

BIO MATRIX

NEWS



**DEDICATED
TO MAKING
A DIFFERENCE**

**FALL 2020
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“ Learn from yesterday, live for today, hope for tomorrow. ”

— Albert Einstein

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

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A NOTE FROM THE EDITOR

Dear Readers:

For over a decade, our newsletter has provided award winning content and material relevant to the bleeding disorders community. Month over month, year over year, our readership continues to grow!

For those who are new to the BioMatrix newsletter, welcome! We hope you enjoy our articles focused specifically on the bleeding disorders community.

To our veteran readers, we're back! Back in print that is! Last year we decided to publish an online-only newsletter; however, due to public demand, we've decided to go back to print. We have come to understand the importance of having a physical, hard copy newsletter available to adorn your coffee tables, counter tops and treatment center offices.

Yes, this is the age of everything being online and electronically available. And of course, we still offer that option for those that prefer it; however, there is something quite satisfying in picking up a magazine and reading

through it while snuggled up on the couch on a crisp fall day. Feel free to let us know if you prefer just the online version by sending an email to info@biomatrixsprx.com.

As most of you recognize, our community is very close knit. As COVID-19 has kept us apart, many of us have felt disconnected from our bleeding disorders family. At BioMatrix, we have been working hard to help minimize those feelings by offering Zoom gatherings on a multitude of topics ranging from insurance and advocacy to our exceedingly popular game nights and cooking demonstrations with Chef Mike.

While we may be social distancing, BioMatrix virtual programming offers a fun way to stay connected with your friends in the bleeding disorder community. Our programs are available free of charge - contact us if you're interested in hosting a virtual event!

Happy Autumn!

Maria Santucci Vetter
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COPAY ACCUMULATORS Redux

BY: SHELBY SMOAK, Ph.D.

By now, many of us with a bleeding disorder or other chronic health condition are very familiar with manufacturer copay assistance programs which help reduce the financial burden associated with our healthcare. Many are now unfortunately also becoming familiar with copay accumulator adjustor policies – PBM-created programs that disallow manufacturer drug copay cards to apply toward a patients' yearly deductible and out of pocket expenses. While they go by different names— Copay Maximizer, Coupon Adjustment Program, Benefit Plan Protection Program, or Out of Pocket Protection Program, among others—they generally operate similarly, and ultimately, these programs jeopardize therapy access, adherence, and increase financial burden for patients. Thus, copay accumulator adjustor programs have been hot topics in the healthcare space in a tug-of-war battle.

Let's take a brief revisit of the accumulator adjustor, and then look at anticipated changes that will impact their implementation in 2021 plans.

REMIND ME: WHAT IS AN ACCUMULATOR ADJUSTOR?

Historically, accumulator policies have not always been obvious nor clearly understood; they are a complicated and often confusing policy. As insurance policies over the last several years shifted more of the cost burden onto patients, the pharmaceutical industry initiated drug copay programs to mitigate the financial barriers to accessing therapies. However, insurers responded by disrupting this financial bridge.

In an accumulator adjustor policy, pharmacies will accept the drug manufacturer copay cards towards prescribed drugs as payment for the cost-sharing stipulated by the insurer for each dispense until the maximum value of the card is reached. In a plan with an accumulator adjustor, the insurer will not apply that cost-share towards the patient's total out of pocket deduction; the pharmacy will be required to collect these cost shares again. At some point, the copay card will be exhausted of its funds and the balance of the out-of-pocket cost will be the patient's responsibility. If a patient cannot afford that and if a drug copay card's balance is \$0, access to the patient's medicine is jeopardized.

WHAT'S NEW FOR 2021?

Earlier this year, The Centers for Medicare & Medicaid Services (CMS) who establishes rules for insurance plans passed new guidelines regarding copay accumulator



adjustors. The new guideline gives insurance plans the right to apply drug manufacturer card amounts to patient cost-sharing, but they don't have to. To quote the language from CMS, they write: "Amounts paid toward reducing the cost sharing incurred by an enrollee using any form of direct support offered by drug manufacturers for specific prescription drugs may be, but are not required to be, counted toward the annual limitation on cost sharing."

This is another perhaps confusing use of language, so let's dig in to better understand what this could mean.



Previously, the debate within CMS circled around whether insurers could prohibit copay dollars applying towards patient out of pocket expenses in circumstances where there was not a generic or biosimilar available. It seemed at the time that CMS was trying to strike the balance between good insurance cost management and maximum access to care for expensive drug therapies by ruling against broad-stroke accumulator policies. However, the new CMS rule rather upends that approach by abandoning directly supporting access to care for patients to these therapies.

The new CMS rule says insurers don't have to apply those funds toward out of pocket amounts, but they can. This move gives insurers the decision-making power in allotting payments from manufacturer copay cards to the detriment of affordable access to care. Put another way: The policy makes it easier for plans to exclude the value of manufacturer copay cards from counting towards an enrollee's deductible and out-of-pocket cost sharing.

The new CMS rule says insurers don't have to apply those funds toward out of pocket amounts, but they can.

More importantly, this shifts the decision of including a copay accumulator policy away from the insurer and onto the employers and individuals who now can be asked to decide if they want a copay accumulator in their plan for that year. In a typical scenario, insurers will provide employers with policy quotes with accumulator adjustors included and then without them. The latter figure will, necessarily, be higher, making it appealing to keep accumulators in plans.

The difference here is akin to when, at the end of a meal, instead of the waiter asking if I'd like to have desert, the waiter shows up with the delicious slice of chocolate cake, places it before me, and then asks if I'd like for them to take it away. The cake (the accumulator adjustor) has already been cut and served, making the decision to turn it down more difficult at that point.

WHAT PLANS WILL BE IMPACTED?

The policy applies to ACA plans and individual and group health plans, including self-insured plans. Four states—IL, VA, WV, AZ—have accumulator laws that restrict their use in small and non-ERISA group plans, and ACA plans in those states will have to follow the copay bans. Yet, that only covers plans that are state governed. For example, if you live in Virginia, as I do, but you work for a company that is national in scope and/or buys large-group employer plans, those federally covered ERISA plans would be immune to the VA copay ban.

HOW WILL I KNOW IF I HAVE AN ACCUMULATOR?

The new CMS final rule stipulates that plans must apply them in a non-discriminatory manner and provide "clear and transparent" information to enrollees and potential enrollees.ⁱⁱ A nefarious practice in previous years has been for insurers to be elusive about accumulator policies. To that point, an investigation by the AIDS Institute reported that insurance plans lacked transparency on copay accumulator programs and that most plans made it difficult to find out about accumulator policies until a person was enrolled.ⁱⁱⁱ Moving forward, the CMS language is meant to change that behavior. Still, the best way to find out if your plan has an accumulator is to call them directly.

IS THERE ANYTHING ELSE?

Drug Channels provides analysis and commentary on current trends in healthcare. They theorize that many copay programs will implement maximizer accumulator programs where the full value of the manufacturer copay coupon is applied in installments throughout the year versus the accumulator adjustor, which applies the manufacturer coupon to the patient's out-of-pocket costs until the card amount is exhausted. While this may sound

like a more "digestible" model, the maximizer will only help the higher income earner who can make those consistent payments while it will yet be an obstacle to access to care for others.^{iv}

More concerning is the indication that Cigna and CVS Health will now use a third party to control the copay card payments for patients. Cigna and their PBM Express Scripts send copay cards over to SaveonSP while CVS and its PBM Caremark will process copay cards with PrudentRx.^v To use the copay cards with these insurers, beneficiaries must enroll separately in the respective program—SaveonSP or PrudentRx—at which point the copay card is handled external to the insurer or the PBM. Enrollees using the cards must also use the designated pharmacy to receive the copay card dollars: Accredo for SaveonSP and Express Scripts, and Caremark for PrudentRx.

In other words, if you receive your insurance from Cigna or CVS and hand over a manufacturer copay card for a drug you receive, you will be kicked over to these companies to handle the cards and drug processing payment. This adds another layer of complexity to the prescription process.



Here, things could get confusing on who is responsible for drug orders and payment: insurer, PBM, or copay card program company. There is not any further evidence at the time of this printing if other insurers will adopt this practice, but it's possible.

WHAT MORE CAN I DO?

Most healthcare organizations are aggressively involved with this issue, so let them know if you have been affected by a Copay Accumulator program.

- HFA is collecting information through *Project CALLS*, so contact them at www.hemophiliamed.org/for-patient-families/navigate-insurance/project-calls/
- NHF is also involved and you can email them at advocate@hemophilia.org

- The Coalition for Hemophilia B has a *B Voice* program for advocacy at www.hemob.org/advocacy
- Contact your Congressperson and ask for their support of HR 7647 which, if enacted, would suspend the use of accumulator adjusters
- You can also contact your BioMatrix Regional Care Coordinator or email the Education department education@biomatrixsprx.com for more information.

We are all here to help.

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HIKING FOR HEALTH

AN INTERVIEW WITH JACOB JANSEN BY JUSTIN LINDHORST

A soft breeze stirred dense foliage as the sun danced with shadows across the forest floor. Under an ancient green canopy, the smell of earth filled the air. Advancing down the trail, the forest welcomed me, and my mind immediately began to quiet as if to match the peaceful beauty around me.



Surrounding myself with the sights, sounds and smells of the forest has always helped me deal with stress, especially during the many challenges of 2020. I'm not alone. Since the pandemic, more Americans are venturing out to local parks and outdoor recreation areas. According to a recent study, fifty-eight percent of Americans have a newfound appreciation for nature as a result of the pandemic.

Even prior to COVID-19, a growing body of research has demonstrated a wide range of mental and physical health benefits related to spending time in nature. These benefits extend to people living with a bleeding disorder.

According to the National Hemophilia Foundation, hiking is considered a low-risk activity – with tons of benefits! Aside from helping to strengthen joints and potentially prevent bleeds, research has identified a series of compounding benefits for active children, teens and adults including better health, improved cognition, greater productivity and less likelihood of obesity. Physically active individuals even have seven to eight percent higher annual earnings!

Jacob is a young man who knows his way around the forest. He is a young professional, an Eagle Scout, and an avid runner. He also happens to have severe hemophilia. Jacob has hiked in forests across the country and counts himself among the few “2,000 milers,” individuals who have hiked the Appalachian Trail in its entirety. I recently caught up with Jacob to discuss hiking, how it has helped him handle the stress of 2020 and the benefits of being outdoors for the bleeding disorders community.

Describe a “perfect day” outdoors.

I am lucky here in Colorado that the weather is pretty great for outdoor activities all year long, so I am almost always outdoors. Personally, I am fond of long days out hiking or climbing. There is something very humbling about watching the sun come up and turn the mountains bright red and orange. This is also when you're most likely to see wildlife. So a perfect day usually includes an early start, coffee by a mountain lake, and more often than not, trying to figure out where I am.

How do you feel after a good hike?

I am very relaxed after a good hike. My body may be tired and sore, but I feel incredibly relaxed.

What do you personally consider the top benefits of hiking/spending time outdoors?

There are both physiologic and psychologic benefits to spending time outdoors. The exercise and aerobic benefits are incredible, having strong joints when you have hemophilia is important for long term joint health. However, for me, the mental benefits outweigh anything else. Mental health is far too often overlooked in everyone's life - not just the bleeding disorder community. Having a space to work through issues and help relieve the stress and anxiety of everyday life is the top benefit of hiking and being outdoors.

How does hiking help you deal with stress or challenges?

The world and its problems melt away when you're in the woods. This doesn't mean problems disappear when you go for a hike, but hiking can provide relief from stress and anxiety to let you clear your head and refocus to address your problems head-on when you return.



How has it helped you deal with the challenges of 2020?

Hiking and climbing helped me immensely during the challenging times earlier in the year. These activities have always been a stress reliever for me. While during the peak of the pandemic I was not able to drive to a remote town to hike, I was still able to explore the trails near my house. Just being on the urban greenways around Denver provided a feeling of normalcy for me during a very stressful time.

What do you want others in the bleeding disorder community to know about hiking?

Hiking is a process. While it may seem simply like walking there is a lot that goes into it. Don't be discouraged by feeling tired or unable to finish a hike, it is just part of the process. As members of the bleeding disorders community, we have other factors we have to consider. Start easy and don't be afraid to take your time. Once you get a feel for how your body responds to walking over uneven terrain, then start increasing. The unevenness of trails will make you use muscles you do not typically use.

Definitely talk with your doctor to see how they want you to medicate for hiking. I personally infuse prior to all of my big hiking days to help protect my joints. The main thing is to remember that hiking IS for you, but it may not look like someone else's version of hiking. Everyone is different and everyone has different goals that they are chasing.

How would you encourage others to get involved with hiking in their local areas?

I would first start with your doctor's office. You should always be sure of your limitations when it comes to hiking, and this is a good conversation to have with your physician. Also, your HTC or physician's office may know of local hiking groups or groups of hikers within the bleeding disorders community. A local outdoors store may have some good suggestions for places to hike based on your ability and goals. There are plenty of websites identifying local trails and routes but be careful as these sites can often misrepresent the difficulty or time required to hike a trail.

You've been an active hiker/outdoorsman who has seen a lot of the country's natural beauty – what are your top three favorites places to hike and why?

1. White Mountains in NH/ME- The Whites have some of the oldest trails in the country, and it shows! The trails are rough, rugged, and some of the steepest I've ever been on. Once you get past that though you are met with tons of wildlife, fragrant fir trees, and on clear days views that can stretch from Canada to the Atlantic Ocean.



2. Rocky Mountain National Park in CO - This park is beautiful in all seasons and has very rewarding hikes for every level. In the summer wildflower-filled meadows are home to moose and elk calves, the fall has beautiful colors with the aspen trees changing and the bugling elk echoing off of the steep rock walls of the park, and the winter opens up opportunities to snowshoe in beautiful mountain cirques.
3. Big Cypress Wildlife Area in FL- This one stands out as it is flat, very flat, and only accessible from November to March. This area of old-growth cypress swamp is some of the most ecologically diverse in the country. Rare plants and wildlife abound in this area, the area is quiet, and it gives a rare opportunity to hike with dinosaurs. Just be prepared to get your feet a little wet while you're there.

What are the top items you bring with you on every hike and why?

I bring the *10 Essentials* on hikes - these are common items for hiking or any outdoor activity; navigation device (map, compass), headlamp and batteries, sun protection (sunscreen, sun glasses), first aid items, knife, fire maker (matches, lighter), shelter, extra food, extra water and extra clothing. In addition to the 10 essentials, I bring the following:

- Small stove. Anyone who I've hiked with knows that I am always ok with taking frequent coffee/tea breaks while I am in the woods.
- Small tripod. I enjoy hiking to places where there may not be someone to take a photo of your hiking group.
- Small closed-cell foam pad. This is great for turning any rock into a top-notch seat. I carried one on my hike of the Appalachian Trail, and it hasn't left my pack yet.

Whether hiking for fun, exercise, a means to relieve stress or all three – spending time outdoors has proven health benefits. Work with your treatment team, make a plan, and find some time to explore the natural beauty of your surroundings. Your mind and body will thank you for it!

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William's Appalachian Adventure

BY KELLY GONZALEZ

William Addison wasn't born to be average.

He had adventure in his soul and that was something his hemophilia would never take from him. But then there's 2020. William would face his biggest obstacle yet. He wanted to trek the Appalachian Trail as a thru-hiker.

Thru-hiking refers to a backpacking expedition on an established, long-distance, end-to-end trail.

Day 98, 1683 total miles; near Tennessee

A short hike can be daunting for someone with severe hemophilia. There are many unknown factors but hiking 2,193 miles is the ultimate test for anyone, let alone someone with a chronic bleeding disorder.

Through influences of his dad and fellow Boy Scouts, William always had an affinity for being outdoors and not letting hemophilia get in the way of living life. His Boy Scout troop hikes "High Adventure Trips" every year throughout the Maine Appalachian Trail. William caught the hiking bug and knew he wanted to trek the entire length of the Appalachian Trail (AT).

The preparation was almost as difficult as making the decision of when, and the direction in which to start the hike. William knew research was tremendously important to make his dream a reality. He made a plan and adjusted it each time his parents came up with various considerations. He and his mom worked with the HTC to customize his dosing requirements and he planned things like the location of the nearest water supply, the likely AT shelter he would stay each night, and just in case, the nearest hemophilia treatment center (HTC).

But then COVID-19 turned into a pandemic and delayed his departure. While bummed about having to miss two start dates, William was steadfast in his commitment to hike the AT this year. While he originally planned a northbound (NOBO) trek, what worked for William was a southbound (SOBO) expedition beginning June 5th, near the northern terminus. Why near? Because Baxter State Park wasn't open above the tree line before he left Maine.

For William to be a thru-hiker, he will return from Springer Mountain, the southern terminus, and then climb the last 15 miles from Abol Bridge to Mount Katahdin with Chris Bombardier and a small group of bleeders, family, and fellow Boy Scouts.

Chris Bombardier is the first and only person with hemophilia to summit the highest peaks on each of the 7 continents. After his fantastic adventure, Chris spent some time with William at a local hemophilia event talking about – you guessed it – none other than hiking. The discussion they shared cemented William's decision to undertake this exciting, yet hazardous challenge.

William wanted to take his trip a step further and raise money for *Save One Life* the same way Chris had when he summited those great mountains. William knew this effort was bigger than himself – not just about his physical ability to complete a great task but raising funds and awareness of the needs of people with bleeding disorders in developing countries as well as proving that living with a chronic condition doesn't have to lead to a limited life. In fact, with proper planning and precautions, life is limitless.

As of this writing, William is on day 120, along the Tennessee–North Carolina border, and has hiked 1888.5 miles! He surpassed his original fundraising goal of \$2,200 in the first month. After revising the goal to an impressive \$22,000 – roughly ten times the number of miles on the AT – generous donors from all over the United States have helped him surpass that target too!

We congratulate you, William, on fulfilling your dream and making a difference in the bleeding disorders community!

Follow William's journey! Visit Facebook:
<https://www.facebook.com/sobo4saveonelif/>

To donate to Save One Life,
<https://saveonelifenet/product/0F4001D/sobo-4-save-one-life>



Chef Mike: Cooking With a Big Heart

BY JEFF JOHNSON

When I first met Mike Hargett, it was via the avenue which most of us with hemophilia or other bleeding disorders meet – at summer camp.

At the time, Mike was one of the “little guys” and I was a counselor. Mike was a quiet and shy kid, but very sweet and cheerful, and he was a great addition to camp and his cabin group. As years passed, Mike and I remained good friends, and I have enjoyed watching him find his way in the world, becoming not only my buddy “Big Mike” but also respected and somewhat famous “Chef Mike.”

Today, “Big Mike” isn’t such a little guy anymore and he’s definitely not quiet (in a good way) but he is every bit as sweet and cheerful as I remember, which I believe is the reason he is so successful as a professional chef. Mike infuses every dish and every demo he performs, with his heart and soul, his bigger-than-life personality, and his endearing charisma. He is clearly making the most of both his proverbial heart and the one given him by his donor, whom I am sure would be proud to see the rich and full life Mike is living.

Mike always knew he wanted to be a professional chef and upon graduating high school he was set to begin an internship in Barcelona, Spain. Unfortunately, this was when his health took a downturn and his internship in Spain was not to be. His illnesses would eventually lead him to receive both a heart and a kidney transplant, and for a time he sidetracked his quest to become a chef.

He began studying hospital administration at a local college, a choice he viewed “responsible” and which would make use of his extensive life experiences in hospital environments. This course wasn’t fulfilling to him though and despite nearing completion of the program, Mike bravely decided to go back to what he loved most: cooking.



He soon enrolled at Le Cordon Bleu College of Culinary Arts in Portland, Oregon, and threw himself into learning to be a chef, graduating with honors. He went on to work an externship at the Ritz Carlton in Maui, a job that would become his favorite professional kitchen position. After his externship, he was hired and stayed on the islands for a time, working and discovering Hawaiian cuisine before returning home to Portland, where he cooked in local restaurants and grocery delis.

His budding kitchen career, however, sadly ended as his transplant team advised him that being on his feet in a high-demand kitchen was not best for his new heart and kidney, so Mike transitioned away from that part of his career.

His illnesses would eventually lead him to receive both a heart and a kidney transplant...

In true Mike-fashion, he never gave up. Today, he’s in the kitchen as a professional private chef, performing in-person and online cooking demonstrations. Additionally, for several years running, he has become the highest bid item at his local bleeding disorders organization’s annual charity auction, where he is auctioned to prepare a several course meal in the winning bidder’s home. Having been at these auctions myself, I can attest that nothing in the program makes people more excited than winning a personal meal from everyone’s favorite Chef Mike!

Having watched Mike grow up, I’ve always been grateful and honored to count him as a friend, and now watching him do his thing in the kitchen as viewers watch, ask questions, and cook along at home, I am also immensely

proud. He has truly found his calling and passion in the kitchen. It gives me great joy to remember that shy kid I met many years ago and watch him now dazzle his audience, impart his kitchen wisdom, and invite everyone along on a culinary adventure. I can't help but smile knowing how Mike has made his life his own, how he overcame and conquered everything life threw at him, is making the world a little more cheerful, and a lot more delicious in the process.

I recently had the opportunity to chat with Mike about his journey. I believe his experiences and outlook make an incredibly inspiring story. I hope you do as well...

What originally inspired you into cooking as a career and passion?

My parents had a deli when I was younger, but my dad was more of a home cook and I wanted to find out the science behind cooking – like why meat is seared, how to make a mother sauce, etc. I wanted to take his recipes and elevate them. Plus, I loved watching the Muppet's Swedish Chef growing up - he was a big inspiration too! I loved the uniform and especially the hat. I loved how he would bring joy and a full belly to people, and I wanted to do that as well.

How has hemophilia affected your journey?

It has definitely been challenging, but you'll find a way to do anything worth doing. I can remember in culinary school I had a serious ankle bleed, but that didn't stop me. I actually brought my powered wheelchair into the kitchen and they accommodated me. Obviously, the irony is I'm a chef and I play with knives for a living. I have had some major cuts and burns over my career, but just like anybody else, I just advocated for myself and treated as necessary. The major thing is I chose to disclose [having hemophilia] to all of the chefs I worked for. I only had one who wasn't accommodating.

What has been the most rewarding thing you've experienced as a chef?

I think the most rewarding thing I've experienced as a chef is doing what I'm doing right now. I've cooked all over the world but being able to do virtual cooking demos for others with hemophilia, heart recipients and kidney

recipients is an honor. I never thought that with everything I've gone through health-wise, I'd be here doing this today. I'm truly the luckiest guy in the world!

What is your favorite dish to cook for others?

My forte is food from Spain. I love the culture, the people, and how food brings everyone together. My favorite dish is paella. It's a rice dish cooked in a paella pan. The reason I love it is because it brings everybody together. It's built on the grill - the best part is the socarrat. It's the crispy crust of the rice that forms on the bottom of the pan.

Least favorite dish?

When a customer asks for a filet mignon or a ribeye to be cooked well done. A little piece of me dies...

If you could work in any kitchen anywhere in the world, where would that be?

El Bulli, but it no longer exists. It was a 3 Michelin Star restaurant in Catalonia, Spain run by famed Chef Ferran Adrià Acosta. He was the first to put molecular gastronomy on the map. There is a three-year waiting list of chefs wanting to work with him. Chef Ferran is famous for a 35-course menu where each course is just one or two bites.

“No, I won't die if I get cut while using my chef's knife!”

Do you think you would have still become a chef if you didn't have hemophilia?

Yes. Not even a hesitation. I love to inspire others in the kitchen and there is no better way to say thank you than a meal from your heart! I define my hemophilia – hemophilia doesn't define me! I can't see myself doing anything else in the world.

Which is more challenging; learning to treat bleeds, or learning professional knife skills?

It's definitely more challenging to learn to treat bleeds. You have to get to know your body and that takes time.





With knife skills, practice makes perfect, but there are so many factors involved with treating bleeds... Get it? Factors? I'm a bleeder! I crack myself up.

What is your ultimate goal as a chef?

My goal as a chef is to create that one perfect bite. Sweet, spicy, tart, bitter, savory, and umami. I love when my food takes you back to a childhood memory of something your grandparents or parents would make for you.

Do you have any heroes or role models in the cooking world?

Some of my top role models and mentors are Chefs Thomas Keller, Tommy Habetz, Tom Douglas, John Gorham, and Dennis YaCua.

Do you have any heroes or role models in the hemophilia world?

My mentor Dwayne Whitis, and my grandfather Jim Bowles, who also had hemophilia and passed away from hepatitis C. He wanted to see me succeed and have a better quality of life than he had. He was my #1 fan. RIP.

If you could prepare a meal for any person in history, who would that be?

I would prepare a meal for Robin Williams. He used humor to help him through tough situations. I grew up watching him and would love to tell him that I too use humor to help me persevere, and I wouldn't have gotten this far if it wasn't for my attitude. Humor is medicine! Plus, if I can't laugh about it all, who can?

If you could tell other people with hemophilia one important thing about the world of cooking and being a chef, what would it be?

I would tell people with hemophilia to be able to accept constructive criticism. You are always learning. Just like with hemophilia, you have to adapt. The same goes for cooking. Good chefs will take you under their wing and want to help you,

to teach you. It's not a job at you or your personality. They want to make you better. Listen, learn and always say, "Yes, Chef!"

If you could tell chefs one important thing about hemophilia what would it be?

No, I won't die if I get cut while using my knives!

Which do you think has helped you grow more; learning to manage hemophilia or learning to be a professional chef?

Both, because they are both part of who I am. I've adapted so many times throughout my life with hemophilia and my cooking career. Both have made me into the man I am today. Hemophilia made me grow up faster and taught me to advocate for myself and to keep pushing when my chefs would tell me no.

Which would be worse - a dull knife or a dull butterfly needle?

Both!

What are you prouder of, conquering hemophilia to live the life you want, or studying and training to become a professional chef?

Both! They go hand in hand! I wouldn't be doing what I'm doing today if I didn't start on prophylaxis at a young age. Prophylaxis allowed me to have the quality of life I wanted and taught me that I had career options. Conquering hemophilia gave me the strength and courage to get outside of my comfort zone and enroll in culinary school. Still going strong 12 years later!

And finally, if you had to create a business card with just three lines to tell the world who Mike Hargett is, what would those three lines be?

- First double transplant hemophiliac in the world
- Never gives up
- Mental and physical health advocate



Mike's story is one of perseverance, joy, hard work, and community. These are things people in the bleeding disorders world know well and hold dear. Despite everything life has put in his way, Mike has pushed through and today is doing what he loves most. He is developing a following as more and more people watch his cooking demonstrations and fall in love with his personality.

Never happy to rest on his laurels, Mike is also in the process of establishing his own non-profit, which will focus on teaching people with disabilities how to meal plan, prep, and practice professional kitchen skills despite whatever physical challenges they face. Mike absolutely and quite literally "cooks with heart."

Always using his own recipe creations, Mike schedules cooking demos with BioMatrix several times a month - sometimes it's an entire themed meal; other, shorter presentations of simple home cooked and economical meals with items commonly found in everyone's pantry. He also shows off his skills during special regional presentations hosted by BioMatrix.

Working with him to bring his skills and personality to more and more people as a BioMatrix-sponsored presenter has been a personal joy. If you would like to be invited to one of Chef Mike's demos, please contact your local BioMatrix representative. Chapter leadership may also submit a request for a demonstration at education@biomatrixsprx.com.



Introducing the Points for Healthy Joints Program!



BioMatrix is pleased to announce a new program encouraging healthy behavior for bleeding disorder patients served by our specialty pharmacy. Starting in October, patients will earn points for healthy behaviors including turning in a monthly infusion log, completing a monthly assessment with a pharmacist, and attending an annual HTC visit. More behaviors will be added in the future. Every behavior carries a point value with each point representing entry to a monthly raffle including fantastic prizes.

Incentivizing behavior in the healthcare space is not a new concept. Many public and private health plans offer incentives

to members in order to encourage wellness and better health^(1,2). Research has demonstrated the effectiveness of these programs in promoting healthy behaviors⁽³⁾. The Points for Healthy Joints program will provide opportunities for patients to live healthy, earn points, and win prizes!

BioMatrix is committed to providing service and support making a difference for those living with a bleeding disorder. From education and community support to focused, individualized specialty pharmacy services, we work closely with patients, caregivers, HTCs, and other support organizations to make life a little easier.

Visit biomatrixsprx.com/bleedingdisorders to learn more about our specialty pharmacy services and to submit a no obligations referral today!

Sources:

1. The Commonwealth Fund. (2020). Public programs are using incentives to promote healthy behavior. <https://www.commonwealthfund.org/publications/newsletter-article/public-programs-are-using-incentives-promote-healthy-behavior>

2. Migneault, J. (2017). Patient incentives from payers encourage preventative care visits. Health Payer Intelligence. <https://healthpayerintelligence.com/news/patient-incentives-from-payers-encourage-preventive-care-visits>

3. Adams, J., Giles, E., McColl, E., Robalino, S. (2014). The effectiveness of financial incentives for health behavior change: Systematic review and meta-analysis. Plos One. <https://doi.org/10.1371/journal.pone.0090347>

TEEN SHARES WHAT IT'S LIKE LIVING WITH BLEEDING DISORDER IN MUSICAL

REPRINTED WITH PERMISSION FROM EAST IDAHO NEWS

A Rigby, Idaho teenager with a bleeding disorder is taking center stage to discuss a topic that's near and dear to her heart.

Sailor Leach, 15, was born with von Willebrand disease, which is a lifelong bleeding disorder where a person's blood doesn't clot well. Leach, along with her mother and five of the parent's six children have the disorder, but it varies in severity between each of them.

Sailor said there are lots of misconceptions made by people when it comes to bleeding disorders. That's part of why she auditioned in January for a musical that's featuring kids with these disorders. In February, she found out she was accepted as part of the cast, and since then, she's been waiting for the day to shine a light on a topic that's less talked about.

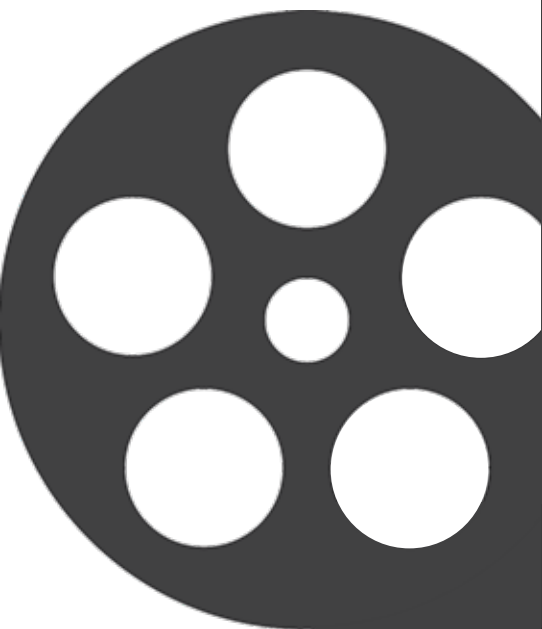
"The musical is to bring awareness," she said. "It's about life as a teenager with a bleeding disorder going through high school."

Sailor is one of 25 teenagers from across the country who are affected in some way due to a bleeding disorder that is in the musical. She was supposed to travel to Chicago to do an intensive workshop then perform live, but plans changed because of COVID-19.



In response to the virus, the musical named "Hemophilia: The Musical" was renamed "Hemophilia: The Zoomsical." Sailor said the cast was asked to record their musical parts over Zoom. They then sent them to editors who've been working to compile the clips so the musical can be viewed on social media.





"Before the musical, I had nobody outside my family that had the same bleeding disorder as me," Sailor said. "Through this musical, I've gained a lot of new friends that I can talk to whenever I need to, and they will get it."

Sailor said living with the disorder can be scary at times, but thanks to the musical and her mom, Robin Leach, she's constantly reminded of the importance of living life to the fullest no matter the obstacles that come along.

"They have to live their life. They have to learn how to cope and deal with issues as they arise. They have to learn how to make those choices for themselves on if it's too dangerous or what risks they're willing to take," Robin said. "I can't put them in a bubble and say, 'No, you can't do this.' That wouldn't be fair to them and their potential."

Sailor admits that while sometimes people treat those

with a bleeding disorder differently and more fragile, she's looking forward to the musical educating people.

"It can really help inform you about bleeding disorders and the people who have them," she said of the musical. "Maybe you'll come across someone who has a bleeding disorder, and you'll know a bit more about their bleeding disorder, so you don't treat them weird."

To view the musical Search *Hemophilia: The Zoomsical* on YouTube.

Reprinted with permission. Brittini Johnson. "Local Teen to Share What It's Like Living with Bleeding Disorder in Upcoming Musical." East Idaho News, 30 July 2020, www.eastidahonews.com/2020/07/local-teen-to-share-what-its-like-living-with-bleeding-disorder-in-upcoming-musical/.



BIOMATRIX

Meet the Team!



Tina McMullen

Regional Care Coordinator

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 Tina McMullen. Tina has served as a Regional Care Coordinator in the Pennsylvania area for over 8 years. She is a fierce advocate, hemo-mom, and one of the kindest people you'll ever meet. We invite you to get to know Tina!

Describe your connection to the bleeding disorders community.

My son Dakota was diagnosed at 6 months of age with severe hemophilia B. A few weeks before his 6 months check-up, we noticed bruising all over his chest. I was terrified our pediatrician would think we were abusing him. The pediatrician immediately ordered a series of tests. Waiting for those results were the longest 2 weeks of my life.

When the results came back positive for hemophilia, our world was turned upside down. We do not have a family history of hemophilia and had never even considered it. We found out on a Friday and on Monday we were at the Children's Hospital of Philadelphia. After all the crying we knew we had to educate ourselves. We started attending educational

The McMullen family is extra protective of Dakota, who suffers from hemophilia B. Left to right: Tina, Megan, Jeff and Dakota.

Sticking Together – Hematologists Help Families Cope with Hemophilia B

When Dakota McMullen was 6 months old, two large, bruise-bruise unaccountably appeared, nearly covering the infant's chest. "I thought, there's nothing he could do to get bruises like that; he's a baby," remembers his mother, Tina, who suspected Dakota's 6-month check-up for fear she'd be suspected of child abuse.

Some three weeks later, the bruises were faded but still visible. Dakota's pediatrician ordered blood tests, which brought the unfortunate news that the child had the bleeding disorder, hemophilia B. An abnormal gene had left him with less than 1 percent of a normal level of coagulation factor IX. A gene in the blood that helps it to clot. The bruises were a sign of internal bleeding, possibly resulting from the simple pressure exerted when his parents picked Dakota up.

Dakota's bleeding incidents increased as he learned to walk. His parents captured their fears and removed all tables, but little bumps and falls that would be shrugged off after a few years for most toddlers required medical treatment for Dakota. The McMullens had an array of 20 emergency room visits for intravenous infusions of factor IX to make Dakota's blood clot normally.

One memorable morning, when Dakota woke up screaming and unable to walk, his family rushed him to Children's Hospital, where his physician, Catherine Marano, M.D., associate director of the Hemophilia Program, recognized the signs of a pelvic bleed. "Ten minutes after he received his IV infusion," recalls Tina, "he was running around again."

Many patients with severe hemophilia receive prophylactic treatments. Like a week, they receive clotting products intravenously to maintain a level of the clotting factor in their blood that is higher than their baseline level. "We recommend prophylactic treatment when patients have shown a tendency to bleed in their joints, in order to prevent progressive joint disease," says Dr. Marano.

Furthermore, Dakota has had two such joint bleeds, which can be very painful and cause long-lasting damage, when leaking blood corrodes joint tissues. Bleeds in muscle are also painful, although less likely to cause lasting damage. Most worrisome are bleeds around the brain, where fluid pressure can reach dangerous levels.

Twenty years ago, the only coagulation factor available was extracted from human blood plasma. Today, Dakota and many other patients with hemophilia receive recombinant factors, manufactured from DNA using genetic engineering techniques. "This synthetic clotting factor is pure and safer than plasma-derived factor," says Dr. Marano.

Time will tell whether it might become medically necessary for Dakota to receive twice-weekly, expensive prophylactic treatments. In the meantime, Children's Hospital researchers are performing pioneering research into treating hemophilia B with gene therapy. Instead of infusing the missing clotting factor, this approach addresses the underlying problem. It introduces the gene, missing in the disease, that directs the body's cells to produce their own clotting factor. In animals, these benefits have been seen to persist for many months.

Katherine High, M.D., a colleague of Dr. Marano's in the Division of Hematology, successfully treated naturally occurring hemophilia B in dogs. A single injection of the genetic material commanded to dramatically increase blood clotting time 18 months later. "We found neuronal expression of clotting factor at a level that would be therapeutic in humans," says Dr. High. "If these results carry over to people, the gene therapy would change a patient's condition from severe hemophilia to a milder case."

Gene therapy experiments for various diseases have shown promise in initial experiments in mice but have faltered when applied to larger animals. Dr. High's encouraging results in dogs with naturally occurring hemophilia strongly suggests that the approach is feasible in people. Her gene therapy is awaiting regulatory approval to begin clinical trials in people with hemophilia B, possibly later this year.

Dakota McMullen is now 2 years old, an active, energetic youngster with a little boy's affection for trains, trucks and other wheeled machines. If the Hospital's hemophilia research fulfills its promise, his later childhood years may give him full freedom to run and play without the nagging worry of a quick trip to the emergency room.



Dakota, an active toddler, loves fire

programs at our HTC and got involved with our local chapter.

What brought you to BioMatrix?

After my son's diagnosis, I became very active in the community. I was on the Parent Advisory Board at the Children's Hospital of Philadelphia. My husband and I were "County Captains" for our local chapter. I wanted to help other families dealing with the same issues I dealt with so when the opportunity to work in the community as a specialty pharmacy rep came up, I knew it was meant to be.

How do you feel you are Making a Difference?

I feel I am *Making a Difference* by being a mom and community member first. Always remembering what I wanted for my son. I look at every community member as family. It is my responsibility to help every one of my "family members" address and overcome any obstacle they may be faced with.

"After all the crying we knew we had to educate ourselves."

What do you cherish about your role as a Regional Care Coordinator?

What I cherish most about my job is working alongside the pharmacy to provide the best possible care. Talking with a new parent who thinks they are all alone. Seeing that flash of relief, of hope, of realization that everything is going to be okay are the moments I truly cherish.

What was your most difficult challenge raising a child with hemophilia and how did you overcome it?

There have been so many challenges over the years. First bleed, first infusion, first day of school, first time away at camp, the list goes on and on. I'll go with the most recent one. When Dakota moved out last year, I worried about everything. My mind was constantly racing. Did he get to work okay? Did he get home okay? Is he infusing like he is supposed to? As weeks turned into months without any issues, I finally realized things were going to be okay.

I did my job of teaching my son how to effectively manage his bleeding

disorder. Worry has now turned into the satisfaction of watching my son spread his wings. He's found the most wonderful young lady, Steph, and now it's their time to start their lives together.

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

My mom, Connie, was my most positive influence. At the age of 27, my mom was widowed with 2 small children. Her strength and determination have always inspired me. I believe learning from my mom is what has gotten me through the tough times and greatly influenced the person I am today.

What is the best advice you have ever received?

Dakota's hematologist told my husband and me from the very beginning, "You cannot put your son in a bubble. There will be some things he cannot do and there are some precautions you will have to take, but by and large, he will be a normal kid."

Those words stuck with me for a very long time and had such a calming impact during a time of confusion and fear.

What motivates you - what is your passion?

My passion is making a difference in people's lives. Showing compassion, empathy, and understanding while helping lead patients to the resources and support that makes life with a bleeding disorder a little easier.

What is your proudest achievement?

My proudest achievement is going from having an infant diagnosed with a bleeding disorder and knowing nothing about it to advocating, educating, and supporting others. Building community and working as part of a caring team that truly is making a difference in the lives of others makes me proud.

Contact Tina:

Mobile: 484-942-4457

Email:

tina.mcmullen@biomatrixsprx.com



Jeff, loving husband of 35 years



Children, Dakota and Megan



Tina's joy, granddaughter Bella



Tina - the early years

BIOMATRIX ON THE *Virtual* MOVE!

Did you know?

Everyone attending our educational and fun Zoom sessions are entered into a raffle for a \$50 gift card. When we reach 50 attendees, we draw a winner!

Raffle winners to date!

May 19 th	Alexander King	August 11 th	Gabi Muncy
June 2 nd	Milinda DiGiovanni	August 11 th	Laura Portales
June 9 th	Tara Lutz	August 28 th	Najmun Nahar
June 18 th	Phil Monin	August 28 th	Darlene Trice
June 30 th	Timothy Wilcox	Sept. 16 th	Diane Gassiraro
July 22 nd	Regly Acosta		

#BioMatrixMugClub

Curl up with your favorite warm beverage and BioMatrix virtual programming! BioMatrix offers a variety of educational and entertaining topics in group and individual settings. All program participants receive this fantastic coffee mug. Have you participated in BioMatrix educational programming? Post a photo using the hashtag #biomatrixmugclub. Learn more!

<https://www.biomatrixsprx.com/bleeding-disorders-education>



THE GREAT *Northeast* JEOPARDY CHALLENGE



Shelby "Trebek" Smoak



Richard "Gilbert" Vogel



Melissa Deeb
BDANENY

Jeremy Griffin
NYCHC

Meagan Murray
CHS

Stephanie Lapidow
HANJ

Linda Mugford
HANY

Rich Pezzillo
NEHA

Bridget Hunnewell
HAM

The **Great Northeast Jeopardy Challenge** was broadcast July 23rd live from BioMatrix Jeopardy studio in cyberspace (Zoom). Six bleeding disorder chapter executive directors and one outreach manager from the Northeast squared-off head-to-head in the competition!

As the contestants took their positions, we met a terrific array of executive directors; Melissa Deeb of Bleeding Disorders Association of Northeastern New York (BDANENY), Jeremy Griffin of New York City Hemophilia Chapter (NYCHC), Meagan Murray of Connecticut Hemophilia Society (CHS), Stephanie Lapidow of Hemophilia Association of New Jersey (HANJ), Linda Mugford of New York (HANY), Rich Pezzillo of New England Hemophilia Association (NEHA), and Bridget Hunnewell, Outreach Manager & Research Assistant for Hemophilia Alliance of Maine (HAM). The master of ceremonies for this highly anticipated event was BioMatrix's very own Shelby 'Trebek' Smoak with his sidekick announcer, Richard 'Gilbert' Vogel.

On hand to observe the fierce competition were a plethora of community members standing by to send a lifeline throwing their knowledge to their struggling executive director. The challenge began with 2 daily doubles in the first round. There was good-natured banter, jests, and the expected Executive Director bravado. There was a lot of education as well, and a few moments of "Hey! I didn't know that!" and "I can't believe I didn't know that!"

In true Jeopardy fashion, after a tense second round, we went to a commercial from our sponsor CSL Behring, who kindly provided each chapter with equal funding in place of a prize.

Yeah, yeah, everyone was a winner, but in the end, it was Rich Pezzillo (NEHA) who scored the most points and currently holds bragging rights as champion of the Great Northeast Jeopardy Challenge.

We formally issue an invitation to all Executive Directors who want to take up the challenge! Organize a group of like-minded executive directors and reach out to BioMatrix at education@biomatrixsprx.com. Let the games begin!



And the winner is...
Rich Pezzillo of New England Hemophilia Association!

BIOMATRIX] ON THE *virtual* MOVE!

Though we're not on the physical "move," we've been busy hosting tons of fun-filled educational Zoom meetings! Read on to see what we've been up to. Plan on joining us soon!!

IT'S *OK OK* TO NOT BE *OK*

July 28, 2020

Presenter: Kelly Gonzalez
RCC: Peggy Klingmann &
PCS: Marcy Foertsch

Awareness for - *Advocacy* -

July 2, 2020

Presenter: Kelly Gonzalez
Host: Nevada Connection

July 16, 2020

Presenter: Kelly Gonzalez
RCC: Jeff Johnson
Host: Idaho Connection

HEALTH INSURANCE BASICS *Everything* You Didn't Know — You Need To Know

August 25, 2020

Presenter: Shelby Smoak
RCC: Peggy Klingmann

Putting The Mask On - *First* -

July 28, 2020

Presenter: Kelly Gonzalez
RCC: LeAnn Wilson

Singing - **HEAL**

This interactive discussion of music, the brain, and healing empowered participants to tap into the healing power of music and into sharing the emotional experience with others.

September 9, 2020

RCC: Hector Heer Presenter: Shelby Smoak

Transition - **TO** - **SELF-INFUSION**

August 6, 2020

Presenter: Kelly Gonzalez
Host: Nevada Connection



THE COALITION FOR HEMOPHILIA B
PATIENT ASSISTANCE PROGRAM

“
ONE OF THE MOST
IMPORTANT THINGS YOU
CAN DO ON THE EARTH
IS TO LET PEOPLE KNOW
THEY ARE NOT ALONE.



SHANNON L. ALDER

BCares Patient Assistance Program provides short-term, limited financial aid to our hemophilia B community members who encounter unforeseen emergencies, including COVID-19 related hardships. The charity and compassion of our BCares partners make this critical funding program possible. Thank you for your support.

The Coalition for Hemophilia B is a national nonprofit serving the hemophilia B community for 30 years.

LEARN MORE hemob.org/bcares

PLEASE DONATE hemob.org/donate

THE COALITION FOR
HEMOPHILIA 
Email: contact@hemob.org
Phone: 212-520-8272

THE 411 ON 504s

Also known as *Transition to School and 504 Plans*, this session provided information and resources to design and implement effective 504 plans, the transition between grades, schools, and alternate academic settings during the time of COVID-19. For caregivers of children with a chronic health condition, it is important to understand legal rights for academic accommodations. Parents came away empowered with a clearer understanding of their child's rights for accommodations in the academic setting.



July 23, 2020

Presenter: Kelly Gonzalez

August 27, 2020

Presenter/RCC: Kelly Gonzalez

August 27, 2020 ¡En español!

Presenter: Kelly Gonzalez

RCC: Eva Kraemer

Navigating TRICARE

August 13, 2020

Presenter: Shelby Smoak, Ph.D.

RCC: John Martinez

We can't overlook our families in the military because even our armed forces houses persons with bleeding disorders. To that end, we hosted Navigating TRICARE: How to Keep Access to Care for Military Families with Chronic Illness. After an overview of TRICARE and an examination of the obstacles to continuity of care in TRICARE communities, we fielded questions about open enrollment, coverage and the necessity of TRICARE pharmacy-approved status for factor medications. All participants walked away with a firmer grip on protocols and support resources available to TRICARE members.

Please join BioMatrix for our next *Navigating TRICARE* session November 10th at 6 pm EST. Email us for an invitation: education@biomatrixsprx.com

Transition to College

College should be an exciting time for new students; however, when living with a bleeding disorder, moving away to school may be more concerning. This insightful session offers students and their parents many tips and tricks for navigating successfully as they prepare to live on campus.

August 11, 2020

Presenter: Kelly Gonzalez

Host: Maria Santucci Vetter, Communications Mgr.



SCHOLARSHIP 101

College is expensive, and many students are searching for ways to reduce the cost of their higher education. To help, BioMatrix held an informative session on Scholarships 101. This very well-attended workshop-style program attracted future and college students as well as parents in anticipation of learning how to best identify opportunities, organize the required information, and submit and track the applications.

In addition to coming away with straight forward tips to leverage opportunities, students were sent a Scholarship 101 binder to help stay organized as well as a fairly comprehensive list of national and state bleeding disorders community-based scholarship opportunities. Best of luck to all students this school year ahead!

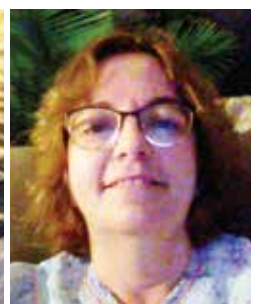
July 1, 2020

Presenter: Kelly Gonzalez with

Maria Santucci Vetter, Communications Mgr.

Host: The Coalition For Hemophilia B

Sponsor: Medexus



Feed Mind + Body — WITH CHEF MIKE! —

Mike Hargett is a professional chef, double transplant recipient, and a person with hemophilia who lives by the mantra that his conditions don't define him; he defines them. Mike trained at Le Cordon Bleu College of Culinary Arts in Portland and completed an externship at the Ritz Carlton in Maui. Mike has gained fame within the bleeding disorder and transplant communities as a cooking demonstrator. In online sessions, Mike shares his enthusiasm for cooking and his "zest" for life as he elevates ordinary household ingredients into savory, restaurant-enviable meals in these interactive events. As the world's first person with hemophilia to receive a heart and a kidney transplant, Mike's positive attitude, good-humored personality, passion for cooking, and perseverance embody his spirit of "cooking with heart."



July 30, 2020
Safe Travels
Presenter: Kelly Gonzalez
RCC: John Martinez

August 27, 2020
It's Ok to Not Be OK
Presenter: Terry Rice
RCC: Rania Salem and
Eva Kraemer

August 27, 2020 ¡En español!
Back to School
Presenter/RCC: Kelly Gonzalez

July 30, 2020 ¡En español!
Safe Travels
Presenter: Kelly Gonzalez
RCC: John Martinez

August 27, 2020
*Transition to School &
504 Plans*
Presenter/RCC:
Kelly Gonzalez

September 9, 2020
It's Ok to Not Be OK
Presenter: Terry Rice
PCS: Susan Moore and
Sarah Henderson

August 22, 2020
It's Ok to Not Be OK
RCC: Jeff Johnson
Presenter: Terry Rice

September 23, 2020
It's Ok to Not Be OK
Presenter: Kelly Gonzalez
RCC: Tina McMullen





OUR Special SOMETHING -for kids-



July 28, 2020

Presenter: Shelby Smoke, Ph.D.

Host: Donna Garner, Patient Care Specialist

Book Author and Reader: Terry Stone



When parents say that their kids have the zoomies, it usually means they are running around frantically dodging ottomans and the family pet. Well, no more. BioMatrix just changed the game and MADE...IT.. BETTER! (the crowd cheers!). It was hosted by BioMatrix's own Donna Garner along with the coolest Education presenter at the mic, Shelby Smoak. Kids and their parents joined us and others from across the country via a Zoom presentation Tuesday, July 28th, for our first ever fun new kid friendly virtual activity program called, Our Something Special for kids.

Kids and parents alike had so much fun. To kick off the event, author and BioMatrix extraordinaire Terry Stone read her children's book, *This is My Something*, (co-authored with Michelle Stielger) to the kids. Then

they went head-to-head with some age worthy bleeding disorder trivia. Next it was time for the final challenge; to engage their zoomies expertise as they went throughout the room to find items that met the scavenger hunt mission at hand - for example, find something green, find something with holes. Sounds easy right? Well, our pint-size participants zoomed around finding items and having a ball.

It was an exciting event that brought parents together with their children, and families together with other families. It was a thoughtful diversion to another COVID-19 quiet afternoon at home. Interested in joining us for a future event, let your local BioMatrix Regional Care Coordinator know or message us at education@biomatrixsprx.com and we'll play soon!



Time for Fun!

ANSWERS TO PUZZLES ON PAGE 27

TOURNIQUET

You can see it with ease!
Look at your vein
I like to squeeze
Just like a boa

SYRINGE

With a plunger tool
I'm a cylinder
That's the job I do
Hold all the factor

FACTOR

Makes it safe to play!
The help I provide
To save the day
I rush to the scene

BLEED

I like to prey!
On your joints and muscles,
With my sneaky way,
I can cause you pain,

BUTTERFLY NEEDLE

To help it get in!
I carry the factor
Head sharp as a pin,
Wings like a moth,

ALCOHOL PAD

For the stick to go in!
I get the site clean,
Near as a pin,
Wipe, wipe, wipe,

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

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

Women — Bleed Too

July 26, 2020

Presenter: Kelly Gonzalez

RCC: Terry Stone

Host: HACA

It goes without saying that 2020 will be a year to remember. Hugs and handshakes have been replaced by virtual events, Zoom connections with creative personalized backgrounds of beaches, forests, and outer space. There is one thing for sure, the Hemophilia Association of the Capital Area (HACA) wants to make sure members feel “out of this world” and grounded during such a challenging

time. Thanks to an informative and personal perspective of living with and caring for a family with vWD, Kelly Gonzalez presented, *vWD: Not the Little Sister of Hemophilia*. As the most common bleeding disorder, patients who live with it don't often feel as though they get the same attention and support as some of the other diagnoses.

“The impact of this can delay treatment, cause affected persons to suffer emotionally and physically because they feel they are over-reacting to their vWD since it's often perceived to be a “mild” condition,” says Kelly Gonzales, BioMatrix Sr. Education Specialist. She discussed the importance of advocating for what you need, especially when you are used to hearing, “It's just vWD.” Never

should your struggles and challenges be minimized or compared to other bleeding disorders. She spoke about the importance of keeping a journal, pictures, and how a bleed affects your school, work, and family life. Along with the additional presentation by Dr. Nance, HACA vWD families enjoyed a weekend full of medical knowledge AND real-life experience on how to take care of your bleeding disorder, advocate, document, and live your best life - and remember, vWD is not the little sister!



BIOMATRIX GAME NIGHT

BioMatrix Game Nights have provided fun-and laughter-filled virtual get-aways for many! Jeopardy, Family Feud, Wheel of Winning, Trivia Quiz, Scavenger Hunt, and our newly released,

Spanish Loteria game are the current choices! Declare victory over your friends! Let the games begin! Contact us today to schedule your virtual game night! education@biomatrixsprx.com

July 16, 2020 – Jeopardy

Emcee: Shelby Smoak

RCC: LeAnn Wilson

July 29, 2020 – Wheel of Winning

Emcee: Shelby Smoak

RCC: Eva Kraemer

Sept. 9, 2020 – Wheel of Winning

Emcee: Kelly Gonzalez

RCC: Tina McMullen

Sponsor: Ellen Rowe/Medexus

July 29, 2020 – Great NE Challenge

Emcee: Shelby Smoak

RCC: Richard Vogel

August 11, 2020 – Family Feud

Emcee: Shelby Smoak

RCC: Rania Salem and Moe Hoque



Time for Fun!

HI KIDS!

Can you guess the riddles? Good Luck!
Answers can be found on page 25.



Wipe, wipe, wipe
Neat as a pin
I get the site clean
For the stick to go in!
What am I?

Wings like a moth
Head sharp as a pin
I carry the factor
To help it get in!
What am I?

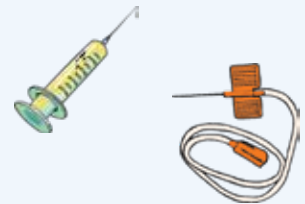
I can cause you pain
With my sneaky way
On your joints and muscles
I like to prey!
What am I?

I rush to the scene
To save the day
The help I provide
Makes it safe to play!
What am I?

Hold all the factor
That's the job I do
I'm a cylinder
With a plunger too!
What am I?



Just like a boa
I like to squeeze
Look at your vein
You can see it with ease!
What am I?



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

Sudoku!

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

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

BIOMATRIX

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