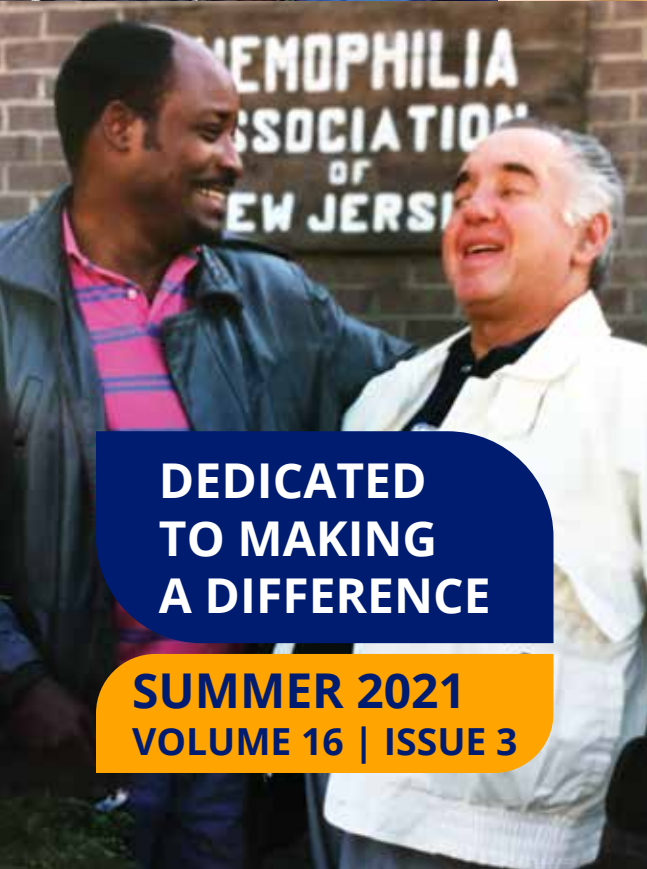


BIOMATRIX

NEWS



DEDICATED
TO MAKING
A DIFFERENCE

SUMMER 2021
VOLUME 16 | ISSUE 3

“ May you *live* all the days
of your life. — Jonathan Swift ”

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.

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TABLE OF CONTENTS

Page 4

ADJUSTMENTS-ADAPTATIONS-TRANSFORMATIONS: CHANGES

Page 8

DISABILITY HAPPENS

Page 12

HEMOPHILIA ASSOCIATION OF MAINE MEETING THE NEEDS OF RURAL MAINE

Page 15

A LETTER TO MY 13-YEAR-OLD SELF

Page 18

"NEW KNEE OR NO NEW KNEE" THAT WAS ONCE THE QUESTION!

Page 20

MEET THE TEAM - JOHN MARTINEZ, RCC

Page 23

BIOMATRIX ON THE VIRTUAL / IN-PERSON MOVE!

Page 26

UPCOMING EVENTS

Page 27

TIME FOR FUN!



A NOTE FROM THE EDITOR

Dear Readers:

How is this year already half over? I suppose I was so busy planting my gardens in between Zoom meetings that spring managed to pass me by. I wish the days would slow down!

Though many continue to take precautions as our society begins to transition back to "normal," it does give me hope for the days to come as live, in-person events begin to dot our calendars. Since being vaccinated, I found it easy to shed the face mask, but it's going to be a while before I quit washing my hands like I'm a doctor about to perform surgery.

This latest issue of BioMatrix News has a little of everything - starting with a great article about change and how to help growing children rise to the challenge of taking responsibility for their bleeding disorder. *A Letter to My 13-Year-Old Self* creatively takes us back in time as an adult man living with hemophilia writes to his thirteen-year-old self. The letter provides deeply personal

insight into what it was like growing up in a different era of bleeding disorder treatment while providing a hopeful outlook for our future.

Another article includes experience from one man's knee replacements while our featured chapter this issue is Hemophilia Alliance of Maine. Our last article introduces John Martinez, BioMatrix Regional Care Coordinator in Northern California.

Finally, for those of you who have children packing up to attend in-person camp this summer, please ask them to journal about their experience. We would love to feature their stories in a future issue of BioMatrix News!

Have a wonderful summer!

Maria Santucci Vetter
Editor-in-Chief, *BioMatrix News*
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ADJUSTMENTS ADAPTATIONS TRANSFORMATIONS

Changes

By Judy Kauffman, RN, MS, CPNP

It's a fact. Life is full of changes, something many of us struggle with. Moving, adjusting to new jobs, schools and neighborhoods can cause stress. Finding new doctors, dentists, and even making our way around a new grocery store can add angst. Many will wonder, "Is this a good change? Will we be happy with the new home/job/school? Will this cause a setback? Did we make a mistake?"

We are allowed choice about many changes in our lives; however, many are forced upon us by circumstances beyond our control. Aging, illness, finances, and the needs of other people are just a few. Adjustments we do not freely choose are most often the hardest to which to adapt. Changes, especially unexpected ones, can affect our emotional, physical, intellectual, and psychological health.¹

The bleeding disorders world has its own challenging sets of circumstances that eventually require adaptation. Just the initial diagnosis of a bleeding disorder in a child requires a new mindset as well as the learning of a new vocabulary and incorporating an unfamiliar medical regimen. This is often accompanied by sorrow and fear as our hopes and dreams get realigned.

What about when your child's provider suggests a switch to prophylactic factor treatment? Your initial response might be colored by anxiety as you imagine so many scheduled infusions. Then, it may be suggested that you consider having a port placed to make infusions easier. Not only will your child need surgery to place the port, but you will need to learn the complicated sterile procedure for port access and infusion. Later, someone is going to suggest removing the port and for you and/or your child to start infusing peripherally. Though it's a scary change, it can provide a great benefit to all involved.

As a Hemophilia Treatment Center nurse, I help patients and families manage many of these changes. I have found that while making adjustments may lead to fear and anxiety in the short term, with support and education, changes can take place and be very positive in the life of the patient and family. Very often navigating through transition leads to personal growth, leaving us stronger than before. Even unexpected and difficult changes can produce some beneficial outcomes.

Throughout the upcoming years, there will be many more reasons for life modifications that you and your family member with a bleeding disorder will face. With some thoughtfulness and anticipation, change can be managed to result in the least amount of sudden disruption possible.

Acknowledge change needs to happen.

Sometimes we get so caught up in fighting change that we actually put it off instead of dealing with it. Denial is a powerful force and it protects us in many ways; however, stepping outside of it and saying to yourself, “Things are changing, and it’s okay” can be less stressful than putting it off. In this initial phase, researching all aspects of an impending change can make a big difference. Having knowledge gives us more control over the situation and more confidence when making decisions.ⁱⁱ

Realize even “good change” can cause stress.

We often think only negative situations cause stress but getting married, moving to a bigger house, or having a baby are all happy, positive life events, but stress and tension will still accompany them. Stress is our body’s way of reacting to change, good or bad. Expect it and give yourself some grace in adapting to the circumstances.

Practice self-care.

Keep a schedule that is as routine as possible - regular sleep, eat healthy foods and exercise 3-4 times each week. These measures will help you manage stress and anxiety.ⁱⁱⁱ

Seek support!

Allow trusted friends and family members to help you. It is okay to ask for help! Let a dependable person provide a couple of hours of childcare to give you time to go shopping, take a walk, or just relax in the bathtub. Even short breaks can rejuvenate you and help you manage stress.

Vent, but not on social media!

It might be a good idea to take a break from social media during times of change and stress. Instead, talk with trusted friends, family or clergy. Reliable people can help you to look outward and come to terms with what needs to happen.

Finally, give yourself a break.

In a time of change, you may feel a little out of control. You may feel like you are not living up to your self-imposed expectations. Remember, you are allowed to do less than what is humanly possible. Nothing says you have to function at 100 percent all the time.

One of the great things about being human is that you are allowed to make mistakes. It’s learning from the mistake that counts. Make a point to incorporate more laughter and fun into your life. Laughing is nature’s mood regulator – it increases dopamine, serotonin, and endorphins that can help you feel better.^{iv}

Keep in mind that your children learn from you. Make every effort to demonstrate resiliency and adaptability with good grace since your kids are watching and absorbing what they witness. It’s not necessary to hide your struggles with change. Acknowledge you’re having a hard time but that you expect to make the necessary modifications to see a situation through. I love the phrase “hard is not the same as bad.” In my house, we repeated those words often, especially when having to adapt to something new.

Let’s discuss some specific changes you might encounter in your life with bleeding disorders:

Your provider suggests a new medication or treatment protocol such as starting prophylaxis, having a port placed or removed, or starting a new treatment product that is very different than what you have previously used.

This is an exciting time in the bleeding disorder world in that there are many new products and treatment plans in development. It’s great to have choices, but it can often feel as though they are coming too fast! However, just because medical advances and new protocols are coming along quickly, it doesn’t mean you are forced to accept them all immediately.

It’s okay to take a deep breath and spend time thinking before making decisions. Use this time to research the new product or treatment and learn all you can. Ask many questions! Ask your providers to help you contact others who have made this change and get their input. And after you’ve spent this time researching and learning, it is perfectly okay to take whatever time is needed to go over the pros and cons of the suggested treatment.



You may need to change hemophilia treatment centers due to relocation or you've come to realize the one you're using isn't meeting your needs.

This change can be very nerve-wracking. Research the available hemophilia teams in your area. The CDC website has a great directory for HTC's. Find it online at <https://www.cdc.gov/ncbddd/hemophilia/htc.html>. Call the center(s) and ask questions. Ask others in your area about their experiences with particular HTC's.

Your first visit to a new HTC may seem strange. Keep in mind every center operates uniquely. The new team may do some things in a familiar way and others completely differently. Give the personnel at the new center time to prove themselves. Remind yourself that different isn't necessarily bad, it's just different.

Sometimes the new provider will suggest a completely new treatment plan for you or your child. It's okay to ask questions and express concerns if the proposed plan feels uncomfortable to you. It's also okay to not accept a proposed change and to ask for more time before making a decision. It's okay to say, "I need some time to think this over. For now, I want to leave things as they are."

One of the biggest changes is the transition for your child from pediatric to adult care. This happens at about 18-21 years old. This is not one change, but many, that should take place thoughtfully over time.

Some HTC's see children and adults in the same clinic setting with the same team members providing care to all patients. Some centers may have different doctors and nurses set up at different locations but share a physical therapist and social worker. Sometimes a young person transitioning into adulthood must go to a completely different center with all brand-new people to find the care appropriate for his or her age.

Whatever model is found in your center, please know that there are more differences to be found between pediatric care and adult care than just location or doctor. The philosophy of care changes with the move to an adult clinic. I once heard a speaker describe the difference as "Pediatric care is comfort care and adult care is cognitive care." I believe we can bring comfort to the adult setting and cognitive care to the parents of pediatric patients.



The shift to adult care is one that parents can help prepare their child and direct them forward.

The term "cognitive care" is a phrase that denotes thinking and becoming knowledgeable about a subject and increased decision-making. In an adult HTC, your young adult will be expected to begin making decisions about his or her care. Prepare your child by helping him or her develop decision-making skills throughout their childhood.

Helping your child as he or she matures through adolescence to adulthood can be stressful.

Decision-making should be part of their lives from the earliest years. We can't give a 3-year-old choice over bedtime or dinner time; however, we can offer 2 reasonable choices and invite the child to decide. As he or she ages, the choices should become more complex and more meaningful. The child learns to consider the options and make the choice that they desire. They also learn to live with their choices, as well as to adapt to the consequences of their choices if needed.

Help your child become an accountable young person by giving them increasing responsibility in the home and family life. Assigning increasingly complex chores as they age teaches them that they have an important role in the family and ultimately in the world. When we do everything for our kids, we are indirectly teaching them their contribution doesn't count.^v

As your child grows, speak with him or her about their bleeding disorder. Do it in a positive and age-appropriate way. Having been a preschool teacher many years ago, I learned the maxim that explanations to children should contain 1 word for each year of the child's life. That means that we should use 3-word descriptions for a 3-year-old and 4 words for a 4-year-old. It can take some thought to come up with short explanations, but it avoids having the child lose attentiveness as you talk. Of course, the teaching you do will contain more words the older the child becomes.

During the early years, your child should learn to say the name of their bleeding disorder and if it is mild, moderate, or severe. They should learn to name their treatment product. Your very young child will not be able to recite dose and frequency, but this can be added as the child matures. Your child should learn to inventory their factor and infusion supplies with you. A parent can make up a checklist for their child to use to determine what items are needed. The natural next step would be allowing your child to make the call to their pharmacy to order what they need (a parent should remain nearby or on the line with their child while they are learning this task).

Learning self-infusion is a huge achievement in the life of a child with a bleeding disorder, and it leads to large gains in self-care ability. If your child receives regular infusions to prevent bleeding (prophylaxis) or is infused on-demand,

they should be involved in the infusion process. The youngest child can take their factor and supplies out and set up the infusion area. Later, they can learn to mix the product, then draw it up.



A big step in self-infusion is learning to identify a vein. Help your child become familiar with his/her veins. NEVER tell a child with a bleeding disorder that he or she has “no veins” or “terrible veins.” If veins are difficult to find or access, explain they will get bigger and easier to access as the child grows. It is okay to say, “Your veins are hiding today. We’ll keep looking to see where they’ve gone.”

Allowing your child to attend a bleeding disorders camp will have several benefits including learning he or she is not alone in having a bleeding disorder and in needing infusions. Your child will see other kids infusing and will learn from them. This is one time when peer pressure is a positive thing - many kids learn to infuse at camp because their friends are doing it! Self-confidence is gained when a child learns they can manage their infusions.

Talk to your child about what you have learned at a clinic visit or what you have researched about new treatment protocols and medications. Gradually, and as they are capable of handling it, the responsibility for their bleeding



disorder care should be transferred to him or her. This will happen at different ages for different children. Use your judgment for these transitions but keep an open mind and consider reaching out to others who may have recently gone through this process.

Transitioning to adult medical care should not mean your young adult must handle everything entirely on his or her own. Make it clear you have many years of experience in managing a bleeding disorder (theirs) and you are still available to help and give advice but that you have trust in their ability to take over their medical care. Ask questions about how they are feeling and if they would like some input or suggestions from you, but do not criticize their handling of things. They will learn, sometimes through trial and error!

Helping your child as he or she matures through adolescence to adulthood can be stressful. This transition involves many adaptations, some unexpected, for both parents and child. You can use some of the tips in this article and apply them to other sudden adaptations. A really great resource for learning about and helping your child with healthcare transition is www.gottransition.org.

Don't forget... ask for help! Trusted friends and family members as well as your hemophilia team can be a great resource to support you and your loved ones throughout all of life's changes!

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ABOUT JUDY KAUFFMAN RN, MS, CPNP

Judy Kauffman is an advanced nurse practitioner specializing in bleeding disorders. A former kindergarten teacher, she earned a Master's in Nursing from Georgia State University and serves as Hemophilia Nurse Coordinator at UC Davis Hemostasis and Thrombosis Center in Sacramento, CA. Judy has also worked as a Pediatric Hematology/Oncology Nurse at Emory University's Children's Healthcare of Atlanta, GA, as a Pediatric Nurse Practitioner at Children's Mercy Hospital HTC in Kansas City, MO, and as a Clinical Support Specialist with a hemophilia pharmaceutical providing education to patients, families, medical providers, and 3rd party payors



Judy has spoken nationally and internationally, served on committees with NHF and Maternal Child Health Bureau Nurse Working Group for Region 7 and the Great Plains Region, has been instrumental in developing research projects, and has written journal articles. Her passion is teaching others about bleeding disorders so they can live their best lives!



Social Security Benefits Application

Part One - General Information

Last Name:

First Name:

Date:

DISABILITY HAPPENS SOCIAL SECURITY DISABILITY (SSDI)

BY SHELBY SMOAK, Ph.D.

Unfortunately, a life with hemophilia may become a life with a resulting disability. This was almost a certainty before modern-day therapies due to the crippling joint damage of long-term hemophilia.

Today, however, it may be something that one faces as a temporary necessity, perhaps after joint replacement surgery, as was the case with me when I had to have a total hip replacement and was unable to work for a year. Or perhaps, hemophilia having done its damage, the need for filing for disability may be more permanent. In either scenario, it's best to know a few primers about disability and be prepared for the possibility. None of us, I believe, really want to declare ourselves disabled, but when we cannot work because of our hemophilia, we may have to lean into Social Security disability benefits for our health and our life.

What is SSDI?

SSDI provides assistance to persons with disabilities. SSDI will pay benefits to you and certain family members if you are "insured," meaning you worked long enough and paid Social Security taxes. SSDI recipients also become Medicare eligible after a 24-month waiting period.

Can I apply for SSDI?

SSDI: Apply if your condition has worsened, and you expect your medical condition to last a full year or longer.

I say: Bleeding disorders don't necessarily "worsen," but the resulting arthropathy and joint damage does, so if you are facing disability as a result of a bleeding disorder, you are likely experiencing the effects of the bleeding disorder "worsening" (arthropathy), but not necessarily the bleeding disorder itself. Therefore, your application for disability will need to involve the hematologist and an orthopedist who

in tandem can verify your situation.

When I applied for disability, my hematologist provided the bleeding disorder verification and necessary lab work, and the orthopedist sent the reports and assessments about my joint damage that became more valuable within the process than the hematologist's.

SSDI: Apply if your condition is severe enough that it keeps you from doing a substantial amount of work.

I say: In some cases, developing an inhibitor might trigger the need for disability in which case the bleeding disorder itself would be the cause of an inability to work. In other cases, the condition keeping you from working may instead be joint damage. These become important distinctions you will need to understand in your application process.

Keep in mind, employees at the Social Security Administration may not have an intimate knowledge of a bleeding disorder and/or understand its long-term effects. If joint degradation is the cause of your inability to work, keeping a steady emphasis on joint damage will help your interviewer better understand your situation. An inability to walk without assistance would keep you from working but having a lifetime of knee bleeds would not necessarily lead someone to draw the same conclusion. Moreover, in my application process, when I continually referenced my hematologist and my bleeding disorder it confused the interviewer since I was facing orthopedic hip surgery and NOT a pending bleeding disorder issue. Nearly all of the interviewer's questions were about the orthopedist's notes.

SSDI: Apply if you have worked 5 of the last 10 years and paid into Social Security.

I say: Past work is a requirement of receiving SSDI. It varies on how Social Security may assess your past work experience, but it is necessary. Your jobs pay into Social Security, making you eligible for those benefits. If you haven't worked and therefore not paid into Social Security, you would be ineligible for benefits. If you are facing a disability and you have not worked and paid into Social Security, Supplemental Security Income (SSI) may be an option.

SSDI: Do not apply if your doctor doesn't believe your condition will prevent you from working.

I say: Full support of all your physician(s), especially your hematologist and/or orthopedist is essential to the process.

SSDI: Do not apply if your condition is expected to be temporary (a year or less).

I say: This was a bit complicated for me as I was facing surgery which would see me recover in about a year and would, therefore, be *temporary*; yet I had no way to support myself financially during that time. Short and long-term insurance policies were not offered through my employer and were cost-prohibitive due to my HIV and hepatitis C. I was caught in a tough spot, but working with my physicians and the HTC social worker, I applied.

In my application, the orthopedist included evidence of ALL my joint damage, which became important in explaining the disability as lasting longer than a year. If the orthopedist had only sent evidence of my hip's joint damage, the case may have never been approved since it was understood that the joint was being replaced and would, ostensibly, end any disability I had due to the hip. It then became important to show the compounded impact of damage to multiple weight-bearing joints. This is how the approval was finally given. I only received SSDI for the year which it was needed. Once my joint was replaced and I was able to return to work, my disability claim ended.

SSDI: Do not apply if you are able to earn more than \$1310/mo.



SSDI: Do not apply if you haven't worked enough to be eligible for benefits.

I say: Both statements are as declared. In my case, I had been a full-time teacher for many years before my application and was eligible.

What additional criteria must be met to be eligible for SSDI?

SSDI: You must have a definitive lab test establishing your bleeding disorder and/or a physician signed report testifying to your condition.

I say: Simply having a bleeding disorder does not qualify someone for SSDI, but having proof of a bleeding disorder diagnosis is essential in the application process.

SSDI: For determining a disability, you must have had bleeding/clotting complications requiring at least 3 hospitalizations in the last 12 months. Further, the hospitalizations must have been at least 48 hours (which may include time spent in the ER) and be at least 30 days apart.ⁱ

I say: Remember, these criteria speak to the bleeding disorder only and would be relevant to cases like inhibitors and/or specific bleeding complications. My application - and most of those with hemophilia - would be a result of arthropathy and joint damage as the disability cause. These criteria will likely take precedent over your bleeding disorder. In fact, according to the CDC, arthritis is the most common cause of disability among adults; arthritis is a form of arthropathy or joint disease, and many physicians use the two terms interchangeably.ⁱⁱ

SSDI: If your bleeding is relatively controlled and you do not meet the above criteria, you may be eligible based upon other factors, noted as "repeated complications of



hematological disorders.”ⁱⁱⁱ A person would need to show severe limitations in one of the following: performing daily living activities, maintaining social functioning, or completing tasks in a timely manner because of problems of pace, persistence, or focus.

I say: Today, many people with bleeding disorders are on prophylaxis regimens to control their bleeding, so it seems SSDI is opening the door to the arthropathy (“repeated complications”) that would make someone eligible for disability. There may be other situations as a result of having a bleeding disorder such as repeated brain bleeds, which may impair cognition and/or motor function.

Any delays with paperwork, callbacks, and appointments will only lengthen the time to process your application.

SSDI: Social Security will determine if you are unable to return to any of your past jobs or any other jobs based on your age, education, work experience, and functional limitations caused by your bleeding disorder.

I say: Social Security may investigate your work opportunities and determine if you are indeed unable to continue in your present job or find another type of work. At the time of my application, I was a teacher and my daily presence in the classroom was required, something I could not physically do. This was before online classes and Zoom, so the physical demands of my job and the limitations of my arthropathy prevented work. However, in today’s world of online classes, there may have been other work opportunities I could have pursued, and which may have prevented a disability approval. But that is only speculation. Others have shared that having to rely on crutches or having to use a splint several times a month turned out to be the reason a disability judge finally approved the application.

What are the SSDI benefits?

SSDI: Typically, SSDI provides a monthly check based on age, income, number of years worked, and projected retirement date, paying about 40% of pre-retirement income. The average monthly benefit for disabled workers is \$1258 in 2020.^{iv} After 24 months, you will be eligible for Medicare.

I say: My prior year pay stubs were provided, which were then averaged and equaled about 40% of that total income. It’s important to know the amount is not simply based on your last paycheck but the year. If you changed jobs within the year with significant salary differences, consider the average as you work out your budget.

You will need to secure insurance while waiting for Medicare. Ending work is considered a qualifying life event for eligibility for an ACA plan. You would also likely be eligible for subsidies to help pay for the insurance, especially if you were now out of work, too.

How long does it take to receive SSDI benefits?

SSDI: It will take 3-5 months to get an initial decision.

I say: It takes a long time. Plan for about a year before approval and then benefits to be received. My approval took 10 months; however, I was exceedingly organized. My paperwork was sent within a day. I communicated immediately with all my physicians and pressed them to submit required reports and signatures, and I was prompt in scheduling my interview and follow-up meetings with Social Security. Even with that, my initial application was denied. I appealed, which added time.

In the appeal, Social Security requested an additional set of x-rays from their approved radiology center. I called immediately and still had to wait several weeks before the appointment. Once these x-rays were completed, it still took another 3 months before the approval arrived. Social Security may also ask you to schedule appointments with their doctors who may have limited knowledge of bleeding disorders. Any delays with paperwork, callbacks, and appointments will only lengthen the time to process your application.

What are the top reasons SSDI claims are denied?

- Lack of hard medical evidence. Doctor’s notes, medical records, exam notes, and test results are vital.
- Prior denial. Restarting a new claim for the same condition does not work. Appeal the original denial.
- Your income. If you are working and earning more than \$1310 a month, you may get denied.
- Failure to follow treatment.
- Failure to cooperate. The requested paperwork must be provided, and you must show up for medical exams.



What should I do if my SSDI claim is denied?

- Appeal the denied claim. Do not restart a claim. This will only add time and confusion to the process. My initial application was denied. I appealed that claim and was eventually approved.
- Do not become discouraged. I have heard from others that the process can take even up to 2 years and that an initial denial seems to be part of the process.
- If a second denial is received, consider contacting an advocacy organization familiar with Social Security disability or an attorney to help further your case. Patient Services Inc. (PSI) deals with many bleeding disorders-related SSDI cases and is available to the bleeding disorders community.

How will I earn income while waiting on SSDI?

This is tough to answer because these are unusually difficult times; in addition to the health complications, financial obligations can intensify the stress of this change. Having short-term and long-term disability insurance policies are meant to serve as buffers during these periods. Outside of that, your income options are limited, especially if you do not have substantial savings to fall back on.

Can I earn money while on SSDI?

Yes. The Ticket to Work program helps the disabled get back to work. Beneficiaries can work a 9-month trial period and receive full benefits. You may receive benefits in any

month you earn less than \$1260 (2020 figure). If you earn more than that, benefits will end.

How long may I receive SSDI benefits?

SSDI benefits will be received as long as you are disabled and unable to work. At retirement age, benefits won't stop. The name changes from "disability benefits" to "retirement benefits" but the amount remains the same.

Hopefully, many questions regarding Social Security Disability (SSDI) have been answered. Traveling the path to applying for SSDI is often difficult, physically and emotionally. Please feel free to reach out to education@biomatrixsprx.com with your questions.

In our fall issue of BioMatrix News, we will examine the topic of short and long-term disability. Stay tuned!

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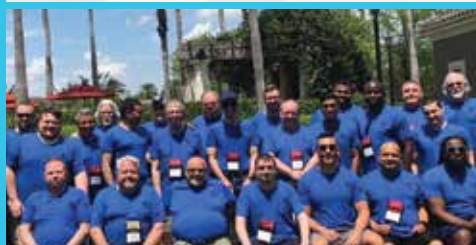
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HEMOPHILIA ALLIANCE OF MAINE



THE HEMOPHILIA
ALLIANCE OF MAINE
FOR ALL BLEEDING DISORDERS

Meeting the Needs of Rural Maine: Deeply Understanding the Importance of Tenacity, Commitment, and Connection

BY TRACEY GIDEON

The Hemophilia Alliance of Maine (HAM) is one of many bleeding disorders chapters in the United States. Small but mighty, it serves patients and families living in Maine - its rural cities, towns and villages - covering just over 35,000 square miles. Ours is the chapter no one thought would, or could succeed, but 10 years later, we are stronger than ever, and we continue to make sure no one feels left out or alone.

Incorporated in 2011, HAM has worked diligently to serve the community through educating, advocating, supporting and assisting individuals and families of Maine living with hemophilia, von Willebrand disease and other bleeding disorders. We are firmly resolved to continue providing this support.

It was 2009 when Jill Packard and I met at the Maine Bleeding Disorders Center in Bangor, Maine (now located in Brewer). Although it wasn't clear at the time, we were going to be the co-founders of the Hemophilia Alliance of Maine, we recognized within moments of meeting how important we would be to each other. We were two moms of children affected by a bleeding disorder, we both lived in a rural state, and we both felt we didn't have the support we needed. Little did we know how impactful our meeting would become for others just like us in the Maine bleeding disorders community.

Our second meeting at Family Camp in New Hampshire was brief, direct and resolute. Demonstrating the importance of tenacity, commitment and connection, we spoke about five sentences to each other. Summed up, we said, "People in Maine need more... are we going to do this? Yes, we are... and no matter what, let's always be honest with each other and have faith." We recognized we were 'Mainers,' people who deeply value the same things - commitment, connection and hard work, and we were meant to make a difference.

You'll hear from many organizations within the bleeding disorders community that the most important meetings often happen at a kitchen table. In many homes, the kitchen table is the



Justin Levesque and his gang of cow kids:
Cabe, Korbin, Joey, Quinn and Devin

place where we break bread, where we have difficult conversations and where we celebrate triumphs. It's no different for HAM. It was at a small, quiet table that we dug deep and built an organization that recognized the people from our state who were feeling disconnected from each other and the larger bleeding disorders community.

With many obstacles in the beginning, it took a few years to establish the organization. First, the medical community and the greater bleeding disorders nonprofit community didn't fully understand the needs of the rural state. At the time, the nearest community meetings were in Massachusetts. A minimum one-hour drive for some Mainers, with many having to travel up to 6 hours to attend!

Additional challenges presented themselves when living in a place where it gets dark at 3:30 in the afternoon, one can see up to four feet of snow for months on end, and the power goes out just about every time the wind blows. Distance made it difficult for the two of us to get together, plus we both had very young children – yes, it was difficult! With the demands of raising families and the physical distance between us, the formation of the chapter was and continues to be a labor of love.

In 2010, after a year of clearing the way, planning programs, and establishing a cooperative meeting model, we ambitiously assumed the roles of Jill as President and myself as Treasurer. A good friend, Ashley Bean, took on the role of Secretary. Others quickly stepped up to support our fledgling organization with their ongoing support, strong voices, passion and commitment. A year later, HAM took its next big leap when Justin Levesque, Lianne Lapierre and Brandi Cullen joined the board.

Fundraising and program development were the areas we tackled first. The primary programs addressed the most



Looking back in time: HAM's early Board Members Vicki Jacobs-Pratt, Justin Levesque, Jill Packard, Tracey Gideon, Brandi Cullen, Lianne Lapierre and Victoria Kuhn.

pressing issues. At the forefront were Hemophilia 101 and self-infusion instruction. Community driven, the programs were identified through surveys supported by the hemophilia treatment center based in Portland. The Bleeding Disorders Center of Maine is, on average, a 4-hour drive for many of its patients. Satellite clinics are now held at the Lafayette Family Cancer Institute in Brewer, reducing the extensive drive for many patients.

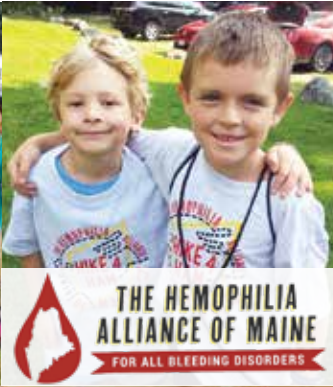


Early events were well attended - *Family Dance, Stick and Swim, Hill Days, and Grandparents Gathering* made fantastic debuts. Diving with determination into advocacy, HAM took on greater responsibility with the inauguration of *Winterfest*, a large annual event, introducing *Hike4HAM* (now the *Unite Hike* as part of NHF's *Unite Walk* program), and creating a stronger national presence via our website and social media.





Victoria Kuhn & James Boutin 2016



Terry Rice rings the start of Hike 4HAM 2017



Winterfest 2016

HAM advanced its progress in 2013 with the addition of Victoria Kuhn to the board. She fueled the organization's commitment to longevity. Subsequently, HAM hired its first paid employee, Executive Director Vicki Jacobs Pratt. A committed nonprofit development professional, Vicki and the board ensured the future sustainability of the organization. Not much later, HAM was blessed with the addition of Janice Yorke and Terry Rice who drove HAM to embrace change and inspired the strength to amplify our voices.

Utilizing a network of dedicated volunteers, HAM launched PIGLET (People Interested Grassroots Local Engagement Together), a unique outreach program comprised of local sub-chapters based on geographic location. Through PIGLET, HAM facilitates meetings and educational programming for small groups of members within their own communities. These groups provide a significantly higher level of access to education throughout the state.

HAM's greatest accomplishment is the work done through shared leadership and deep collaboration. By emphasizing our small but mighty approach and deeply valuing our partners, we have found our most success in saying YES to opportunity. Much of our work is done in collaboration with other New England chapters, as well as our care provider partners and national partners.

Today, we hold several events throughout the year to meet the needs of our regional and statewide populations. June

18th was our 10th anniversary and we celebrated with a virtual birthday party; however, we really look forward to meeting with families at our annual Unite Hike for Bleeding Disorders - our first in-person event in over a year and a half coming in September!

At an event several years ago, one grateful mom expressed, "We sometimes get so wrapped up with the woes of hemophilia. We need to keep in mind how far we have come, treatment, education and the resources we have available. We also need to remind ourselves that as caregivers we aren't giving 100% to our affected loved ones if we aren't also caring for ourselves. We are so grateful to have HAM for these connections and education to remind us we aren't alone. It is comforting."

Contact info@mainehemophilia.org, 207-631-7550
mainehemophilia.org

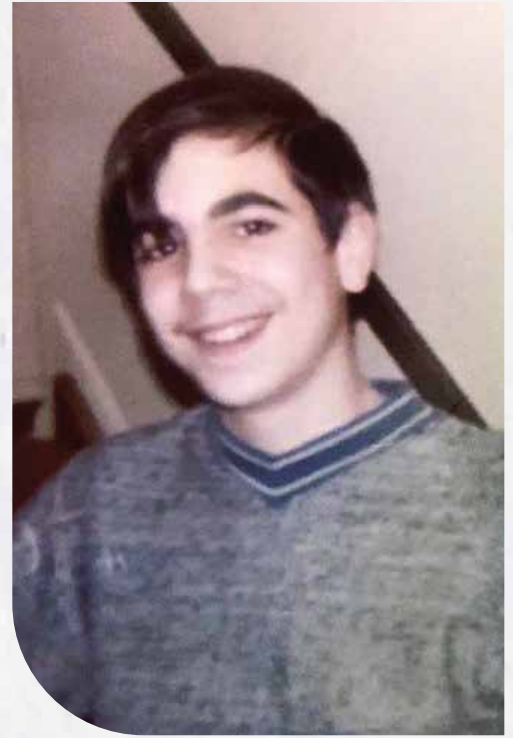


Would you like to have your chapter featured in BioMatrix News? We would love to learn all about you! Contact your Regional Care Coordinator for more information or email us at info@biomatrixsprx.com.

A LETTER TO MY 13-YEAR-OLD SELF

BY RICHARD VOGEL

Life is an unknown. And that's what makes living it so special. Having a bleeding disorder makes it twice as difficult. What if we had some insight into our future? Not that we could change our life but to encourage us when moments look dark. As a 65-year-old man with severe hemophilia, I look back and remember the uncertainty, the worries and fears, and the deep desire to actually live my life no matter what obstacles it had in store for me. If I could write a letter to my 13-year-old self it would go something like this...



Dear 13-year-old Me,

Things look sort of dismal right now lying on the couch with yet another bleed – a knee the size of a basketball, even after having it aspirated. As always, you'll get through. It was pretty disappointing you couldn't go to Woodstock with your older brother that weekend, but you couldn't put pressure on your knee, so walking was out. But you don't tend to blame disappointments in life on your hemophilia. Your motto will be, "Tomorrow is another day." Always know you are a fighter.

There will be some milestones in your life that will make you become the man you are today. For one, you will have outlived your life expectancy by 45 years so far! When you were born in 1956, you were not expected to make it to your 20th birthday. And you almost didn't. Remember when you had that brain bleed at 3? For someone with hemophilia to survive a brain bleed being treated with whole blood was nothing short of a miracle. Or luck. Look at the bright side – just by surviving you earned a place in medical history.

You don't realize this yet, but Mom and Dad don't treat you any differently than your siblings. They want you to live a normal life even though, aside from whole blood and plasma, there is no other therapy for hemophilia. When you were 9, Dr. Judith Graham Pool discovered cryoprecipitate "cryo," which helped with your bleeding episodes. Three years later, you learned how to self-infuse this new lyophilized product called clotting factor.

In time, you will see major advances in hemophilia therapies... and these advances will also cause you to

suffer some heartache. Because of the vast amounts of donated blood needed to make this new clotting factor, you will contract blood-borne hepatitis B and non-A non-B, which years later will be called hepatitis C. Christmas 1973, at 17, you will have jaundice, but it won't get you down.

In the early 1970s, you'll be busy living your life. It's a time of change, politically, musically and creatively, and you are determined to be a part of it, despite hemophilia. You'll participate in sit-ins protesting the Vietnam War, have fun at Grateful Dead concerts, and discover photography, first as an art form and later, a career. Mom and Dad know it will be difficult for you to hold a steady job because of the spontaneous bleeds, so they will support you in whatever you want to do. They'll even be okay with you growing your hair long when you tell them it will help you fit in and maybe no one will notice how you limp.

Over the next few years, you will have some great experiences and will learn to live life on your own. Traveling cross country in your van and spend months in New Mexico doing photo-documentary work for the New Mexico Solar Energy Commission and photographing the construction of solar greenhouses on various American Indian reservations are in your future.

That will be the start of wanting to help others, but you won't realize it for a while. Your photography career will continue in New York City, first apprenticing for a well-known fashion photographer and then opening your own studio. You will take your first trip by plane and sit staring out the window like you're 13 again - the start of your desire to travel and see the world. Living in Greenwich Village, you will develop a wide range of musical tastes hanging out at clubs like Max's Kansas City, the Bitter End, and the Village Vanguard. Enjoy those times. You won't have regrets.



Confirmation



8th Grade Class President



8th Grade Graduation



Long hair and a big fish!

I am sorry to tell you though, in 1982, in addition to hepatitis, you will contract HIV from the clotting factor you're using to control your bleeding. You will be at the Perry Street Theater seeing *A Christmas Carol* with Orson Wells as Scrooge. Halfway through you will have a spontaneous elbow bleed and rather than ruin the evening by leaving, you will sit in pain until you can get home to infuse. You're used to the cloudy factor you'll infuse that night, but the next day you will be sick with flu-like symptoms. That's the HIV. Once the news channels report that HIV is found in the blood supply, you will figure it was inevitable. After all, by then you will have received many doses of clotting factor and blood transfusions.

When you do find out about HIV, the doctor will tell your wife (yes...you get married – twice!), “Why would you want to have kids with him, he will be dead in five years.” You won't complain though. You won't ask, “Why me?” You'll just go on living your life.

At 27, you're still a little naive. You've grown up with these doctors, they've kept you alive. Why would doctors and national organizations tell us to keep infusing when HIV was in the blood products? You trust them, but no one trusts them more than Dad. When the first legal trials against the pharmaceutical companies start, many doctors begin testifying against their own patients.

Dad will walk up to my doctor after she testifies for the manufacturers, a woman he considers part of our family, and will tell her she has broken his heart. For a man who doesn't show his emotions, it is devastating. He won't ever speak to her again. This memory will stay with you forever. You will realize that day what a true advocate he has been.

But you're a fighter. A survivor. You won't let HIV bother you. Your attitude is, “I was exposed to this virus, but maybe I've built antibodies.” Maybe you will or maybe you're just lucky, but you'll stay fine until 2010 when you develop thrombocytopenia. Possibly from the HIV, it seems your body will begin to turn on itself and start destroying platelets. This will lead to another brain bleed. Again, you will survive, even if the hospital misreads the CT scan and doesn't infuse you for three days. After that, you do start taking HIV anti-viral drugs. Maybe this will also help you survive the pandemic of 2020 - yes, we have one of those coming! Just maybe you'll be lucky again.

Even at a young age, you will never want to be a burden on society, so you will always work. Your first job will be in the shipping department of a men's store, and you will drive an ice cream truck after high school graduation. You will have a career as a professional freelance photographer, will start your own trial consulting business, and will advocate for people with bleeding disorders. You inherited the best of both worlds; Mom is a creative optimist while Dad is always pragmatic. It will take you years to see this, but the catalyst for your advocacy is another milestone in your life. Dad passes away when you're 39.

The future will have its ups and downs but by persistence, hardheadedness, and a little luck, I'm here to say you will make it!

He will have taken better care of your hemophilia than you do. He made sure you had insurance. He will have held blood drives in your name so you could use blood credits to get clotting factor, which insurance wouldn't cover at the time. He will have helped the Hemophilia Association of New Jersey (HANJ) pass legislation so insurance companies would be required to cover clotting factor.

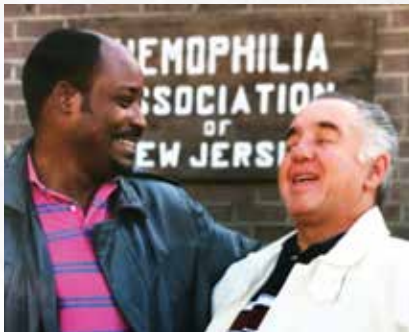
With Dad gone, you will have to take control of your hemophilia. Following in his footsteps, you will jump in with both feet, serving as a HANJ board member and the New Jersey representative on the board of the recently formed Hemophilia Federation of America. In later years, you will serve as president of each of those organizations. It will be an honor when you received HANJ's Past Presidents Award, which includes Dad's name alongside other former presidents.

Side by side with advocates, you will be involved in getting the Ricky Ray Hemophilia Relief Fund Act of 1998 passed and funded. This will help patients and families get the compensation they rightly deserve. At 13, you haven't yet heard of Ricky Ray – he won't be born until 1977. Another young person with hemophilia – Ryan White will be born in 1971. Their lives will come to have much meaning for you.

Later in 2009, you will become a voting member of the Federal Advisory Committee on Blood Safety and



Then president, Anna DeSimone, presented Dad with HANJ's Past Presidents Award.



Richard Johnson, former HANJ Outreach Coordinator, laughing it up with my father.

Availability, which "...provides advice to the Secretary of Health and Human Services through the Assistant Secretary for Health on a range of policy issues related to blood, blood products, and tissues." You will continue to use your voice on behalf of and for the welfare of the bleeding disorders community. Dad would have been so proud of you.

You will reach another milestone in your life - 65 years old! I'll fill you in, not even talking hemophilia, as we get older, *everything* gets more difficult. Throw in some joint damage and diminished range of motion and you're in for a bumpy ride. Things most people take for granted like buttoning the top button of a shirt are a challenge. By the way, what is the worst thing you can ask a man with hemophilia at the dinner table? Please pass the salt. Never lose the humor. It is what helps you get through the bad times.

I want you to know you WILL endure. Don't give up! You will find yourself in a very small group of surviving veterans - men over 60 with hemophilia, HIV, and other co-morbidities. You will

be absolutely delighted to be in a group of old men with diabetes, high blood pressure, high cholesterol, and osteoporosis. Your kidneys will leak protein, but you know what? It's a small price to pay to still be here, working, helping people, traveling, whipping up a great meal, and enjoying life!

There will be many times in your life you will ask yourself if you made the right decision. Don't doubt yourself. You won't forget your failures so confront them head-on. They will give you the drive and determination to succeed. Despite the challenges, you will survive.

The future will have its ups and downs but by persistence, hardheadedness, and a little luck, I'm here to say you will make it! As your favorite group, the Grateful Dead will say next year, "Sometimes the light will be shining on you and sometimes you will barely be able to see but what a long, strange trip..." it will be.

**Be happy,
65-year-old You**

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“New Knee or No New Knee?”

THAT WAS ONCE THE QUESTION!

BY FELIX L. GARCIA

As someone born in the 1970s with severe hemophilia, I have experienced significant joint damage. With that, the question of joint replacement has come up. My parents faced this question for the first time when I was in elementary school.



At the time, the chosen course on my behalf was an arthroscopic synovectomy over the summer before entering middle school. That was fun... well, not fun, but necessary. It bought me a little time before actually having to get a full knee replacement. About 3½ years is what it yielded.

This was around the end of the 1980s and I was still not offered the choice of prophylaxis treatment to help extend the life of my knee. I know, I know... it sounds like the dark ages

to young people with hemophilia and their parents. What can I say? There was life before prophy. Halfway through my sophomore year, my knee crumbled beneath me and there was no question – I needed a new knee. The question became, “How soon?”

Deciding on whether to have a knee replacement isn't the only consideration. *When* becomes a big issue. In high school, I waited until summertime to have surgery so I wouldn't lose a whole year of classes. That meant going to school and dealing with a lot of pain for an extra 3 months while getting around with a severely damaged knee, which meant more damage overall. We also have to look at our financial circumstances and whether the out-of-pocket costs could be afforded at that specific time. Financial issues can have lingering consequences.

Too often I hear from other bleeding disorders patients who put off joint replacement surgeries because they're

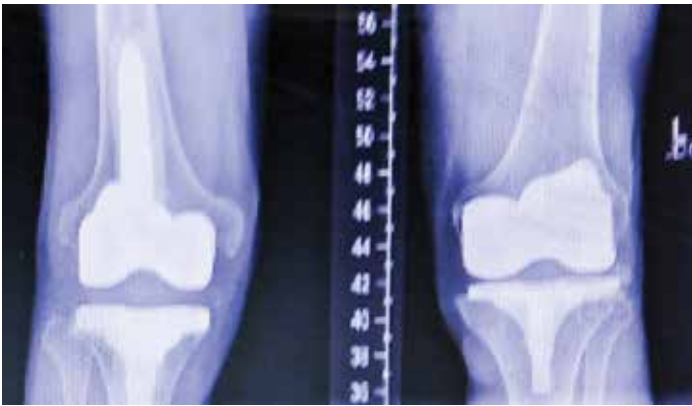
afraid the results will be worse than what they currently deal with. When it comes to knees, it's easy for me to say, “Do it, do it, do it!” but not every joint is created (or re-created) equally. This has to be a well-thought-out medical and personal decision made carefully given all of a person's mitigating circumstances.

An elbow may have other risks and options, and ankles are even more of a consideration because they bear the full brunt of a person's weight, and the medical technology is not nearly as advanced as it is with knees or hips. The decision to have joint replacement surgery is a family concern. It will affect everyone around you. Of course, your doctor will play a huge role in your conclusion, but do not be too quick to put limits on who to include on your pre- and post-surgery teams.

Since my first knee replacement in 1991, I had my other knee done in 2014. However, that was not the end of my knee saga. The first knee I had replaced lasted me 25 good, long years – well outliving its 8-10-year expectancy offered back then. So, I once again found myself asking, “New knee or no new knee?” I'm a husband, father, grandfather, and still a son to my parents who were to be a big part of my care team. After living years with limits and pain, I still had some hesitation.

In my 20s, I worked in construction (not recommended for most with a bleeding disorder) and I took pride in building and creating. I found satisfaction in the sweating and working “like a man” (to fulfill the machismo in me). In time, things have changed and even though much of my work is on a computer these days, I still very much enjoy doing my own home improvements and repairs.

As time went on, my growing limitations had me calling on others to do the work for me and it was a definite bruise to my ego. I know it's old-fashioned, but as a husband, I still



enjoy being the provider, protector, and Mr. Repairman to my wife. As a father, I miss not being able to keep up with my kids. As an employee with a job to maintain, I didn't want to be less of an asset as I recovered. "New knee or no new knee?" The question reverberated in my head.

As I sat on the roof waiting for my son to reload my nail gun, I realized, "This is why I had surgery."

My biggest new knee advocate was my wife. She didn't like seeing me in pain and frustrated all the time. She was with me through my last knee replacement when we were still in our newlywed stage. She knew what to expect. My children were also encouraging, promising to help. With teenage boys who normally don't say two words in a row, that's a big deal. Then there were my parents. The last time, they drove 300 miles to be by my side. They maintained the household and the kids and made the trip back and forth from their home to ours several times during my recovery. With all this heavy on my mind, the decision was made – it was time for a new knee!

There are a lot of ducks to get in a row before having any major procedure. Some of the tasks have to do with insurance coverage, providing proof of necessity, doctor's schedules and availability, and the availability and preparedness of caretakers. Something many forget to consider in advance is their physical therapist. Meet with a therapist before the procedure. It's important to establish a good connection and understanding with the person that is going to get you moving again and will be helping you achieve the desired outcome. It's important to be on the same page when it comes to setting expectations. It's very uplifting when your therapist views your progress as his or her own goal and is great at cheering you on.

Keep in mind even after the physical therapy sessions end, your personal commitment to improvement continues. My knee didn't go bad all at once and it will take some time to get it to where I'll be satisfied.

Probably the most important thing and

one that should never be left out of the preparations is to get in the right frame of mind. *You will be the patient* (repeat this to yourself). You will still be the partner, the dad, grandfather and son, but for this short time in your life, you will need to be the patient and allow others to help you. Let them.

Get it in your head your caretakers will want to take care of you. Get it in your head you will probably need some sort of pain management but understand it's meant to be short-term. Don't take what you don't need. Get it in your head, this will be uncomfortable – even painful for a while, but it will be worth it to be out of constant pain.

Once you and your doctor have decided a joint replacement is the way to go, my recommendation is to set a goal and keep your focus on it. For one surgery, my goal was to be strong enough to ride my motorcycle again. For this latest surgery, I focused on being able to hike and play ball with my kids again. Whatever your objective, make it as big as you are willing to work. The bigger the goal, the longer it may take. One goal I had was to build a shed. Not one of those snap-together plastic things, but one for which I would have to pour cement. A trip to the store for lumber and materials, shaking the dust off my rusty old toolbox, my new knee and I were ready.

There's nothing like sitting on the rafters of a roof you just nailed in yourself. I made and lifted the 4 walls myself, perfectly square I might add, then my son helped me attach the rafters and metal roofing. I finished the trim, installed a sliding door, and the job was done (I'm making it sound easier than it was).

As I sat on the roof waiting for my son to reload my nail gun, I realized, "This is why I had surgery." I know everyone who has a joint replacement is not going to turn into Bob Vila (I had that skill set before surgery), but so many of us have things in life we have given up in exchange for fewer bleeds, less pain, and because we simply couldn't do certain activities safely anymore.

Think about what that is for you and then ask the question, "New knee or no new knee (elbow, hip, ankle)." Lately, I've been hitting the basketball court with my boys for some much-needed cardio and just plain fun shooting hoops. It feels good. Thank you, new knee!



BIOMATRIX

Meet the Team!

BioMatrix is dedicated to making a difference in the bleeding disorders community. Our team of Regional Care Coordinators and Patient Care Specialists provide support that draws on personal experience and a genuine commitment to the bleeding disorders community. Our "Meet the Team" segment invites you to get to know our incredible staff a little bit better. In this edition we feature John Martinez.



JOHN MARTINEZ
Regional Care Coordinator

"Providing culturally sensitive and language-specific educational opportunities is of utmost importance to empower the Latino bleeding disorders community."

John Martinez is an educator, caregiver, advocate, volunteer and consummate professional dedicated to serving the bleeding disorders community. His involvement goes back to the mid-nineties when he and his wife set out to ensure families were connected with the right resources and support to navigate life with a bleeding disorder. That commitment continues to this day. John has a strong interest in helping families navigate care, especially those who do not speak English as their primary language. He and his family live in northern California where he remains very involved with the bleeding disorders community.



John with Leticia, his wife of 29 years.

Tell us a little about your background.

Born in Tulare, California, I am the 4th of 8 children. My parents were migrant farm laborers from northern Mexico. When I was 8 years old, my family moved to Clovis, California, where my father attended an adult school to learn English, earned a high school diploma and entered an auto mechanic program. With his Journeyman certification, he spent well over 20 years working for the University of California. My parents greatly valued education as an opportunity to improve and create a new life. With that, I attended Fresno City College and the University of Phoenix, earning a Bachelor of Science degree in Business Administration.

Before working in the bleeding disorders world, I spent 19 years as a teacher at Clovis Adult Education (CAE), part of the Clovis Unified School District in Fresno County. After winning a federal grant that allowed CAE to open a community technology center in Fresno, I spent the next 12 years running the facility. Services provided included computer classes, English as a second language, job search assistance and a pre-school program.

What brought you to BioMatrix?

After 14 years of volunteering in my local bleeding disorders community, I was offered a position with a specialty pharmacy. A few years later at a national event, I met a BioMatrix care coordinator from Florida and we struck up a conversation. I was very impressed with what he had to say about BioMatrix – the ethics, the value placed on teamwork and the dedication to the community. It piqued my interest and soon an official interview was arranged. I have happily been with BioMatrix for 2 years.

Describe your personal connection to the bleeding disorders community.

My involvement in the bleeding disorders community began in 1995 with the birth of our son, David. At 4 months old, I noticed the baby had a small bruise on his knee - it seemed to cause him some pain. At the next pediatric appointment, we discussed the bruise with his doctor, who, in an over-abundance of caution, recommended blood work and a knee scan. We watched as our son was poked and prodded and seen by several doctors. We were informed that David had an accumulation of blood in his knee that needed to be drained. We were confused but also trusted the physician.

And so, a needle was pushed into his knee to relieve the pressure and we returned home. Within a couple of hours, we received a call informing us there was an irregularity with David's PT blood work and we needed to come back to the hospital immediately.

After our son was admitted, a hematologist told us David had hemophilia. He gave a vague explanation that it involved coagulation needing intravenous medication and that a social worker would be arriving to talk with us. Since my wife's primary language was Spanish, I asked for someone who could explain what was happening in her language. We waited for 3 days – apparently, no Spanish speaker was available. When we were finally home with our son, we began our own search for information and made appointments with a genetic counselor and a hematologist. Although our family members were supportive and tried to offer comfort, it was difficult to explain the seriousness of the diagnosis. As parents, we struggled to absorb the new reality for our son.

Two years after receiving the diagnosis for our first son, we welcomed our second, Daniel, who was also diagnosed with severe hemophilia A. This time, we knew more, but not as much as we should have.

After several years of limited access to information, we were finally made aware of the Hemophilia Foundation of Northern California. The first family event we attended resulted in a meeting with a well-known hematologist who helped us understand how to better advocate for our sons. That meeting led to a life-changing medication adjustment for our eldest son. He went from spending an average of 5 days a month in a wheelchair to never being dependent on one again. With new understanding and access to more regiment options, my wife and I began advocating for major changes in both of our sons' treatments. With these changes, the boys began a life of sports – soccer, baseball, basketball and karate.

We began meeting with other families in the Central Valley area and sharing the information we had learned, especially with families who spoke Spanish. Soon after, we began coordinating educational events and support groups with the blessing of the Hemophilia Foundation of Northern California. We spent the next 14 years volunteering in the Latino community of the Central Valley area advocating for families such as ours.



John's joy.



John on vacation in 2018 with his family, including his lovely mother-in-law, Elva.

My wife had dealt with bleeding issues related to her menstrual cycle since she was 12 years old; doctors always told her it was normal. After the hemophilia diagnosis for our son, we began questioning if she might have a bleeding disorder. At the time, we were told only boys could have hemophilia and that, at worst, she was a symptomatic carrier. Being unable to convince the HTC to test for a bleeding disorder, she discussed the issue with her gynecologist who then ordered the blood tests.

She was officially diagnosed with mild hemophilia A. In 2002, we welcomed a baby girl, Victoria. It took quite a bit of continual advocacy, but we were finally able to have her tested and obtained a diagnosis of mild hemophilia as well. With the experience of my wife's undiagnosed bleeding problem and the struggle to obtain a proper diagnosis for her and for our daughter, the subject of women's bleeding disorders and proper diagnosis has become an important issue to me. I am happy to work in a field that allows me to educate others about these issues.

Who is the most positive influence in your life, and in what way?

My wife, Leticia, has been a consistent and positive influence in my life since we met 30 years ago. She has always encouraged me to work hard and explore new avenues and challenges, including the ones eventually leading me to working with BioMatrix.



Having fun on vacation with his family.



Assisting Educating Advocating For The Bleeding Disorders Community.



How do you feel you are *Making a Difference*?

Providing culturally sensitive and language-specific educational opportunities is of utmost importance to empower the Latino bleeding disorders community. I am *Making a Difference* by sharing my experiences and knowledge to help families better participate in the crucial decisions necessary for positive health outcomes.

What is the most cherished part of your job?

With the myriad of problems that can present themselves when living with a bleeding disorder, I greatly enjoy learning about new resources available to assist families. It is especially satisfying to work with the Latino community and be in a position to offer Spanish-language education and information to families who may struggle with the language barrier in medical settings. I am passionate about

empowering families to improve the quality of life for themselves and their loved ones.

What advice would you give a newly diagnosed family?

When working with newly diagnosed families, I am a strong proponent of asking questions and exercising a parent's right to understand their child's diagnosis. The role parents play in making medical decisions regarding their child is absolutely vital. My advice to a new family is to keep asking questions. Get educated and trust your instincts. Advocacy and education are key to providing the best possible life for children in the bleeding disorders community.

For myself, three of my proudest moments were watching my sons and daughter walk across the stage to receive their high school diplomas, *bleed free*.



Proud moments!



www.hemophiliafed.org

BIOMATRIX ON THE *Virtual & In-Person* MOVE!

After more than a year, we are slowly and carefully transitioning back to in-person events. This past quarter we've had both! We've even participated in a few hybrid events where a BioMatrix Care Coordinator attends in-person while our Education Team presented online. Read on to see what we've been up to!

COVID-19 *Road to Recovery*

APRIL 29, 2021
Presenter: Terry Rice

Transition To School

APRIL 14, 2021
Presenter: Kelly Gonzalez
RCC: John Martinez
Host: Exception Military Family Program

SCHOLARSHIP *101*

JUNE 2, 2021
Presenter: Kelly Gonzalez
Communications Manager:
Maria Santucci Vetter
Host: The Coalition for Hemophilia B

Camera-On *Photography*

MARCH 25, 2021
Presenter: Shelby Smoak
with Rich Vogel
RCC: Terry Stone
Host: Virginia Hemophilia Foundation

Putting The Mask On *- First -*

APRIL 21, 2021
Presenter: Kelly Gonzalez
Comms Mgr: Maria Vetter
Host: The Coalition for Hemophilia B

APRIL 27, 2021
Presenter: Kelly Gonzalez
RCC: Richard Vogel
Partner: Novo Nordisk
Host: CT Hemophilia Society and Bleeding Disorder Assoc. of Northeast New York

Awareness for *- Advocacy -*

JUNE 17, 2021
Presenter: Terry Rice
RCC: John Martinez
Partner: Novo
Host: Bleeding Disorders Foundation of Washington

JUNE 26, 2021
Presenter: Kelly Gonzalez
RCC: Marcy Foertsch and Peggy Klingmann

Feed Mind + Body

APRIL 10, 2021
With Chef Mike!
Presenter: Terry Rice
RCC: Terry Stone
Host: HACA

MAY 14, 2021
With Chef Myles!
Presenter: Terry Rice
RCC: Marcy Foertsch
Partner: Medexus

Navigating TRICARE

JUNE 3, 2021
Presenter: Shelby Smoak
RCC: Justin Lindhorst

Music Trivia

MAY 4, 2021
Presenter: Shelby Smoak
RCC: Marcy Foertsch
Partner: CSL Behring

BIOMATRIX GAME NIGHT



APRIL 9, 2021
Who Knows Best?
Presenter: Shelby Smoak
RCC: Richard Vogel
Host: New England Hemophilia Association

APRIL 22, 2021
Loteria!
Presenter: Shelby Smoak
RCCs: John Martinez and Eva Kraemer

JUNE 17, 2021
Wheel of Fortune
Presenter: Terry Rice
RCC: LeAnn Wilson

JUNE 30, 2021
Loteria!
Presenter: Shelby Smoak
RCC: Felix Garcia
Partner: Takeda
Host: Arizona Chapter NHF

MAY 5, 2021
Presenter: Shelby Smoak RCC: Richard Vogel
Host: Hemophilia Association of New Jersey

On Cinco de Mayo, HANJ presented a family-friendly game evening. We began with a little trivia. Did you know that Cinco de Mayo commemorates the anniversary of Mexico's victory over the French Empire at the Battle of Puebla in 1862? It's a little like the story of David and Goliath, a small Mexican army defeating the powerful French Empire. Inspirational and perfect for our community.

To get the evening off to an entertaining start, Richard Vogel demonstrated how to concoct a Cadillac margarita. Education Specialist, Kelly Gonzalez deejayed a game of *Loteria*, a Latino form of bingo. In addition to traditional *Loteria* pictures, our special BioMatrix version includes bleeding disorders images and Spanish words. While Kelly called out the game cards in English and Spanish, Rich attempted to supply the jokes. HANJ presented the game winners with gift cards. We had much fun – ¡mucha diversión!

TENNESSEE

David Tignor

On Saturday, May 1st, Greg Jameson and his family hosted the annual **Be a Factor 5k** to help support camp and programs of the Tennessee Hemophilia and Bleeding Disorders Foundation (THBDF). In addition to raising funds for THBDF, it was definitely nice to get out, be among community members, and help bring awareness to bleeding disorders. After all the participants crossed the finish line, awards were given out and door prizes were drawn. BioMatrix is always excited for the opportunity to support this event year after year!



OHIO

Shelia Biljes

Thursday, May 13th was a big day for the ladies of Northern Ohio as they gathered together in person for the first time in well over a year! A **Tea Party**, sponsored by Octapharma, paved the way for a celebration that lasted most of the afternoon. Molly's Tea Room in Medina is the perfect place to bring your daughters, mothers and lady friends for good food and over 50 flavors of hot and cold tea. Once the ladies were seated, face masks were removed, and the conversation unleashed!



Enjoying a spot of tea!

BioMatrix Education Specialist, Kelly Gonzalez attended virtually over Zoom to present "Putting the Mask on First" and the ladies were reminded they cannot take care of others until they take care of themselves. While tiered platters brimming with delectable treats were served and teas selected, the ladies talked. It was not nearly enough time to catch up on a year's worth of stories, but it was a good start. Masks back on, everyone shared hugs and planned to meet again soon!

OHIO

Shelia Biljes

Families in Northern Ohio gave a warm welcome to local HEMA Biologics' representative, Molly McCue, as they gathered May 13th for a meal at Brew Garden in Middleburg Heights.

During dinner, Molly presented facts about HEMA

Biologics' factor product, SEVENFACT®, and also played a game where the guests had to guess whether her family facts were true or false. It was a fun ice breaker and the group of 27 guests proved to be very perceptive at the game. After Molly fielded many good questions from the group, we moved on to a unique and fun craft.



Molly McCue showcases her macramé skills.

Miya Timura took us back to the 1970s with macramé lessons. Each family made a beautiful macramé planter to take home and display. Let me just say, figuring out the knots is not as easy as it looks but everyone managed to successfully complete the project! The families were glad to reunite for a live event and stayed, talking until the room closed. Thank you to HEMA Biologics for a wonderful introduction dinner!

OHIO

Shelia Biljes

April showers certainly brought May flowers in the form of polka dot whirly pinwheels as the ladies of Northern Ohio gathered May 20th for a very special **Educational Luncheon**. Novo Nordisk's Educational Speaker, Judy Doyle, presented *Six Tips to Thriving* at Burntwood Tavern Grille in North Olmsted. The event began with a game of *Purse Inventory*. The ladies sorted through their purses to gain points for items such as hand sanitizers, lipstick, pens, keys - extra points for every key that doesn't really open anything. Points were subtracted for every credit card in their wallet and much laughter filled the room as women found bar coasters, children's toys, a pair of scissors, and several other odd items including a tape measure!



Judy looks on as two friends, Kristen and Amber smile for the camera!

Each lady shared their story of how they belong in the bleeding disorder community. Judy's program was refreshing and well received. It led to great conversation lasting into the afternoon. Lunch at the Burntwood Tavern is an unforgettable event. Each meal on the menu is delicious. The ladies left the event full in their tummies and hearts.



Happy faces! June and Charlene

DELAWARE

Tina McMullen

It felt so good to be attending an in-person event out in the sunshine with beautiful, warm weather enveloping us! BioMatrix and Octapharma were pleased to sponsor the **Brandywine Valley Foundation's Educational Fishing Boat Charter Event** Sunday, May 23rd. Adults and children alike were so enthusiastic to board the 85-foot Thelma Dale IV fishing boat docked at Fisherman's Wharf in Lewes, Delaware. And off to the blue seas of the Delaware Bay we sailed!

Anticipation and excitement filled the air every time someone had 'something promising' on their fishing line. Although no huge sea creatures were caught, small fish, baby sharks, and even a stingray brought smiles and delight to those aboard.

Special guest Seth Rojhani, Octapharma Patient Educator, was on hand to greet guests and talk one-on-one about his life and experiences living with hemophilia. Eventually, the group worked up an appetite and BioMatrix was at the ready to sponsor lunch, which included a variety of legendary "Wawa" hoagies and snacks.

Families cast their poles, socialized, and even saw a few dolphins. It was a beautiful day to float on the water with the Brandywine Valley Foundation community. This event was such a success we are already planning on making this an annual activity. Thank you to Brandywine Foundation President, Gail Novak and Octapharma's Paul Brayshaw for a remarkable day!



Gail, Seth and Jose



Gail Novak and Tina McMullen planned a perfect day!



Paul and son, Porter



Harry caught a fish!



All aboard!



"Sign the 9"



Bella and Tina McMullen with (back row) Phil, Wyatt, Emily and Paige



Walter and Tina



All in the family! Robert, Gail and Luke



Matt and Jenni



Kelechi, Gail and Tina

DELAWARE

Tina McMullen

BioMatrix and Medexus joined in sponsoring an evening of **Education and Wilmington Blue Rocks Baseball** for the community of the Brandywine Valley Hemophilia Foundation June 4th. The evening kicked off with an educational dinner at Timothy's Riverfront Grill in Wilmington hosted by Medexus. Hemophilia Territory Manager Kelechi Arungwa presented a program on all the different ways Medexus supports the bleeding disorder community. She touched on topics about their scholarship program, support of summer camps, and "Sign the 9", a program whereby signing up, "You can help donate IXINITY® to people in the U.S. who can't afford to be without it."

After dinner, the group headed across the street to the Daniel S. Frawley Stadium to watch the Blue Rocks take on Hudson Valley. Unfortunately, due to a nasty storm that had just rolled through during our dinner time, the game was eventually postponed. Still, families hung out and socialized until the fireworks. The Brandywine Valley chapter might be on the smaller size, but the love they have for each other is a huge blessing to be a part of. Thank you to Medexus, Foundation President Gail Novak and the entire bleeding disorder community for an amazing evening. It was so wonderful to once again be with people in-person! BioMatrix looks forward to co-sponsoring again next year!

BIOMATRIX

Our cookbook brings together recipes from our family to yours!

Our team of Regional Care Coordinators has provided their very best recipes – from appetizers to entrees and desserts.

To request your free cookbook, contact your local Regional Care Coordinator or request online:

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

“The table is a meeting place, a gathering ground, the source of sustenance and nourishment, festivity, safety, and satisfaction. A person cooking is a person giving: Even the simplest food is a gift.”
— Laurie Colwin



Upcoming Events

JUNE 24, 2021 OHIO

Ladies Flamingle and Suncatcher Class
Hosted by BioMatrix and Medexus
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Brew Garden; Middleburg Heights

JUNE 24, 2021 OHIO

Tips to Adulging and Anime Drawing
Hosted by BioMatrix and Novo Nordisk
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Brew Garden; Middleburg Heights

JUNE 25, 2021 OHIO

Amish Ladies Brunch and Craft
Hosted by BioMatrix and Medexus
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Carlisle Inn; Sugarcreek

JULY 15, 2021 OHIO

Singing to Heal
Hosted by BioMatrix and Novo Nordisk
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Bucci J-Bella Restaurant; Strongsville

JULY 31 and AUGUST 1, 2021 VIRTUAL/FLORIDA

8th Annual Back 2 School Awareness
Foundation Hope & Life
786-534-2900; fhlusa.org

AUGUST 5, 2021 OHIO

Back to School Family Dinner
Hosted by BioMatrix and Takeda
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Maps Airplane Museum; Canton

AUGUST 26, 2021 OHIO

Ladies Lunch
Hosted by BioMatrix and Genentec
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Bonefish Grille
Westlake

SEPTEMBER 16 OHIO

Sewing B for Hemophilia B Sewing to Relieve Anxiety
Hosted by BioMatrix and Medexus
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Pins and Needles Quilt Shop
Middleburg Heights

NATIONAL EVENT!



SEPTEMBER 24 FLORIDA

2021 Hybrid Symposium
The Coalition For Hemophilia B
(212) 520-8272, hemob.org
Renaissance Marriott Orlando

OCT. 2, 2021 PENNSYLVANIA

Adventures in Learning
Eastern PA Hemophilia Foundation
484-445-4282
hemophiliasupport.org
Spooky Nook Sports; Manheim

OCT. 12, 2021 PENNSYLVANIA Annual Meeting

Eastern PA Hemophilia Foundation
484-445-4282
hemophiliasupport.org
Hilton Hotel Philadelphia

Time for Fun! Puzzles on page 27

bleed	8	7	4	2	9	1	5	6	3	9	1	2	4	8	5	3	7	6
hemophilia	8	7	4	2	9	1	5	6	3	9	1	2	4	8	5	3	7	6
joint	9	5	3	6	7	4	1	8	2	2	6	1	8	5	9	4	3	7
infuse	7	6	8	1	5	2	1	6	9	3	4	7	5	2	1	1	1	1
pain	2	4	1	8	5	7	4	4	2	1	6	8	1	4	9	9	9	9
elevate	8	7	9	2	6	3	6	9	7	5	7	5	7	5	7	5	7	5
memory	4	6	9	5	1	7	1	7	1	7	1	7	1	7	1	7	1	7
disorder	1	2	5	4	8	3	9	6	7	4	7	2	3	8	5	1	4	7

Time for Fun!



Hi Kids! Using the words in the word box, see if you can fill in the blank spaces in the story. Good luck! Answers are on page 26.

WORD BOX

pain memory
 elevate disorder
 infuse hemophilia
 bruise joint
 bleed swollen

As Mike walked to the baseball fields to meet up with some friends, he saw his buddy, Sean, sitting in front of his house. "Hey, Sean! Are you coming to play ball with us?"

Sean frowned as he said, "Nah... I can't. I'm having an ankle _____ and can't play today."

"What's an ankle bleed? Does that have something to do with your _____?" Mike asked as he sat down with Sean.

Sean replied, "Yep, that's right. Yesterday, when I skidded into home plate, I hurt my ankle and it caused it to start bleeding inside the _____."

"Oh," said Mike, "So, that's why you left early. It looked like you were limping when you left the field."

"I needed to get home right away so I could _____ my clotting factor," Sean explained, "Clotting factor is medicine that helps to control the bleeding in the joint."

"Ouch. That doesn't sound like much fun, Sean.

How bad does your ankle hurt right now? Are you in a lot of _____? asked Mike.

"I sure had a lot of pain last night!" Sean exclaimed, "My ankle was very _____ and had a huge blue and purple _____ on it. It doesn't hurt anymore, but I need to stay off of it for a while and let it heal."

"I remember you telling us that when you get hurt, you use R.I.C.E. - rest, ice, compress and _____ - did I get that right?" Mike asked.

Sean was surprised, "Wow, Mike! You have a great _____!"

Mike laughed and said, "I try to pay attention. I want to be a doctor one day. Maybe you would let me ask more questions about your bleeding _____?"

"Anytime!" Sean happily agreed.

"How about right now?" Mike said as he got up, "Stay right here. I'll go ask your mom for a deck of cards and some of those great cookies she makes!"

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

Sudoku!

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



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

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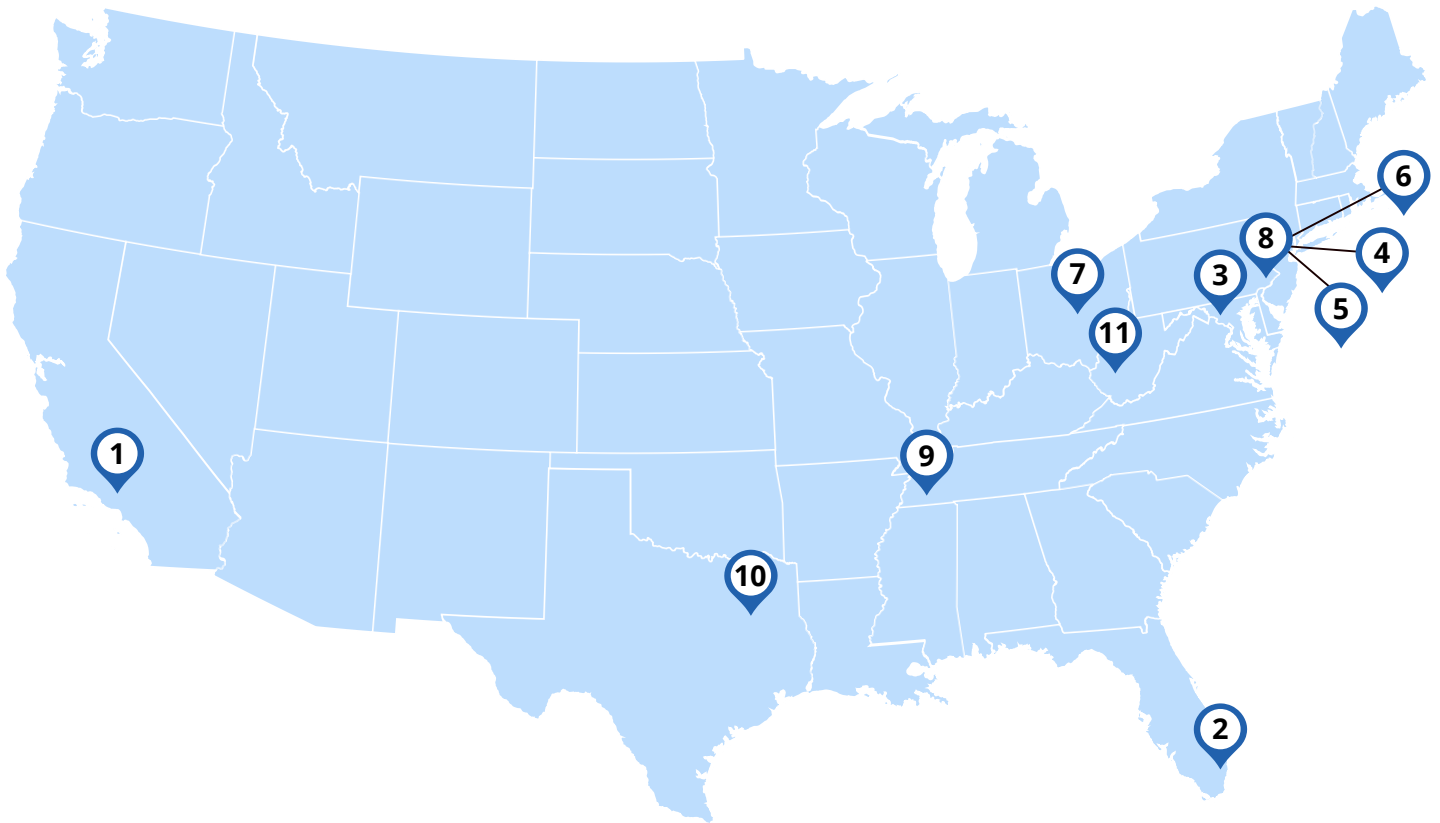
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Specialty Pharmacies



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2. Plantation, Florida
3. Columbia, Maryland
4. Glen Rock, New Jersey

5. Totowa, New Jersey
6. New York, New York
7. Dublin, Ohio
8. Garnet Valley, Pennsylvania

9. Bartlett, Tennessee
10. Tyler, Texas
11. Charleston, West Virginia

