATE or from the underlying maternal condition.

Pediatric Use

Safety and efficacy studies have been performed in 91 previously treated, pediatric patients age 1 year to <18 years who received at least one dose of ADYNOVATE as part of routine prophylaxis, on-demand treatment of bleeding episodes, or perioperative management. Adolescent subjects age 12 to <18 (n=25) were enrolled in the adult and adolescent safety and efficacy trial, and subjects <12 years of age (n=66) were enrolled in a pediatric trial. The safety and efficacy of ADYNOVATE in routine prophylaxis and the treatment of bleeding episodes were comparable between children and adults. Pharmacokinetic studies in children (<12 years) have demonstrated higher clearance, a shorter half-life and lower incremental recovery of factor VIII compared to adults. Because clearance (based on per kg body weight) has been demonstrated to be higher in children (<12 years), dose adjustment or more frequent dosing based on per kg body weight may be needed in this population.

Geriatric Use

Clinical studies of ADYNOVATE did not include subjects aged 65 and over.

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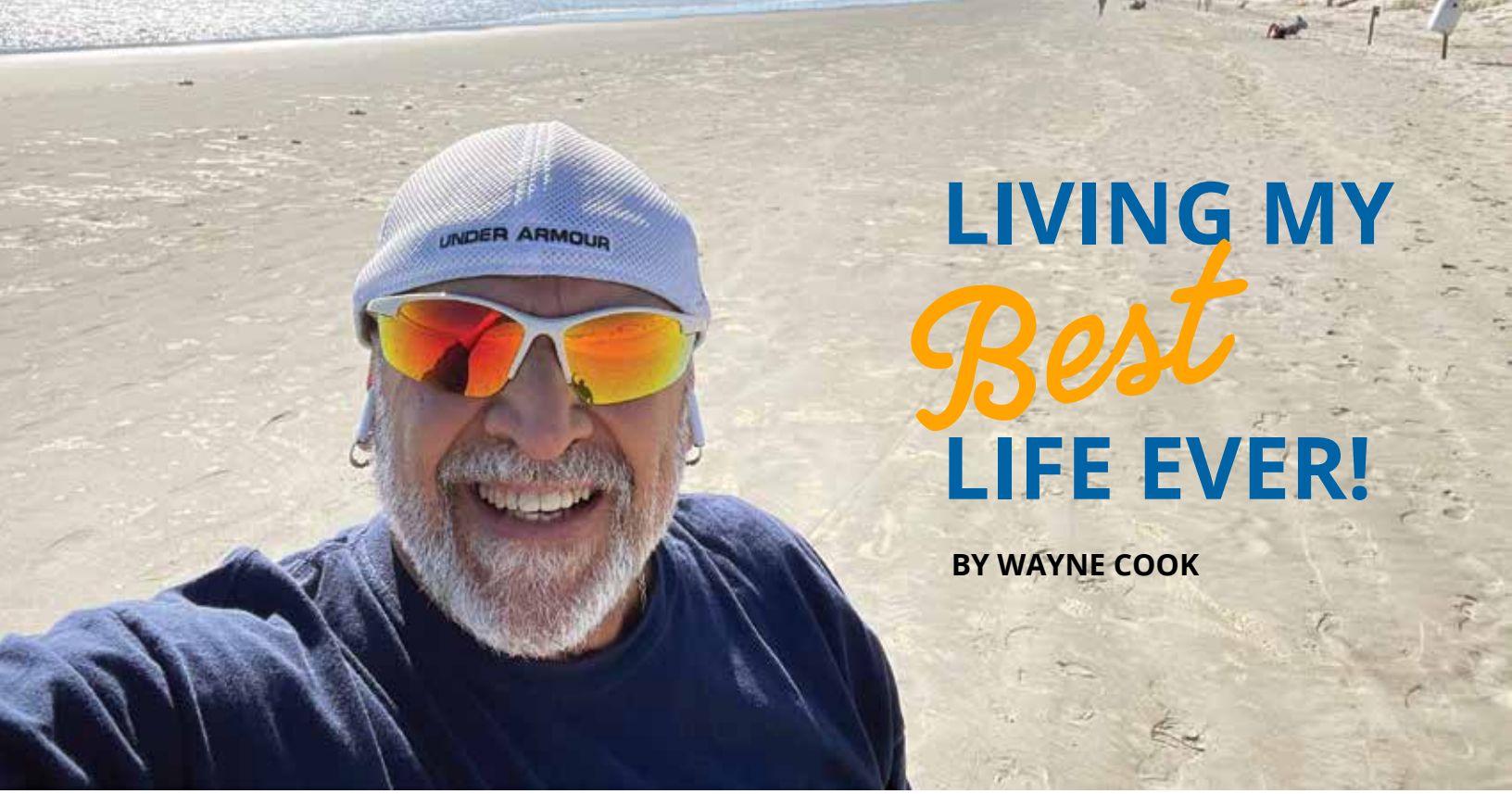


LIVING MY *Best* LIFE EVER!

BY WAYNE COOK

In 1966 when I was five, I spent over a month in the hospital after having my tonsils removed. I was diagnosed with severe factor IX hemophilia. I remember being in the room when the doctor told my mother the outcome of the tests and the prognosis of my life expectancy. She was told I would be lucky if I lived to see the age of 20. Well, here I am at 61 and going strong! I wish that doctor was still around so I could show him I'm a survivor!

I grew up in a very rural county in upstate New York where we weren't afforded the education or the treatment options available for people with hemophilia. When I got hurt, I was taken to the hospital and I received doses of fresh frozen plasma and spent lots of time there healing. I'm not sure my parents fully understood hemophilia or if they had just decided they wanted me to live a regular, albeit shortened life. Despite the problems, my parents let me live a typical life. I did things all kids did and played just like everyone else.

As I grew older, I started to learn how serious my hemophilia was. I sought education, learned a lot, and began to get involved in the hemophilia community. I learned how to advocate for myself and how to become an advocate for others with hemophilia too. As the years went by, I realized how badly bleeding episodes had affected my joints. At only 28, I had my right knee replaced. At thirty, my left knee was replaced.

Although I contracted hepatitis C through tainted clotting factor, by some miracle I was lucky enough to not contract HIV.

However, along with depression, I have experienced plenty of other health challenges through the years: at 38, I suffered my first heart attack and spent two weeks in the hospital and eight weeks out of work. There wasn't a family history of heart disease, so it was surprising. It was also difficult for the doctors to work out how to use blood thinners for my heart while treating my hemophilia.

At 45 and 46, I had each of my knees replaced for the second time. Around this same time, I also went through countless treatments for hepatitis C. It almost took my life due to the toxicity of the treatment, but finally I was able to beat the virus. Unfortunately, at 50, I suffered two more heart attacks, and at 55, I developed diabetes. Then at 60, I was diagnosed with cirrhosis of the liver developing from the hepatitis C. I took a week to pity myself and

With wife, Kelly

Grandsons Anthony and Landon

Stawberry picking with Anthony




then, like always, put my foot down and said, "This isn't going to beat me either!"

I was so excited for my 60th birthday because I was now officially in our community's "elite survivor's" club. Now at sixty-one, I feel my age some days, but for the most part, I am in a spot in my life where I feel healthy and happy. I look at life differently now as I know my clock is ticking faster and faster. No day is taken for granted no matter what might be thrown at me. When something stresses me, I take time out to relax and turn off the outside world.

Even though I am still dealing with liver disease and other health issues, I have been off antidepressants for over a year. My wife and I moved to a warmer climate and closer to where we always wanted to be – the beach. We love our new home and yes, even though the summers are hot, it makes me feel so much better! I am outside all the time enjoying working in my yard, playing golf three days a week, or at the beach. I have learned to stop asking "Why me?" and start asking "Why not me?" I have learned to put myself first and started taking better care of myself and my own wellbeing.

Life is much too short to take anything for granted. I have never let hemophilia or any other health issue be my life sentence. I have many more years left to enjoy, not only with my children and grandchildren, but to spend quality time with the love of my life, my beautiful wife, Kelly. We have too many things left to do, places to see, experiences to have and life to enjoy.

Through all the good times and bad, ups and downs, and pain and suffering that I've had in my life, I have to say, it's been a pretty darn good life and I wouldn't change it for one minute!

MEETINGS ON THE ROAD

IN-PERSON, OCTOBER-NOVEMBER 2022

WE'LL BE COMING TO THESE STATES:

- Missouri
- Georgia
- Texas
- Minnesota
- Virginia
- Michigan
- North Carolina
- Colorado
- Ohio
- Pennsylvania
- California
- Illinois
- New York

THE COALITION FOR HEMOPHILIA

HEMOPHILIA AND AGING

BY DAVID CLARK, PH.D.

What happens to people with hemophilia as they enter their senior years? We don't really know much about that. Historically, not enough people have lived long enough to find out. Before factor concentrates, people with hemophilia often only lived into their teens – really just starting life.

The availability of plasma-derived factor concentrates, starting with cryoprecipitate in the mid-1960s for hemophilia A, and factor IX complex for hemophilia B in the late 1960s and early 1970s, began the process of bringing hemophilia lifespans to today's near-normal levels. Unfortunately, those life-giving products came with the risk of infectious diseases that also limited the lifespans of people with hemophilia.

We might have known more about aging with hemophilia by now, but the AIDS crisis in the 1980s wiped out a huge part of our community. Our hemophilia elders are a sparse, but lively, group. We're now in an era of safe, highly effective products with a healthy middle-aged population who can expect to find out what happens as they age. The Hemophilia Treatment Center (HTC) network, in addition to providing care, is also a resource for keeping track of the health of patients over their whole lifespan. That information is invaluable for researchers looking to see what happens to patients under many conditions, including as they age.

One of the primary principles in medicine is that every person is different. That's why we have to study a large number of subjects in order to find out what the typical or average behavior is. I have a friend in the hemophilia B community who had a heart attack. He survived and is now probably doing better than before his heart attack. Should we use him as a model for how to treat a heart attack in a person with hemophilia? No, his case is one good piece of data, one piece of evidence, but we need much more before we really know what happens to most people and the best way to treat them.

So, let's start with heart disease, the number one killer of Americans. Since a heart attack is caused by a clot blocking one of the coronary arteries that provide blood to the heart, many people have proposed that having hemophilia should tend to protect patients from heart attacks. However, heart attack clots are mainly caused by platelets, and most people with hemophilia have normal platelets. The research shows that we can't really guess about these things. From the few studies that have been done, it appears that people with hemophilia have just as many heart attacks, but they tend to survive them more than does the general population.

As I've gotten older (I'm 72 and don't have hemophilia), I've come to realize that the greatest danger is not dying but being debilitated. It's quality of life. You might survive a heart attack, but if it damages your heart so you can't participate in your normal activities, that can significantly reduce your quality of life. You not only want to live a long time; you also want to be as healthy as possible.

The typical hemophilia patient brings a number of conditions with them into old age. One of the most important is high blood pressure (HBP). We don't know why, but people with hemophilia have a greater tendency to develop HPB, which can cause a number of issues

including heart disease, stroke, dementia, kidney disease, eye problems and more. HBP is called a silent killer because people often don't know they have it until it causes a problem. It's important to know your blood pressure, and if elevated, get treatment.

Another thing some hemophilia patients bring into old age is infectious diseases, especially those old enough to have been treated with plasma-derived products. Infections with HIV, the AIDS virus, and the hepatitis C virus are common in older people with hemophilia. We also don't know that much about AIDS in the elderly; people with AIDS are only more recently living into old age. We do know about hepatitis C, and it presents its own set of challenges.

People with hepatitis C tend to develop liver cirrhosis and liver cancer. Now that we have fairly easy treatments for hepatitis C, people are encouraged to get tested and treated. The longer you wait, the more potential damage to your liver. Even after treatment some people are left with significant liver damage that might still lead to liver cancer. Hepatitis C is also a risk factor for diabetes, another common disease of aging.

Aging with hemophilia is one of this community's next adventures.

One obvious issue many hemophilia patients bring into old age is mobility concerns. Many people have damaged joints from repeated bleeds. It doesn't get any better as you get older. Some of this can be treated, but the important goal is to prevent further damage. Keeping up with your prophylaxis to prevent future bleeds is key, as is keeping active. We know that exercise is instrumental in strengthening your joints.

Mobility issues can lead to a higher risk of falls and other injuries. Falls are often the beginning of the end for elderly people. In addition, there is some indication that people with hemophilia tend to have low bone density, potentially allowing bones to fracture more easily. Accidents are the fourth leading cause of death (they were third before COVID came along). Accidents become more prevalent in older people because of both physical and mental decline.

Aging can also interfere with treatment. Patients may have more problems finding and accessing veins for intravenous infusion. This might seem like a small thing, but it can have a significant effect on an older person with hemophilia who needs factor. Vision and coordination problems may also interfere. The difficulties may also lead to anxiety, missed infusions and reduced independence. The development of more treatments that can be given subcutaneously will be a big improvement.

The community has begun to focus more on mental health, and that can be a special need for older people, with or without hemophilia. Retirement can bring the loss of a sense of purpose. Reduced independence can bring the need for additional help. Loss of friends and family

members can result in loss of caregivers and loss of companionship. Depression, anxiety and potentially dementia can undermine not only one's mental health, but also their physical health.

After all that, there are conditions affecting everyone with or without hemophilia as they age, for instance, cancer, diabetes and COPD. We don't yet know whether hemophilia influences such conditions, but even without additional complications, they are serious.

All of this also applies to carriers and women with hemophilia. Unfortunately, they face a double burden. Not only do we not know much about women aging with hemophilia, we don't even know a lot about women aging without hemophilia. Women have been ignored for far too long. We are beginning to understand, for instance, that heart disease works differently in women. The symptoms of a woman having a heart attack can be quite different than those in a man. These differences can delay getting treatment and lead to greater damage to the heart.

Aging with hemophilia is one of this community's next adventures. A 2018 editorial in the medical journal Haemophilia [Haemophilia, 2018, 24, 15-16] ends with this statement: "Haemophilia care is no longer about treating bleeds but rather about treating the individual as a whole with all their accumulating comorbidities."

So, what should the aging person with hemophilia do? Pay attention! Many of the conditions listed above are easier to treat when they are discovered early. Have an annual physical exam, and don't delay asking your doctor about any new symptoms you develop. One of the big advantages for hemophilia patients is the HTC network. They are dedicated to comprehensive care and encourage annual visits. Beyond that, take good care of yourself. Eat healthy (lots of fruits and vegetables), exercise, get enough sleep, stop smoking and try to reduce stress.

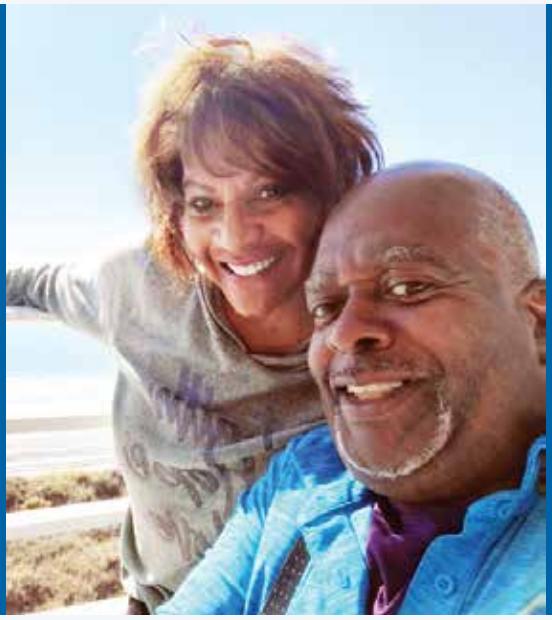
ABOUT DR. DAVID CLARK

David Clark is an independent consultant to the biotechnology, plasma and tissue industries. He has 35+ years of experience in the development and manufacture of plasma and tissue products, including factor VIII and factor IX concentrates, primarily with the American Red Cross. Dr, Clark holds a Ph.D. in chemical engineering from Cornell University.

My hemophilia journey began when I was born in Marlboro County, South Carolina in 1957. At 6 months old, I rolled off the bed and sustained bruises that would not go away. I was diagnosed with severe hemophilia A at Charleston Naval Hospital where the doctors told my parents I would probably not live past my teens.

GROWING OLDER: TAKING IT *Day-By-Day*

BY WARREN P. INGRAM



In the late 1950s and into the 60s, good medical care was not always equal for people of color in the south. Wisely, my parents decided to become career military in the Air Force so they could get the care I would need.

When I was 3, my father received orders to deploy to Okinawa, Japan. It was while living in Okinawa that my memories of bleeding episodes began. Treatment consisted of fresh frozen plasma and long hospital stays. My parent's first major scare with me happened at about 5 years old. I had been playing outside, fell and bumped my head. Later that day my mom reported I was not myself, becoming lethargic and incoherent. They brought me to the USAF Military hospital where I went into a coma lasting 3 days due to a brain hemorrhage. On the 4th day, my mother recounts that upon her arrival she found me sitting up in my hospital bed eating a bowl of cereal. Her prayers had been answered.

In 1964, we moved to Otis Air Force Base on Cape Cod, Massachusetts. I continued to receive care at military hospitals until my father retired from the USAF in 1970. Between 1964 and 1970, I averaged two weeks per month in the hospital to receive fresh frozen plasma along with many casts and braces. It was later determined the casts and braces were not an appropriate treatment as they caused many issues for my knees.

Surrounded with love, Warren, wife Sharon and daughters Emma and Jasmine

With son, Patrick

My target areas were knees, hips, elbows, wrists and shoulders. At 13 years old, I started on home infusion treatment which changed my life. I was given independence and my life seemed almost as normal as someone without hemophilia.

At 18, it was determined I would eventually need hip replacements. As a teen, working was a challenge. I learned early on that physically challenging jobs were not going to work for me, especially if I had to be on my feet. I also learned I needed a job that offered generous health benefits. In 1983 I found a great opportunity with AT&T that provided a good salary and great benefits.

1959, 2 years old with parents, Queen and Percival

1961, 4 years old

1963, 6 years old with Dad

1965, 8 years old, leg casted

In 1985, I found out I had contracted HIV through contaminated factor VIII. This was devastating news. I was also experiencing a lot of bleeds at that time, so bad that I had to use crutches to go to work. This led me to have a bilateral hip replacement in 1986. The surgery was a great success. I no longer bled into my hips and regained a lot of mobility.

During these years, however, I lived with a lot of stress and anxiety because there was no good treatment for HIV. I saw it as a death sentence. Except to get the necessary treatment, I did not want to associate myself with hemophilia and didn't have any relationships with other hemophiliacs.

Eventually, I was transferred to Alpharetta, Georgia for a new position with AT&T. I was doing well in my new surroundings, but HIV was still in uncertain territory. I decided to join a support group at my local chapter. This proved to be life-changing; I soon met other people like myself who were not only dealing with hemophilia but also with HIV. These friendships led to my involvement in becoming an advocate for the bleeding disorders community.

Because of my HIV status, I didn't believe I would ever get married but in 1998, I met the love of my life, Sharon. We were married the same year and raised two daughters and a son together.

I was diagnosed with hepatitis C in 1995 and lived with it until it was cleared in 2018. In 2002, I went on disability because of the on-going joint issues I was having, mostly with my knees and hips. That same year, my right knee was replaced, and then my left in 2005.

In 2006, I was diagnosed with hereditary hemorrhagic telangiectasia (HHT), a condition that causes abnormal connections to develop between arteries and veins. This caused me to have such bad nosebleeds that at one point I was having weekly blood transfusions receiving 2-3 units at a time. I was tired and weak all the time. When I was first diagnosed, there was no real treatment for HHT. Today an intravenous drug is available and every couple of months I receive an infusion to prevent the blood vessels from bursting.

2016 saw a right hip revision, followed by a left hip revision in January 2017 with another that same year in August.

At 65, past bleeding episodes have taken a toll. It has become difficult to do the day-to-day things most people take for granted. I now must use a power chair, rollator or scooter – take your pick!

I always assumed there would be issues with my lower body, but my younger self would not have imagined my troubles in aging would involve elbows, shoulders, fingers and back. These joints bothered me in my youth but stopped in my later teens. However as I approached 60, I began to lose range of motion in my elbow and shoulders, which interferes with doing simple things. For example, since my elbow won't bend properly, my right hand can't reach my mouth to eat.

Through the years, Sharon and I have led a variety of workshops at NHF annual meetings. One of our favorite workshops centered on talking with younger couples about our experiences and how we dealt with my hemophilia.

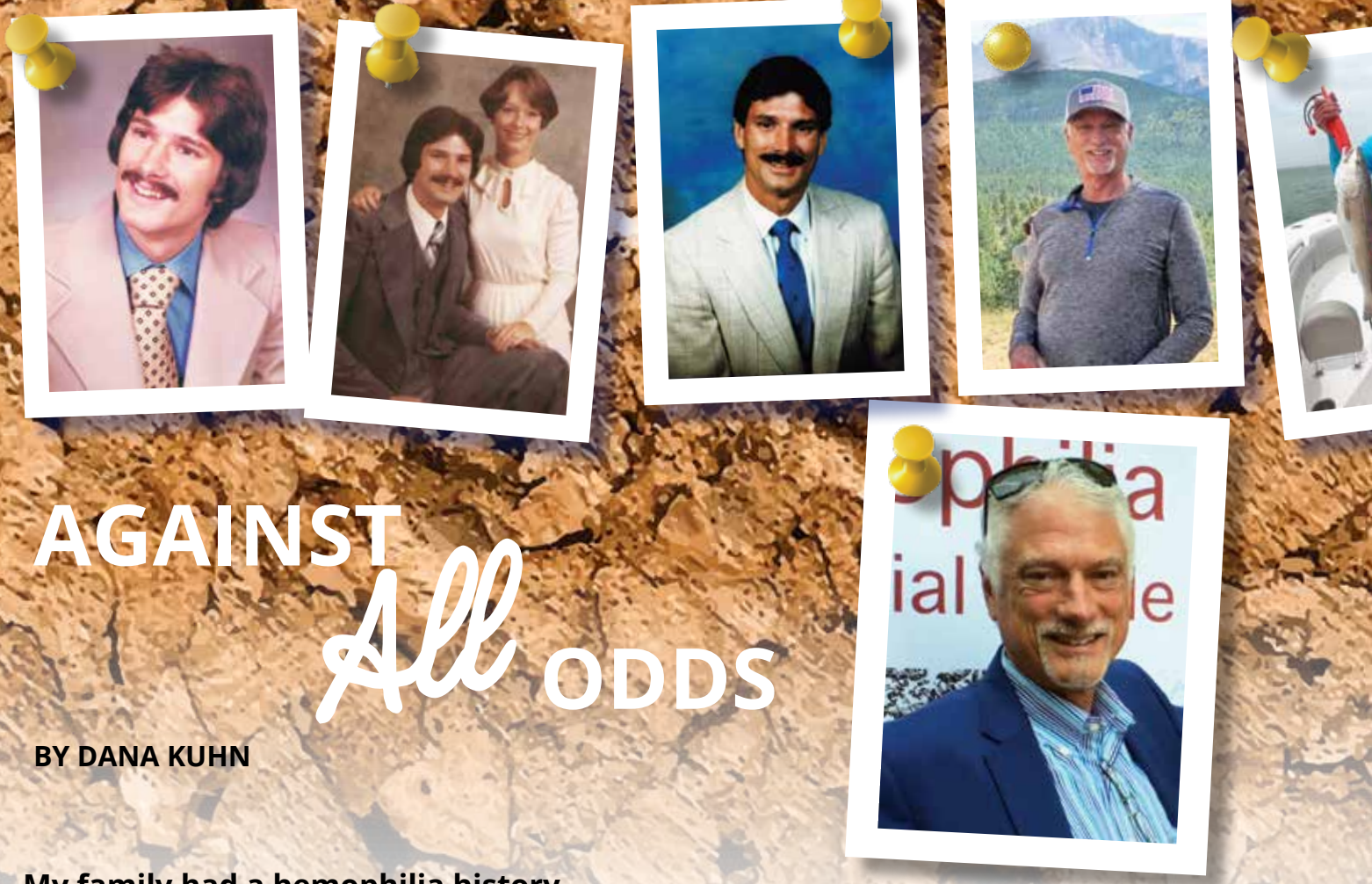
At one particular session, Sharon mentioned that I watch a lot of television. As a young child, my parents wouldn't allow me to play for fear of an injury, so I spent a lot of time watching TV – it became my friend. As an adult, it's much the same way. There were probably ten guys at that session who said they were the same way. This was an eye opener for the wives when they realized they weren't alone and that television was their husband's coping mechanism.

I don't have the drive or desire to do a lot of things that I used to enjoy. Living with a lot of pain is a challenge, but I'm still here! With all the trials I have in front of me, I lean on my faith for strength and always try to look at the glass as half full rather than half empty.

I enjoy a lot of things as an aging adult – especially being married to my wife. When Sharon came into my life, she took on being an advocate with me and for me. She is my partner in every way and my biggest support.

My best advice for aging with hemophilia is to try to stay connected with people and events in the community. You can still learn a lot and the friendships are uplifting and immeasurable!

Be blessed and stay encouraged!



AGAINST *All* ODDS

BY DANA KUHN

My family had a hemophilia history, but we weren't aware of it. My mother's brother was undiagnosed and died from a bleeding ulcer. My mother had four boys, the first two were born with hemophilia and the second two without. My older brother and I didn't know we had hemophilia until we were 19 and 17 years old.

Throughout our younger years we were very active and played sports. We had a lot of sprained ankles, swollen elbows and muscle bleeds. People would often ask why it would take us so long to heal from these injuries. It was often thought we were faking it in order to get out of going to school. Eventually my mom said, "Enough is enough, something needs to be done."

My mom and our family physician researched the cause of this possible bleeding problem. It was discovered that my brother and I might have something called hemophilia. My mom contacted the National Hemophilia Foundation and spoke to someone who counseled her to take her sons to a medical clinic for testing. She did exactly that, and we were both diagnosed with mild-to-moderate hemophilia A.

Back in the early 1970s we didn't know anything about factor or how to treat our hemophilia. We already had an established lifestyle and continued our risky activities and experienced bleeds in what we now understand were target joints. We accepted our injuries and would treat with an icepack until they eventually got better.

In my early adulthood years of the 1980s, I was living in Tennessee, married, and having children when I started to go to a Hemophilia Treatment Center. I was told about clotting factor and cryoprecipitate available to treat bleeding episodes. However, I never personally needed it until I broke my foot at age 30. I ended up going to an emergency room, told them I had hemophilia and that I needed something like cryoprecipitate or factor VIII. The doctors decided to give me factor instead of cryoprecipitate. I was never told it could have been infected with HIV. In that single dose of contaminated factor, I received both HIV and hepatitis C.

Having hemophilia, HIV, and hepatitis C, who would have ever believed I would live so long! I endured two grueling years of Alpha Interferon treatments for hepatitis C, yet it had less than 33% efficacy in clearing it. When I subsequently almost died from hep C, I wondered why the Alpha Interferon ended up working after all.

While friends and acquaintances were dying of HIV/AIDS all around me in the 1980s, I wondered if I would be next. When my wife, Patty, died of AIDS, which I unknowingly transmitted to her, I wondered, "Why her and not me?"

Dana with older brother, Robin

Robin, Dana, Shawn, Hans and Rayer

A God-given passion for discovering the truth behind the contaminated blood products, the unnecessary infections and deaths of so many blood brothers, the unnecessary death of my wife, and the need for blood safety drove me to be a leader in advocacy.

Due to my generation's passion, advocacy and leadership, children and young adults now have the safest and most efficacious clotting products. Tears of joy come to my eyes when I see children and young adults living without permanent joint damage, having safe prophylactic treatment, experiencing limited pain, and having quality of life ahead of them. In contrast, my generation knew about pain and permanent damage after each bleed, and contaminated products.

My age group wasn't initially treated prophylactically. Many didn't live to see the advantages and treatments that are available today. For so many, even the treatment for HIV caused complications. For many others, hepatitis kicked in, destroyed their liver and claimed their life.

My biggest concerns with growing older are not the wrinkles, grey hair, aches and pains associated with past bleeds, not being as active as I once was, or developing other aging medical conditions. My two biggest concerns are maintaining quality of life and not being forgotten and appreciated for the battles and scars we endured to make this community safer and better.

This year I slipped on a patch of ice, fell on my hip, crushed my sciatic nerve and had bleeds into every muscle from my gluteus maximus to the abductors. The nerve damage was so severe I couldn't walk at first, but eventually was able to get around on crutches. It takes a long time for nerves to return and work correctly. It took 5 months of physical therapy before I was close to being healed. I definitely contribute the slow healing to age. As you grow older the bleeds will stop, but everything else takes longer to mend.

This accident concerned me with the importance of quality of life. Now that I have retired, I feel I am sometimes perceived as old and no longer a vital member of society. I think being perceived as not important or useful is what bothers me the most as I age. I still have much to offer our community but sometimes feel like a racehorse put out to pasture.

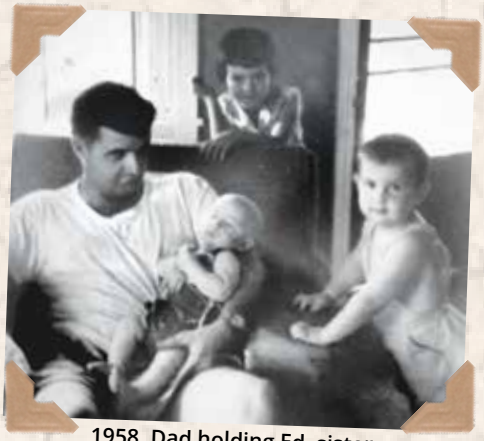
Nevertheless, I continue to live one day at a time and look for opportunities to share my experience, encouragement, empathy and care with all those I encounter. I find purpose in each day, and find joy and fulfillment in seeing younger people with hemophilia live healthier, safer lives.

Now at the end of my sixties, I give thanks to God for life and continue to live "against all odds!"

I'M *NOT* GIVING UP YET!

BY EDWARD BURKE

Father's Day 2022 with daughter, Killeen



1958, Dad holding Ed, sister AnnMarie and brother Jim

My maternal grandfather had severe hemophilia A. He was injured while working on a construction site. The doctors thought he was having an appendicitis attack, but he was actually bleeding into his abdominal cavity and consequently passed away at age 35. This was when my family became aware of the hemophilia in our lineage.

Since my mom knew she was a carrier of hemophilia, she explained to my dad that if they had sons, there was a 50/50 chance of them having severe hemophilia. Sure enough, all three of us had it! When we were young, we would often wake up at night with an elbow hurting or blood everywhere from a tooth coming in. My parents had their hands full.

I was the first to self-infuse in my family after I learned at hemophilia camp. I was always giving my brothers their doses as well!

My brother Michael was four years younger than me. He went out for high school wrestling. At a match, he made a 13 second pin in the heavyweight division, making the sports page of our local paper. Our pediatrician, who never treated us for hemophilia, saw the news article and called the school. He alerted them that my brother should not be allowed to wrestle due to his hemophilia. Instead of being applauded and congratulated, Michael was thrown off the team.

For two years in my early 20s, I was secretly part of a men's ice hockey league. Mom didn't know it, but my dad did, and would come watch me play. He would remind me, "Don't tell your mother!" While my mom watched TV, I would drag my bag of hockey pads and sticks upstairs.

One night when I came home, she decided to investigate what all the noise was about. When she saw me with my gear, she said, "What's this?" I told her I had good news and bad news. She asked, "What's the bad news?" I told her I played ice hockey. She said, "Oh really? What's the good news?" I told her, "I'm team captain, and we're on a championship run!" She looked at my father to ask if he knew about this, but he was out of the room and up the stairs! He knew when she saw the hockey equipment he had better run! During a game, my knee twisted up, and it just wouldn't stop bleeding. That was the last time I played. The injury resulted in my first knee replacement.

My older brother James passed away at 24 years old in June of 1980 following an accident. My father was destroyed – he died of a broken heart just two years later.

Michael and I were diagnosed with HIV at our Philadelphia treatment center in 1985. My mother was already crying

1968 Ed (far left) with brothers, Jim and Mike, paternal grandmother, and sister, Ann Marie

1968 Ed, AnnMarie, Jim and Michael (center)

1973, Michael, Jim, Mom and Ed

when we walked into the room. We were given the news that we tested positive for HIV and that we had about seven years to live. I asked, "So you're saying by 1992, my life will be over?" The doctor explained those were the statistics. In a way he was right... in October 1992, I got married! Joking aside, thirty years with my wife and she has seen a lot of this too, having attended many blood brother funerals. Sadly, my youngest brother, Michael, passed away at the age of just 35 in 1997 – his death tagged as hemophilia-related AIDS.

My mom is currently 88! She is still very much a hemophilia mom. Everything her sons went through continues to weigh heavy on her heart.

Sixty years of life with hemophilia and I have a pretty good pain threshold, but the bleeds hit hard. One time I was driving my friend to the airport and almost took my car out of the lane because of a breakthrough bleed in my elbow. The bleed was so bad I couldn't move my hand to steer the wheel. Taking a weekend trip to attend a meeting or event and I feel the effects of aging. I was in Nashville, returned home and waited three days for my knees and ankles to get back to normal just from being on foot and walking around the city.

As we age, we learn things like pain may feel like a bleed, but it's not a bleed, it might be arthritis or just a muscle ache. It feels like I wake up with something every day. I can still bleed into my artificial joints! The pain is sometimes intolerable.

Living long enough to have arthritis is not something I had banked on. I've had all these target joints and some just don't work as they should - like my right pointer finger that doesn't bend like it's supposed to.

But the most difficult part of growing older is when we lose a friend. I try to stay close with the friends who are still here. Everyone young enough not to have been exposed to tainted clotting factors should watch the movie *And the Band Played On*. It will serve as a reminder that the "hemophilia holocaust" shouldn't have happened to our community. Even with advances in medical treatment, HIV/AIDS and hepatitis C continue to claim the lives of people in our community who were exposed to tainted blood products in the 1980s.

One misconception is that people with hemophilia have "thin" blood so they can't have heart problems – WRONG! My second AFib (Atrial Fibrillation) put me in the emergency room. My daughter was outside the ER yelling at the medical staff to let her in with my clotting factor because although she didn't know what was wrong with me, she knew I needed to get factor. The cardiologist put me in the ICU and told the nurse to start blood thinners immediately. All I could say was, "HOLD ON, I *AM* A BLOOD THINNER! I DON'T CLOT!" My cardiologist told me, "Hemophilia really puts a kink in the armor and changes how we can help you."

In addition to AFib, I have psoriatic arthritis. It's difficult for a cardiologist or rheumatologist to treat with their go-to medications. For example, the medication I take for the psoriatic arthritis treats the symptoms, but it also lowers the immune system. That complicates things when combined with my HIV medications. As we grow older, other medications may be problematic when combined with medications we take for hemophilia and HIV.

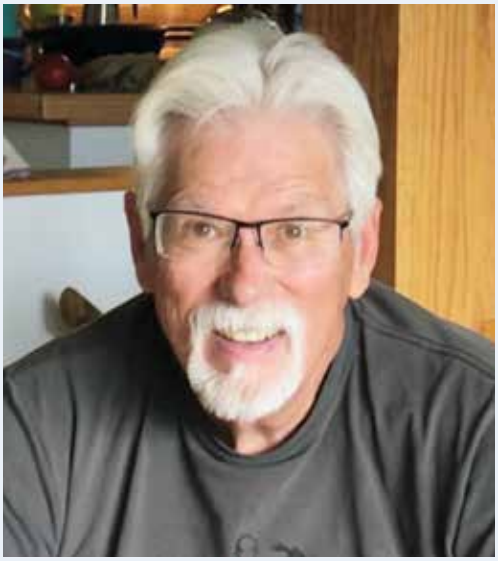
Many times, I have been wakened in the middle of the night. It's my daughter calling. Every three or four weeks, she wakes up from a bad dream and has to check on me. I tell her I have no plans to go anywhere anytime soon and that I feel fine. It's heartbreaking to know your daughter is so concerned about your health that it keeps her up at night.

1981, Ed with dad, James

In my retirement, to stay busy and make a little extra money, I signed up with a talent agency and have been doing movie parts and voice overs, and I play guitar and have done performances. I enjoy trying to entertain others. My dream for retirement was to keep playing and entertaining, but it has become more difficult as my left hand's ability decreases as the arthritis increases. I often ask myself, "Is it a bleed or is it arthritis?"

These are the things we deal with as we age, but we must keep living life to the fullest! I am still active in the bleeding disorders community and will participate in a hemophilia walk in the fall. I enjoy spending time with my wife and watching my much too beautiful 21-year-old daughter grow into a mature young woman.

My advice to the younger set is to always stay positive! Be active and stay engaged in the bleeding disorder community. Make friends. Reach out to your community brothers and sisters when you're having a problem – they will always be there for you! My close blood brothers and I have been saving each other's lives and sanity for years!



Young IN HEART, BODY AND MIND

BY RICK STARKS

My life began in 1954 in a Shreveport, Louisiana military hospital. Having a circumcision at birth led to the discovery of my severe hemophilia. Eventually, my mother, grandmother, three aunts, and a younger brother were also diagnosed with hemophilia.

I don't remember much of my early childhood, but a lot of it was spent in hospitals. Throughout my life I have experienced the full gamut of treatments beginning with whole blood transfusions administered with reusable steel needles that were autoclaved and put back into service, to the current regimen of long-lasting factor infusions every two weeks.

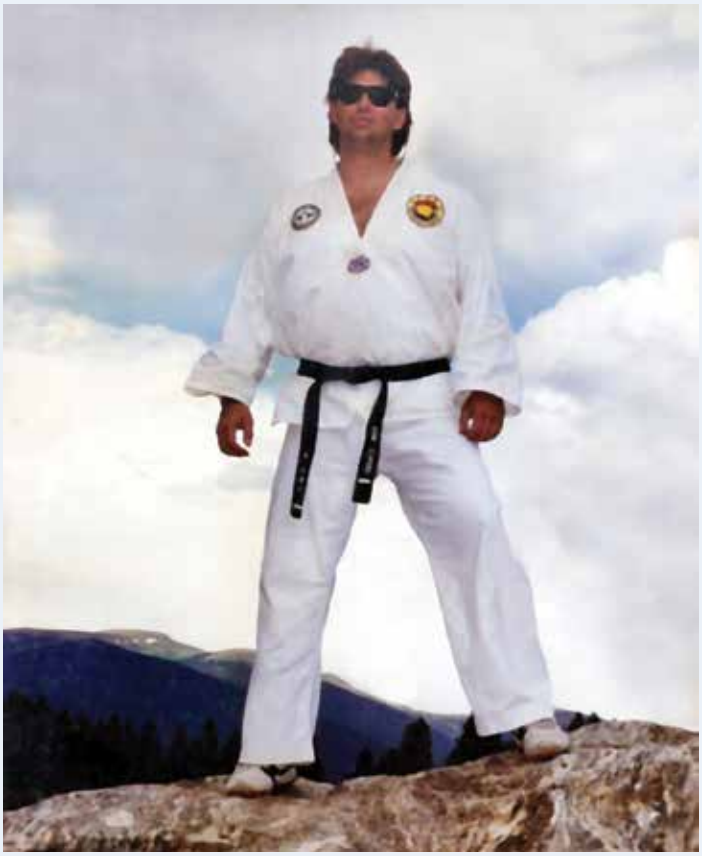
Supposedly, there are approximately 200 people with severe hemophilia over the age of 65 in the United States. I consider myself fortunate since I am one of the survivors.

Many think my life with hemophilia has been difficult, but it's the only life I know. Though I might not have always handled it wisely, I have dealt with hemophilia my entire life. Unexpected bleeds, personal setbacks and disappointments are things people with a severe bleeding disorder experience in everyday life. I have reconciled myself to my condition, making peace with it as I grew older and accepted the challenges as they arose.

So, how did I arrive at my present state of mind? We need to start at the beginning.

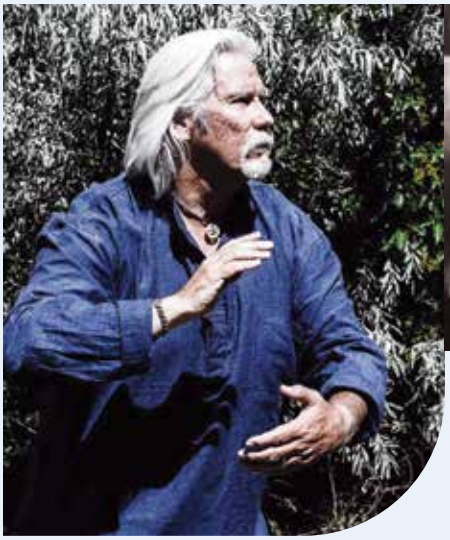
My earliest memories are of the loneliness felt being in the hospital. Being the oldest in a family of three boys and three girls, my parents couldn't visit often. Mom needed to care for my younger siblings while Dad was always working, often two jobs to support our family. Going from a bustling houseful of kids to a sterile hospital setting with few visitors was isolating and frustrating, to say the least. But for my parents, there were just not enough hours in the day to squeeze in anything but short visits. It must have been a tremendous burden on them.

My school years weren't very exciting either. Often during gym class, I was forced to watch from the sidelines. As a youth, I was picked on and bullied relentlessly. This continued through high school. Nothing was ever done about it, but it did teach me to endure, and I learned it said more about them than me.



I realized my mind would give up long before my body.

In high school, I had the opportunity to see a movie that motivated me to become better. My uncle had taken me to a theater to see *Enter the Dragon*. I will never forget it. It was the first time I had a peek into the world of martial



1956: with Dad

1957

1962: Helping my little brother

arts. I felt inspired, and at the age of 18, began training. I began to develop physically, becoming stronger, more flexible and more confident. I realized my mind would give up long before my body. Well, except for bleeding episodes. Those continued, and during this period, I bled a lot. I would train, get injured, go to the hospital for treatments, heal, and train again. It was a constant merry-go-round. Despite all odds, my skills improved and eventually led me to earn a Tae Kwon Do State Championship.

Knowing they would disapprove, I hid my new-found interest from my parents, doctors and nurses. I kept my hemophilia a secret from the Tae Kwon Do instructors as well. I viewed hemophilia as a weakness and feared the instructors would refuse me as a student. This secrecy has become one of my greatest regrets. Looking back, I could have saved myself a lot of pain and joint damage had I been open about my health issue.

Ultimately the injuries and bleeding episodes caught up with me. By the time I was 40, I had both hips replaced. My ankles were so bad that I could no longer walk more than a couple of blocks. I had to give up Tae Kwon Do, something that I deeply loved. It felt like a part of me died at that point.

In my late 50's, I had become quite sedentary, "blossoming" to 260 pounds, which led to a heart attack. I guess I was fortunate again as it proved to be a structural defect not caused by anything else. However, my blood pressure was high and I was placed on medication to control it.

That's when the fighter in me kicked in again. I began looking for a form of exercise that was gentle yet effective. I discovered Tai Chi. My initial experience post heart attack was watching, learning and moving to Tai Chi DVDs. Then I attended a Tai Chi seminar and found my first instructor. He taught me to move within myself, to accept my limitations, but to believe they were only temporary. He pushed me and taught me to enjoy life again and inspired me to become an instructor.

Through Tai Chi, I learned to recognize my patterns of thought and action. I became aware of my body and my movements. I learned to be mindful, to understand my strengths, and to recognize and overcome my weaknesses.

Today, I feel as well as I did in my 30s and 40s. My blood pressure returned to normal, and I was able to discontinue the medicine. In fact, my blood pressure is as good now as it was in high school. I adhere to my clotting factor prophy schedule religiously, but other than that, I am medication free.

Both my ankles were replaced in 2019, making movement a pleasure again. I walk at least a mile or two daily and continue to train in Tai Chi. I meditate daily and play guitar and bass guitar for the artistic part of my life. I believe for a peaceful, contented life you must honor your body, become spiritual in some form, and embrace an art form.

As we age, I believe these are a few important guidelines:

- Live in the present moment. Often, what we remember are the most painful aspects of our past, but it has nothing for us other than a way to keep us from repeating it. The future is not to be of concern since it hasn't happened yet, and most of our worries won't happen. Be in the *now*.
- Wake up grateful. Learn to develop a sense of gratitude and wonder. Arise with a feeling that the day is yours. Expect the best every single day. Get up, shower, and get dressed. Turn the day into a search for something wonderful. Don't let a bad moment ruin your entire day.
- Smile more! Smiling can actually change a bad mood! Share a smile and a kind word. It makes you feel better and can change another person's day completely.
- Get rid of something every day. I try to eliminate something every day that hasn't been used for a while, or that can be useful to someone else. It can also be a thought or habit. Give up the idea of your limitations!
- Don't quit. It is never an option. Just giving up one time can be the beginning of a habit.

As we progress through life with a bleeding disorder – and there will be more than 200 of us in the future – we must set an example of self-care. Not just as an example for future generations, but to maintain our happiness and peace of mind today.

I plan on living to 120. Will you join me?

GROWING OLDER IS A *Complex* SUBJECT

BY JOE MARKOWITZ

Joe with wife, Sherry, and their grandkids

Let's start with the growing old part. I was born in 1950, and some of my first memories of doctors were from being treated in emergency rooms. However, my first memory of a meaningful conversation with a doctor was when I was visiting a hematologist in Yonkers, New York, with my parents. He told me about a hemophilia patient who died from licking an envelope. I have not licked one in about 60 years. The other bit of news he shared was that I'd probably die in my 20s.

So, doctor, I guess you were wrong. I'm still here at 71.

There are two aspects of growing old with hemophilia that I feel are worth discussing. Hemophiliacs of my generation generally have arthritis and experience pain and mobility issues. However, with the highly effective products now available, the stress caused by hemophilia is no longer related to bleeding. The stress is from the decades-long degeneration of joints that bled back 50 years ago, mostly before college.

High School Prom 1967

Surgery, unimaginable several decades ago, is now fairly routine as long as the expertise of your hemophilia treatment center is behind you. I've been lucky enough to have bilateral knee and one hip replaced, so I am no longer experiencing joint pain. The surgeries were accomplished with no bleeding, but lots of factor, including during the post-surgery physical therapy period.

Then there's the second aspect of growing old, the aspect unaffected by hemophilia. As we age, our bodies seem to find new ways to torment us. As a kid, I thought having hemophilia meant I wouldn't have any other bad medical things happen to me. What I didn't understand is that at about the same time you get on Medicare, your body wants to take advantage of the great insurance and dumps new ailments on you.

Look around at men in their 70s, and you can be sure each one has at least one of these conditions: high blood pressure, high cholesterol, enlarged prostate, vision and hearing problems, arthritis or diabetes. These conditions are not unique to hemophiliacs but the result of living a long life.

Having hemophilia, with or without a co-morbidity, complicates the medical intervention for some of these conditions. For instance, if a person with hemophilia has AFib, aspirin and blood thinners are not the go-to treatment. Many arthritis medications have caused stomach bleeds that can be made more complicated with a bleeding disorder.

So maybe growing old with hemophilia requires more caution and planning than most people need. But we ARE growing older and leading full and happy lives. And that is certainly a great, previously unexpected outcome!

DEAR FRIEND

BY NICHOLAS CIRELLI

I am fourteen years old and have severe hemophilia A, factor VIII <1%. This information has been drilled into my head from the day I was born. I now rattle it off much like I give my friends my cell phone number or Instagram name.

Not long ago, I was selected to be inducted into the Junior National Honor Society at my middle school. As part of this honor, I was tasked with creating a community service project. I considered some of the more typical projects, such as volunteering at a soup kitchen for homeless people or collecting items for the local animal shelter, but I decided on something that hit closer to home. I requested permission to use my community service project hours to write letters to people in the hemophilia community to share my experiences with parents of newly diagnosed children or to thank the older generation of people with hemophilia for what they went through so that I have such safe medication to control my bleeds. I decided this project would best coincide with World Hemophilia Day, April 17th.

Recently I watched the documentary called *Bad Blood: A Cautionary Tale*. I did not know much about the tainted blood crisis before viewing it, so many of the facts and events shown gave me a new perspective on living with hemophilia. The result of watching this film was that it made me feel sick to my stomach. The physical and emotional pain you had to go through as boys and young men is something I've never seen before and hopefully never see again. Watching how young men were disregarded by society for doing nothing wrong, for simply being born with hemophilia, felt evil and sickening. It made me feel angry how many were taken advantage of, lied to, and even cast out by others. After finishing the film, I sat down and thought long and hard about what past hemophiliacs had endured. Then, a new feeling began to arise in me. At first, I didn't know what this feeling was or why I was feeling it. Then, I understood. I began to feel lucky.

My mom had this saying that came along whenever something happened to me. Whether I received a sunburn, had a bleed, fell down, or pretty much anything else, my mother would say in a cheerful tune, "It could always be worse." As a younger child, I almost always shook my head and continued to complain about what I felt was worth complaining about. But after watching this movie, not only do I understand what Mom was trying to say, but I also understand why she was saying it. I am lucky, very lucky, and things could be worse, much worse. The younger me would think, "What could possibly be worse?"

I wish I could turn back time and tell my younger self that being a hemophiliac now seems like heaven compared to being a hemophiliac years ago.

My life is so different because of what you have gone through. I do not need to worry about whether my clotting factor is safe. I do not experience frequent bleeds and, as a result, do not have frequent hospital visits. Having hemophilia is something that rarely comes up in school or with my friends simply because everyone knows I have it and they know I am okay. They do not treat me differently because of it. These things are royalties that many in the past were not able to experience. The sacrifices you made are remarkable and everlasting.

If there is one thing you can take away from this letter, I want you to know there are many young boys who are incredibly grateful for you. You rose and awoke a nation to an issue that had been under the surface for far too long. Because of you, I am alive and healthy today. I don't have to wake up and wonder when my time will come because I know whenever that time is, it will never be because of my hemophilia. You are my hero, and a hero to many others.

I cannot imagine what you have gone through. Even as a hemophiliac myself, it seems foreign to me what your younger life looked like compared to mine. The scars left from this time, whether emotional or physical, will always be with you, and for that, I am truly sorry.

The battle I am fighting is still long and hard, but it is miniscule in comparison to the grand war you have endured. I wish to offer you my thanks. You have changed my life in ways I did not know were possible. If you ever feel alone, I want you to know this - there is an entire generation of boys who will live normal lives thanks to you. Every single one of them should look up to you as their own personal hero. Thank you.

Nicholas Cirelli

BIOMATRIX

ON THE MOVE!

It's been a busy quarter – our Regional Care Coordinators have been out in the field meeting with many in our bleeding disorders community. Read on to see what we've been up to! Our Education Team continues to be at the ready to provide in-person or virtual programs as the need arises. If your group of any size is interested in scheduling an education session with our team or for a current list of programs available, please contact your RCC or message us at: education@biomatrixsprx.com.

TENNESSEE

David Tignor and Cyndy Coors

Livie and Lily work together at the arts and crafts table

With approximately 160 people in attendance, the Tennessee Hemophilia & Bleeding Disorders Foundation's (THBDF) ***Annual Meeting*** took place June 3rd–5th at Embassy Suites in Murfreesboro. Inspired by artwork from a former THBDF's Camp Freedom camper, the theme of the meeting was *One Blood-One Family, We Are Not Just a Disorder, We're a Community*.

Kaiyah and Mathias visit the BioMatrix booth with mom, Tehya

Along with time to socialize and meet with industry exhibitors, adults had several educational sessions to choose from including a presentation on *The Right to the Right Insurance* led by BioMatrix's Shelby Smoak, Ph.D. This program prepared participants to overcome barriers to accessing medication, reviewed patient rights, explored medication coverage challenges and presented tools to avoid a delay in therapy. The kids/teens program took place off-site at Deer Run Retreat Center in Franklin where outdoor activities such as swimming, gaga, climbing tower, giant swing and archery were enjoyed.

David and Max

Saturday evening brought several activities for attendees, including Bingo, a trivia game, arts & crafts for the kids, raffle drawings, and a blind auction where participants used THBDF "Funny Money" earned by attending sessions and visiting booths to bid on items. Additionally, a music room was available for community members to bring their musical instruments, have a jam session and relish the camaraderie of playing music together.

We welcomed many individuals and families at the BioMatrix booth to talk about what our specialty pharmacy has to offer. As an educational sponsor, we look forward to supporting this event annually!

NEW MEXICO

Felix Garcia

It's Gary versus the Saran Wrap ball

At about 5:00 pm I was beginning to feel a little restless as I usually do before hosting an event. This ***Educational Dinner*** was at Nick and Jimmy's Bar and Grill in Albuquerque June 7th. I teamed up with CSL's Amber Dobbins, who brought in community speaker Krissy to tell her remarkable story on activism. On the subject of advocacy for yourself or your child, Krissy drove home the message, "If It doesn't feel right, keep asking questions."

Bernadette tries her hand at unrolling the goodies

Following Krissy's presentation, we had a little fun. Using plastic wrap, we rolled up little knick-knacks, goodies, and BioMatrix and CSL Behring promo items into balls. In our community it's not about the prize, it's about the game and who gets to win. Laughter ensues as everyone took turns trying to unwrap the ball to win prizes. Making it even more challenging, contestants had to wear an oven mitt. Everyone won a little something and we all had a whole bunch of fun!

Dave shows Gary how to maximize prizes

NEW MEXICO

Felix Garcia

New Mexico is known for hot air balloons and a love of the arts, so BioMatrix and Octapharma teamed up June 15th to combine them for an awesomely interactive community event at ***Painting with a Twist*** in Albuquerque. The evening started with…complications, of course. Earlier in the week, I had been exposed to COVID-19 and Octapharma's Elizabeth, and I had to improvise how to proceed with our program to ensure a safe environment for everyone.

Gary and Dave channel their inner artist

Elizabeth was a great sport and picked up my slack to make this program an uplifting success! I joined via Zoom and

was able to participate from a distance. What better way to start a successful southwest event than with tacos? So on the way to the venue, Elizabeth picked up taco dinners for everyone at Garcia's Mexican Grill. Tacos were the way to loosen creative energies! The group proceeded to receive instructions on how to paint their own versions of hot air balloons against blue New Mexico skies.

This fun event allowed our community to come together and spend time relaxing, networking, getting those artistic vibes flowing and remembering that BioMatrix and partners like Octapharma are always looking to provide a great environment for everyone!


Bernadette is an artist!


Lakeia and Carla in full concentration


Arlene adds final touches to her work

OHIO

Shelia Biljes

Father's Day weekend was the perfect time to celebrate men in the bleeding disorders community of Northern Ohio. The ***Men's Event*** held June 18th at Supersonic Pinball Arcade in Cleveland closed its doors to the public as BioMatrix and HEMA Biologics co-sponsored a casual get-together that included lunch, video games, pinball and great conversation. Representing HEMA Biologics was Regional Account Manager Nick Miller who shared his story about growing up with hemophilia. BioMatrix Regional Care Coordinator Richard Vogel spoke on *Awareness for Advocacy* and led the men in a discussion over lunch. The event provided a forum for guys to get together, talk, hang out and ask questions, such as about the recommended sports for children with severe hemophilia. For grandfathers, dads and sons in attendance, this event proved to be a relaxing way to spend an afternoon!


Pinball Wizards: Carter and Ben


Team BioMatrix: Moe Hoque, Shelia Bilges and Joe Piscitello

VIRGINIA

Terry Stone and Michelle Stielper


BioMatrix booth visitors

What a day! It felt like old times, you know when people gathered under the same roof laughing, learning and enjoying being together. Well, those good ole days are back, and the Virginia Hemophilia Foundation (VHF) wasted no time to get us all together for their ***Annual Meeting*** on a warm June 25th at Glen Allen's Virginia Crossings Hotel.

It was like we never missed a beat. Friends and families just picked right up where they left off, but with news to share…babies, graduations, newly rescheduled trips promising great adventures and the like. In addition, VHF had a full day of programming to engage the group. From a panel discussion on *Keys to Effective Grassroots Advocacy* on the state and federal level to *Aging as a Person with Bleeding Disorders*, there was something for everyone. Oh, and those kids we haven't seen in a while? Well, a handful of them won VHF scholarships and are heading off to college. Hooray to all the recipients and to VHF for hosting a wonderful day of learning and togetherness!

NORTH CAROLINA

Marcy Foertstch

BioMatrix was pleased to join industry partners from several pharmaceutical companies as Gold Sponsors for the Bleeding Disorders Foundation of North Carolina's (BDFNC) ***Ultra Rare Bleeding Disorders and VWD Education Day***.


Big smiles from Regional Care Coordinators Kelly Gonzalez and Marcy Foertsch

Held June 26th virtually and in-person at UNC Friday Center in Chapel Hill, the day was filled with breakout sessions focused on patients and families affected by a platelet disorder, ultra-rare factor deficiency, or von Willebrand Disease. We were honored to have our own BioMatrix Education Specialist and Regional Care Coordinator Kelly Gonzalez present *Horses and Zebras*. Kelly spoke about the importance of advocating for yourself, partnering with your physician and building a team to ensure optimal outcomes in your care and treatment.

Thank you to BDFNC for hosting this inaugural event! We were pleased for the opportunity to spend time with the community families of this beautiful state!

DELAWARE

Tina McMullen

All aboard *Great Getaway* fishing boat for Brandywine Valley Foundation's ***2nd Annual Educational Fishing Boat Charter Event***!

BioMatrix and Octapharma sponsored the event in Lewes June 26th with special guest speaker Dr. Claudio Sandoval. While heading out to sea under bright blue skies, Dr. Sandoval spoke to the group about chronic illnesses and the health care system. BioMatrix provided lunch that included a variety of legendary "Wawa" hoagies, chips, and soft pretzels.

Lines were cast and everyone, adults and children alike, were so excited each time someone had a nibble on their hook. Baby sharks seemed to be the favorite catch-of-the-day and one flounder was caught, which amazed the children. While families fished, they socialized and got to know each other. We even saw a few dolphins!

Although there were no big catches to take home, everyone had a wonderful time on the open sea.

Thank you, Brandywine Valley President Gail Novak, Octapharma's Paul Brayshaw, and the bleeding disorders community for coming together to celebrate this spectacular day!

The Boys: Rob, John and William

Gail Novak gets fishing assistance from the charter fishing pro

Mr. Flounder

Allyson and her dad Chris stop for a photo with Robert

Victor and son Adam are patient fishermen

OHIO

Shelia Biljes

It's time to Flamingle! A group of over 50 guests wearing pink gathered June 27th at Medina's 17 Public Square to celebrate the beloved Flamingo at this all-time favorite ***Let's Flamingle Family Event*** in Northern Ohio! Of course, it was just an excuse to gather, learn and have fun. Sponsored by Novo Nordisk, local representative Judy Doyle and speaker Dr. Jennifer Domm, hematologist at Nashville Children's Hospital who, in true *flamingle* spirit, wore a shirt covered in pink flamingos, presented *Coping with Pain* with the group joining to share stories and thoughts. In addition to highlighting the importance of accurately expressing and describing pain to your physician, Dr. Domm shared several new and old techniques to deal with pain often experienced by bleeding disorders patients.

Forrest with Dr. Domm and his mom Edna

Grandma Ora with granddaughter Tiffany

Carter gets in a flamingle mood!

Pink designer cupcakes and cookies wrapped up the meal, and after the presentation, we took the opportunity to distract from pain with laughter and games, which included *Flamingo Trivia* and a round of *What's in Your Phone*.

Thank you, Judy and Dr. Domm for sharing your expertise. We had a blast!

Edna present a painting created by her son, Forrest, to Dr. Domm

OHIO

Shelia Biljes

Flowerpots, pinwheels, and iced tea marked the start of summer as women of Northern Ohio gathered for a ***Ladies Lunch*** at TGIF in Brooklyn June 28th, sponsored by Novo Nordisk. Dr. Jennifer Domm of Nashville's Children's Hospital led an interactive overview of hemophilia titled *Living Well*. With new faces joining the regulars, the ladies shared stories of their children's diagnoses and supported each other throughout the presentation. Newcomer Gloria spoke about the love of her life and his

Kitty and Gloria display their adorable rain boot planters

Jen and June find menu favorites

struggles with hemophilia. She took us back to his hospitalization just months after marrying in 1967 and spoke of their 50 years of ups and downs of life with a bleeding disorder. Young mom Stephanie conveyed her son's struggles with seclusion, and seasoned mom June expressed the challenges of her daughter obtaining a proper diagnosis. So many stories... we could have stayed and shared all day!

Novo Nordisk representative Judy Doyle recapped information about their products, and then it was game time! Group favorite *What's in Your Purse* revealed some remarkable things we stuff in our bags and forget! Proving everyone listened intently to the speaker, the ladies easily answered bleeding disorders questions during a competitive *Trivia* game.

Wrapping up the event, Edna presented Dr. Domm with a painting created by her talented son, Forrest, that will be hung on her Nashville office wall. Everyone left rejuvenated and excited about meeting again next month! Thank you to Novo Nordisk for sponsoring this delightful afternoon event!

Girl Time! (Left) Amber, Stephanie, Jen, Gloria, Deborah, Debbie, Judy, Dr. Domm, (Right) Charlene, Kelly, Cheryl, Brooklyn, Starr, June, Debra, Edna, and Kitty

NEW JERSEY

Richard Vogel and Carolina Luna

Leonardo, Marlen, Adriana and Adrian enjoy a round of mini golf

"Hot town, summer in the city, back of my neck gettin' dirty and gritty." Like most of the country, New Jersey has been in a heat wave this summer. And what's the best way to cool down but to jump in a pool! Hemophilia Association of New Jersey (HANJ) did just that July 16th for the bleeding disorders community with their *2nd Annual Summer Camp Wellness Gathering* at the Eagle's Landing Day Camp in North Brunswick. Eagle's Landing has ALL the fun one camp can offer including a beautiful 20-acre facility with 4 sparkling pools, a spray park, soccer and softball fields, 3 full-size basketball courts, a sand volleyball court, and a 9-hole mini-golf course.

Angel, Liliana, Ulises, Jaime and Diana with Carolina Luna

Larissa keeps cool!

HANJ added a special feature to this year's gathering! CSL Behring sponsored a special swim clinic presented by avid swimmer and person living with hemophilia, Tim Gams. When Tim was first diagnosed as a baby with severe hemophilia A, doctors at a hemophilia treatment center gave his mother two pieces of advice that changed his life: begin his treatment immediately and get him involved in swimming. Tim starts his clinic with 15 minutes of on-deck instruction including a brief introduction, stretches and a demonstration followed by drills and guided games in the water.

DJ Harry kicks up the beat!

***Come Together: The Intersection Between Joint Health, Hemophilia and Joint Pain*, an interactive workshop focusing on the importance of joint health for those living with hemophilia was presented by Sanofi.**

More fun took place after lunch with everyone enjoying activities from the water slide to the big water bucket. For those who wanted to stay dry and indoors, owner of Integrative Herbalism Jim Furey discussed herbs and herbal formulas used for centuries for pain and inflammation. Jim explained that some common herbs have anti-platelet properties and should be used in moderation. He also cautioned that not all herbs are recommended for persons with a bleeding disorder.

On this hot New Jersey afternoon, it was a pleasure to see all the smiling faces as we ate, played and learned together!

OHIO

Shelia Biljes

Sand, surf, sun and relaxing by the sea (or Lake Erie in this case) made for the perfect summer theme for our monthly ***Educational Lunch Meeting*** of the Northern Ohio ladies July 22nd. Seashells and buckets adorned the tables at Tony K's Bar & Grille in Berea along with mermaid tails and Margaritaville coffee samples as BioMatrix and Bayer teamed up for this event. Bayer Hemophilia Community Consultant Wendy Perkins presented *Transitioning: Guiding a Young Person with Hemophilia to Independence,* receiving wonderful feedback from the group that included several daughters of the ladies in attendance.

Kelly, Wendy and Charlene

Marie and Gloria

As the presentation wrapped up, lunch was served, and it was time for trivia and games. When quizzed with questions about Bayer products and Wendy's background, it was clear everyone had paid close attention. *What's in Your Purse* never gets old! This time we awarded points for every item in each lady's purse that matched an item in mine. I was amazed and embarrassed at a few things pulled out of my bag – 17 pens, seven packs of gum, a lone earring, a glue stick, a tape measure, six lip balms and a computer cord gadget that I have no idea how to work. Anyone still carrying a checkbook was given 10 bonus points for being on the same technological level as myself. So much fun!

Kids will be back in school soon, but these moms will continue to meet monthly to laugh and learn together. Thank you to Bayer for sponsoring this month's gathering.

FLORIDA

Marcy Foertsch and Peggy Klingmann

BioMatrix and Bayer hosted an ***Educational Dinner*** July 27th at Tampa's Brio Tuscan Grille for local bleeding disorders families. BioMatrix Education Specialist Shelby Smoak, Ph.D. presented *Safer Travels: Beyond 2022*, which focuses on safely traveling domestically and internationally with the continually changing health guidelines. He and Bayer's Hemophilia Community Executive Barbie Arrebola encouraged attendees to share stories about their travel experiences, what helped them on their journey as well as the challenges they may have faced. We thank Bayer for their continued support in sponsoring these events!

VIRGINIA

Terry Stone and Michelle Stielper

Nothing says "Summer Fun" like a day at the beach. Salty air and warm ocean breezes offered a perfect atmosphere for the Virginia Hemophilia Foundation's (VHF) ***Community Picnic*** on a beautiful July 31st Sunday. The picnic shelter at Little Island Park in Virginia Beach was abuzz with lots of conversations. I know there is plenty of sand at the beach, but BioMatrix supplied even more. We brought the colored craft kind so kids could create sand art treasures to take home and remember the day spent with VHF friends. After lunch, families lingered with one another a little longer, while some hit the beach or cast a fishing line and basked in the sunshine. We couldn't have asked for a better day to just be together. Thanks to VHF and the event sponsors for much fun with friends at the beach!

Ariana's sunny smile matched the sunny day!

OHIO

Shelia Biljes

Partnering with Octapharma and HEMA Biologics, BioMatrix hosted the ***Annual Back to School Family Event*** August 2nd at Swings-N-Things Family Fun Park in Olmsted Falls. Despite 90-degree heat, we had a perfect day as we gathered in the back pavilion shaded by giant oak trees while a breeze kept us cool.

Summer is flying by, and families are thinking about school supplies, new clothes, teachers and bus schedules. We add a few other thoughts to consider such as 504 plans, storing factor at school, medic alert bracelets and educating school staff about bleeding disorders. Over dinner, Octapharma Patient Experience Manager Bri Vieke spoke about their products and programs. Next up, HEMA Biologics National Sales Director Nicole Henry gave insightful information regarding inhibitors and their treatments.

Children then had the chance to win school supplies by identifying infusion supplies. More fun followed with go-karts, bumper boats, and mini-golf – just a few of the attractions. Guests enjoyed the fun until well after dark! Thank you to our sponsors for sponsoring this fantastic family event!

TENNESSEE

LeAnn Wilson and David Tignor

Je'Deon aims for just the right angle

Amanda Wilson, ED

Janet zooms in as LeAnn observes

Kodi smiles while mom Beverly focuses her shot

Jennifer photographs her daughter's graduation cap

Central BBQ in downtown Memphis, community members gathered August 4th for a great night of food, fun, and photography. Included as part of the *Women's Retreat* weekend, this event was hosted by the Tennessee Hemophilia & Bleeding Disorders Foundation (THBDF) and sponsored by BioMatrix and Medexus. Michael McElhaney, Territory Manager for Medexus, started things off with a lively discussion about his company's continued support of the community through programs like *Sign the 9*.

Shelby Smoak, Education Specialist for BioMatrix, launched into *Camera On: Photography and the Art of Healing*. Shelby encouraged the audience to use art as a way to help manage the stress and pain of everyday life and of a bleeding disorder. He then guided participants in a photo shoot where mobile phone cameras came out and everyone learned about camera angles, lighting and lens zoom! This dinner set the stage for what would be a great weekend at the THBDF Women's Retreat. Many thanks to the Chapter and to Medexus for joining BioMatrix in making this photography event a success!

FLORIDA

Hector Heer

Maria, Luis and son Ian enjoy playing golf!

Families had a great time August 6th at Foundation Hope and Life USA's ***Back to School Awareness*** event held at Topgolf! Everyone had a chance to hit some golf balls at this electronic driving range facility in Doral. The highlight of the event? Each child was excited to receive a brand-new backpack stuffed full of supplies to start the new school year in great form! Many thanks to Executive Director Ana Calero for all her work in organizing this fantastic event!

TENNESSEE

David Tignor

Robby, Caleb and David

Robby shoots

The ***16th Annual "Pitchin' for Caleb" Cornhole Tournament*** was held August 13th at Centennial Park in Crossville. This fundraiser led by the Wood family to honor their son, Caleb, is a fun, unique and uplifting way to raise money for Tennessee Hemophilia and Bleeding Disorder Foundation's (THBDF) Camp Freedom.

Anyone can participate, no matter your skill level! The entry fee gets you a spot to compete, a T-shirt and lunch. Teams consist of 2 players, randomly drawn. Over the many years of attending this tournament, I've gotten to know the Wood's extended family, repeat participants and newcomers. I am not an experienced player by any means, but I always have a fantastic time playing, getting pointers and hearing encouragement from the seasoned players. Lots of laughter, good sportsmanship, some stiff competition – it's a wonderful way to spend a Saturday. Of course, the opportunities to win prizes and raffles are icing on the cake!

Caleb takes aim

I believe this is a fantastic fundraiser for THBDF and am so glad BioMatrix is a sponsor. Our community benefits from the Wood family's hard work and dedication! If you enjoy cornhole and would like to participate in this annual tournament, I encourage you to keep an eye on the THBDF website, www.thbdf.org, for the *17th Annual Pitchin' for Caleb Cornhole Tournament*, which typically takes place around the second Saturday in August. I look forward to participating again next year and plan to practice between now and then!

FLORIDA

Marcy Foertsch and Peggy Klingmann

Mily Cepeda

CSL Behring and BioMatrix held an ***Educational Dinner*** August 17th at Tampa's Brio Italian Grille. Wonderful speaker, Mily Cepeda, Ph.D. spoke about her personal experiences as a Patient Advocate Caregiver with CSL Behring. Mily answered many questions and offered helpful information on bleeding disorder issues. Entertainment followed dinner in the form of a BioMatrix Trivia game with categories such as *It's in Our Blood*, *Insurance is My Jam* and *The Drug Chain*. The winning team took home Yankee Candles for relaxation after the heated competition. Many thanks to CSL Behring for partnering with us for this enjoyable event!

Save One Life: Wheels for the World

Justin and Rich's Excellent Adventure Continues...

BY RICHARD VOGEL

Justin and Rich with Chris Bombardier (center)

When we last left our heroes in 2019, pre-pandemic, Justin had completed well over 80 miles of a 62-mile "Century Ride" after getting lost in the Massachusetts countryside. I picked Justin up at Newark, NJ airport, and our adventure began. After not seeing each other in person for quite a while, our first words were, "I believe our adventure through time has taken a most serious turn. This should be most triumphant!" After two years of virtual rides, we were back on the road to Ipswich, Massachusetts, where Save One Life Executive Director Chris Bombardier led a group on a mountain bike ride on a trail through the Willowdale State Forrest.

It's broken!

This year was the 10th anniversary of Barry Haarde's first cross-country bike ride for *Save One Life*. Barry rode many miles to raise awareness and funds for the organization, and BioMatrix is proud to be a continuing sponsor of this event.

We continued our excellent adventure through NY, CT and MA - our overnight stop was in Danvers, MA, 10 minutes from our destination on Sunday, August 14th. As Kansas played on the radio, we turned to each other and exclaimed, "All we are is dust in the wind, dude." After piling on the carbs and getting a good night's rest, we drove to the start of the ride at Willowdale State Forrest.

The nature of road biking, with long, smooth stretches of tarmac and undulating climbs, means an ability to churn out mile-after-mile of long, sustained, steady-state efforts is the name of the game. The focus is on lower body strength. Mountain biking on the other hand, is the polar opposite. With rugged, off-road terrain, extreme gradients and a greater focus on bike handling, bikers need to produce short bursts of very high power. Pushing over rocks and up short, steep climbs while freewheeling down the hills and attacking the terrain requires suitable fitness. The need to jump over obstacles and control the bike on loose surfaces also places a much bigger focus on upper body strength for more of an all-round workout.

Not to go unnoticed in this event, Justin opted for breaking the mountain bike in two places while jumping a dip in the trail. His Wheels for the World legacy continues!

After 2½ hours, the riders returned with bumps and bruises from the trail but that was quickly forgotten after refreshments were served at Ipswich's True North Brewery, where camaraderie and conversation was the best medicine for aching muscles.

Save One Life is doing great work in raising public awareness about people with bleeding disorders in the developing world and providing aid in various forms. If you are not aware of the organization or their mission, I urge you to visit their website, https://saveonelife.net/

After an overnight stay at my house in New Jersey, Justin and I parted ways at the airport quoting "So-crates. "The only true wisdom consists in knowing that you know nothing."

Justin: "That's us, dude."
Me: "Oh yeah!"

Until next year's adventure, "Party on!"

Justin with Chris Bombardier Laurie Kelly

Riders line up

On the path

TENNESSEE

David Tignor

Livie's face is brightly painted!

Jimmy takes 3rd overall, 1st in his age group in 23:13.87, 7:27 pace

Murfreesboro's beautiful Gateway Island Park was the place to be August 27th for Tennessee Hemophilia & Bleeding Disorders Foundation ***4th Annual Blazin' for Bleeders 5k Run/ Fun Walk***. The 5k Run/Fun Walk helps raise bleeding disorders awareness and funds for THBDF services and programs. A delicious gelato cooled everyone off and kids enjoyed face painting. BioMatrix sponsored breakfast and coffee for participants, attendees, and volunteers and we very much look forward to supporting this fundraising event next year!

Gary and Alfonso ham it up !

J. R. Martinez

Raffle Prize Winners

Eva, Eva and Jolita

TEXAS

By Felix Garcia

Texas in the heat of August… can you think of a better place to be? Yeah, me too, but did I mention the National Hemophilia Foundation and being with members of our bleeding disorders community, HTC staff and chapter organization personnel from all over the country? Now that's the place to be no matter the temperature and that's where we were August 25-27, 2022 for ***NHF's 74th Annual Bleeding Disorder Conference*** in Houston!

Every NHF Conference has a reason for being important and standing out. This year we were back to an in-person conference, and that's celebration-worthy in itself!

In the opening session, Dawn Rotellini, NHF COO, offered tribute to her mentor, teacher, champion and friend, Val Bias. For those of you who don't know, Val was a blood brother who dedicated his life to our community. Starting as a bleeding disorders camp counselor, then director, Val continued his journey as an advocate for those with bleeding disorders, first as co-chairman of NHF's Blood Safety Working Group, then as a Washington DC lobbyist for NHF, and eventually, as NHF's CEO. He stood by our side as we made our way through the 1980s when many were affected by tainted blood products. After serving 11 years as CEO, he retired. Val was a mentor and inspiration to many of us. He passed away late last year and will be sorely missed.

Keynote speaker, J. R. Martinez kicked things off with a rousing challenge to come together and inspire one another to remember we have a choice, "adapt and overcome or be victims" of our disease state. If you're asking if that's the same J. R. Martinez from *Days of Our Lives*? Yes. From *Dancing with the Stars*? Yes, again. The US veteran injured in Iraq turned movie star and motivational speaker? Yes, yes, yes! That's the one!

The BioMatrix team was in full force throughout the event. We hope you had a chance to meet us and play our BioMatrix Jeo*Pardy* game. Did you bend the ears of Eva Kraemer or Rania Salem to share in their knowledge and experience in the bleeding disorders community? Maybe you joined us for a quick photo op and stood next to the handsome men, Justin Lindhorst and Hector Heer. Did you meet our fearless leader, Kimberly Epps? Thank you for stopping by and visiting with us. We appreciate each of you and enjoyed catching up!

On behalf of myself and that of the entire BioMatrix team, we look forward to seeing you at the next NHF Bleeding Disorder Conference!

BioMatrix Booth Team extraordinaire: Hector Heer, Felix Garcia, Rania Salem, Justin Lindhorst and Eva Kraemer

Kimberly Epps with Justin, Hector and Felix (hiding behind Justin)

Upcoming Events

OCT. 1, 2022 ILLINOIS
Unite Walk
Bleeding Disorder Alliance Illinois
312-427-1495, https://bdai.org/
Brookfield Woods Forest Preserve; Brookfield

OCT. 6, 2022 PENNSYLVANIA
Annual Meeting
Eastern Pennsylvania Bleeding Disorders Foundation, 484-445-4282
https://hemophiliasupport.org/
Sheraton Valley Forge Hotel; King of Prussia

OCT. 7–8, 2022 OHIO
Family Education Weekend Camp
Northern Ohio Hemophilia Foundation
216-834-0051, https://nohf.org/
Maumee Bay Conference Center; Maumee Bay State Park

OCT. 8, 2022 NEVADA
Unite Walk & Renee Paper Picnic
Nevada Chapter NHF
702-564-4368, https://hfnv.org/
Floyd Lamb Park, Las Vegas

OCT. 15, 2022 OHIO
Women's Retreat – A Full Day of Crafts, Food, Nature and Education!
BioMatrix with Medexus, Octapharma and Northern Ohio Hemophilia Found.
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Green Cabin Berea Metroparks; Berea

OCT. 15, 2022 VIRGINIA
Medical Symposium
VIrginia Hemophilia Foundation
804-740-8643; vahemophilia.org
Great Wolf Lodge; Williamsburg

OCT. 16, 2022 VIRGINIA
Unite for Bleeding Disorders Walk
Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Great Wolf Lodge; Williamsburg

OCT. 22, 2022 NEW MEXICO
Fall Education Event
Sangre de Oro, Inc., 505-341-9321
https://sangredeoro.org
Marriott Pyramid
Albuquerque

OCT. 23, 2022 OHIO
Cleveland Browns Watch Party
Lunch, Browns game, kids activities
BioMatrix and Bayer
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Brew Garden
Strongsville

OCT. 29, 2022 FLORIDA
Creepy Crawl Fun Walk or 5K
Hemophilia Foundation of Greater Florida, 800-293-6527
hemophiliaflorida.org
Harber Park at Baldwin Park
Orlando

NOV. 4–5, 2022 OHIO
Annual Meeting
Northern Ohio Hemophilia Foundation
216-834-0051, https://nohf.org/
Drawing to Heal will be presented by BioMatrix on Nov. 5th
Kalahari Conference Center; Sandusky

NOV. 9, 2022 ZOOM!
Feed Mind & Body with Chef Mike!
Cooking Demonstration
To Register: https://bit.ly/chefmike-119
Contact: Rania Salem, 513-470-5500
rania.salem@biomatrixsprx.com
or Eva Kraemer, 608-852-3777
eva.kraemer@biomatrixsprx.com

Nov. 17, 2022 FLORIDA
Educational Dinner and Trivia Game!
BioMatrix and CSL Behring
Contact: Marcy Foertsch, 941-518-7063
marcy.foertsch@biomatrixsprx.com
Cooper's Hawk Winery; Tampa

DEC. 2–4, 2022 MAINE
Winterfest
Hemophilia Alliance of Maine
207-631-7550, www.mainehemophilia.org
Samoset Resort; Rockport

DEC. 3, 2022 OHIO
Holiday Event
Lunch, crafts and fishies!
Northern Ohio Hemophilia Foundation
216-834-0051, https://nohf.org/
Greater Cleveland Aquarium

DEC. 4, 2022 PENNSYLVANIA
Annual Meeting & Luncheon
Brandywine Valley Hemophilia Found.
www.brandywinehemophilia.org,
info@brandywinehemophilia.org
Mendenhall Inn; Mendenhall

DEC. 8, 2022 FLORIDA
Insurance Basics Educational Dinner
BioMatrix and Bayer
Contact: Marcy Foertsch, 941-518-7063
marcy.foertsch@biomatrixsprx.com
400 Beach Seafood & Tap House; St. Petersburg

DEC. 17, 2022 DELAWARE
Education and Holiday Cookies
Brandywine Valley Hemophilia Found. with NovoNordisk and BioMatrix
www.brandywinehemophilia.org,
info@brandywinehemophilia.org
Mazzella's; Wilmington

Time for Fun!

Puzzles on Page 35

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

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

1. **TRUE** – Hemophilia is a rare blood clotting disorder that makes it harder for a person's blood to clot properly.
2. **TRUE** – Factor 8 and 9 are the two most common types of hemophilia.
3. **FALSE** – Approximately 80% have Factor 8 deficiency, while 20% have Factor 9 deficiency.
4. **FALSE** – Although boys are most often affected, girls can also have symptoms and require the same treatments.
5. **FALSE** – Hemophilia is a lifelong disorder. No one will "outgrow" it.
6. **TRUE** – Severity level is based on how much clotting factor is made by the patient's body.
7. **FALSE** – If a patient suspects he or she is having a bleeding episode, it **should** be treated promptly.
8. **FALSE** – Hemophilia is the deficiency of a protein, not of a vitamin.

Time for Fun!

Hi Kids!

Let's see how much you know about bleeding disorders. Circle TRUE or FALSE next to each question, then check your answers on page 34. Good luck!

1. Hemophilia is a rare disorder that makes it harder for a person's blood to clot properly.	**TRUE**	**FALSE**
2. Factor 8 and Factor 9 are the two most common types of hemophilia.	**TRUE**	**FALSE**
3. Of hemophilia patients, 50% have Factor 8 deficiency and 50% have Factor 9 deficiency.	**TRUE**	**FALSE**
4. Only boys can have hemophilia.	**TRUE**	**FALSE**
5. Boys will outgrow their hemophilia by age 25. Girls will outgrow it by age 15.	**TRUE**	**FALSE**
6. Hemophilia is classified as *severe*, *moderate* or *mild*.	**TRUE**	**FALSE**
7. "When in doubt, infuse" is advise that *should* be *ignored*.	**TRUE**	**FALSE**
8. Having hemophilia means you're just missing some vitamins in your body.	**TRUE**	**FALSE**

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

Sudoku!

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

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

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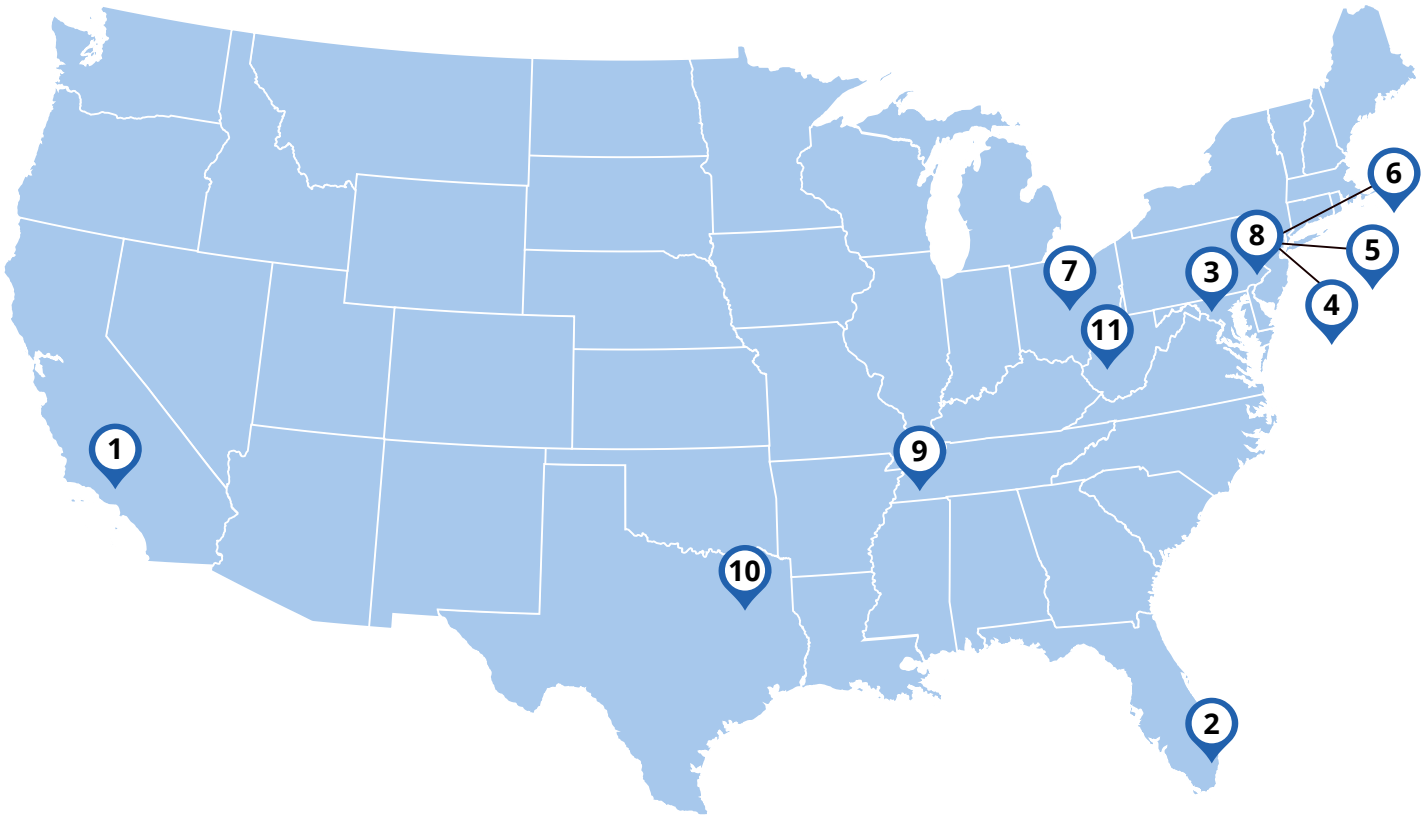

Specialty Pharmacies

1. Canoga Park, California
2. Plantation, Florida
3. Columbia, Maryland
4. Totowa, New Jersey
5. Totowa, New Jersey (Reproductive)
6. New York, New York
7. Dublin, Ohio
8. Garnet Valley, Pennsylvania
9. Bartlett, Tennessee
10. Tyler, Texas
11. Charleston, West Virginia

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BD002 10/22