

BIO MATRIX

NEWS



**DEDICATED
TO MAKING
A DIFFERENCE**

**SUMMER 2020
VOLUME 15 | ISSUE 3**



“ Nothing shakes the smiling heart. ”
— Santosh Kalwar

ABOUT BIOMATRIX

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

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

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

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

MISSION + VISION

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

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

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

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

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

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

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

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

FINE PRINT

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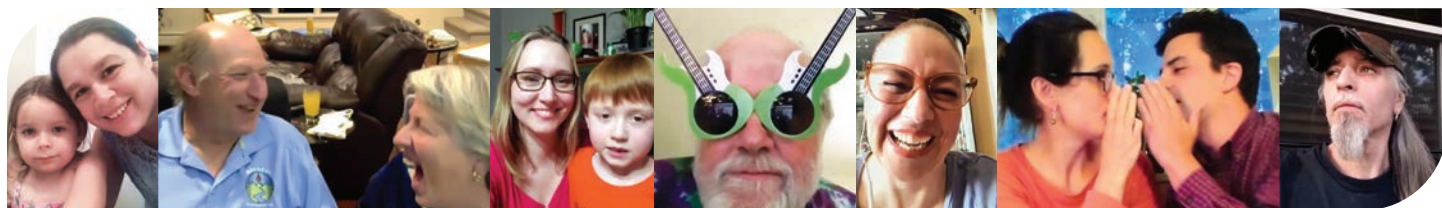
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TIME FOR KIDS



A NOTE FROM THE EDITOR

Dear Readers:

Just a few months ago, an occasional company Zoom meeting was the norm. It did the trick, but it certainly did not take the place of being with my co-workers. Today, however, I am reminded just how lucky we are to have such a way to communicate!

Before the pandemic, the BioMatrix Education Department already had a series of virtual meetings that we held on occasion. Little did we know just how valuable it would become! Yes, it still doesn't quite take the place of seeing each other in person, but given the situation we find ourselves in, I am personally thrilled to have a way to stay connected with and see the faces of my community friends.

Our collection of topics is broad – with titles such as *It's OK to Not be OK*, *No Need to Bleed*, *Singing to Heal* and many more. Our virtual meetings have helped keep us connected with the bleeding disorders community across the country. We've seen old friends and have had the chance to meet new people, some that do not often attend events in person.

In so many ways, these sessions have been a blessing. In fact, they have given me the opportunity to see even more people than in a typical month. Hands down though, the most fun Zoom meetings have been our Game Nights. Is our community more competitive than normal or are we just bigger hams? Regardless, the hour spent at a game night always brings a smile to my face.

In this issue of BioMatrix News, we've listed many of the Zoom meetings that have taken place. Getting a "great" picture has been challenging – low resolution, funny faces and laundry room backgrounds prevail! Kids bouncing in, dogs demanding to be walked, phone interruptions and connection problems have all added to the unique nuance of a virtual life.

Please consider joining us when you see an invitation! Better yet, call us and we will be thrilled to set up a session just for you and your group. Let's get together for a pound of education and a ton of laughter!

Keep happy and healthy!

Maria Santucci Vetter
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BEING CERTAIN IN A TIME OF UNCERTAINTY

BY: SHELBY SMOAK, PH.D.



How are we to reopen our country, our states, our cities, our bleeding disorders community, in this time of great uncertainty? How can we be certain we are doing the right things and doing them the right way?

Ultimately that kind of certainty eludes us. Only time can reveal those answers. But there are other things of which we may be certain, and it is these things upon which we can build confidence in moving forward and reopening.



Let's look at what we can be certain of in these uncertain times:



WE NOW KNOW FAR MORE ABOUT COVID-19.

In early March when most of the U.S. went on lockdown and a State of Emergency was declared, fear drove so many things: What is COVID-19? How do you get it? What happens if you catch it? How can you stay safe? While our fear of things – snakes, ledges, fire, deadly viruses – is an inherent survival response and in many cases keeps us alive, we cannot live in a continuous, unending state of heightened fear. Our bodies and our minds cannot endure such constant stress. With many questions answered, our fear has diminished, and our response to navigating life with COVID-19 can be more rational.



COVID-19 IS NOT GOING TO MAGICALLY DISAPPEAR IN THE NEXT FEW MONTHS.

While it is wishful thinking to hope that summer will take care of COVID-19, almost all health experts agree that will not happen. Accepting that COVID-19 is still here will help you make choices that are smarter and safer as we move forward with reopening stores and businesses. Assume that COVID-19 is with you in those places and protect yourself against it.

SOCIAL DISTANCING CAN REDUCE COVID-19'S SPREAD

Your proximity to someone who is possibly contagious has an enormous impact on the virus's ability to infect you.



More space equals less risk. It's as simple as that. The CDC has continually emphasized that "maintaining 6 feet social distancing remains important to slowing the spread of the virus."ⁱ

HANDWASHING FOR 20 SECONDS CAN REDUCE COVID-19 INFECTIONS.

Handwashing is something everybody can do and it goes a long way toward keeping you safe. For one, soap molecules have been clinically demonstrated to kill the virus by attracting the virus to the soap molecules, dissolving the virus's protective barrier, and dislodging it from your hands.ⁱⁱ The CDC recommends washing your hands especially when you've been in public places, and always before touching your eyes, nose, or mouth – a thing the average person does 23 times an hour – since knowing this is how the virus enters the body.ⁱⁱⁱ



WEARING A FACE MASK WILL REDUCE THE SPREAD OF COVID-19.

Although this has been debated and the resistance to mask-wearing has become a hot topic, the certainty is that masks will reduce the risk of exposure. They do this in two ways: first by reducing viral transmission and second by quelling a person's habit of touching their face. Combined with social distancing, masks provide another layer of defense against COVID-19.





MITIGATION STRATEGIES LIKE SOCIAL DISTANCING AND MASK-WEARING WILL BE AN INDIVIDUAL CHOICE IN MANY SITUATIONS.

States, businesses, communities, and bleeding disorders organizations are all responding differently to reopening. Although the CDC has issued guidelines to advise these entities on reopening, a uniform message is lacking as is any enforcement. For example, the Virginia Department of Health, where I live, “requires people to wear cloth face coverings when spending time in indoor public settings.”^{iv} However, the Virginia Department of Health does not have

“Nobody can say what the other side of this looks like, but all can agree we will get there.”

a police force, nor is it the responsibility of local police departments to necessarily enforce this. Some Virginia businesses have placed a greeter in the doorway to turn away those not wearing masks, but most do not police their stores either.

In many states there are no face mask requirements, reinforcing even more the individual choice involved in that protective strategy. Ultimately, individuals, business owners, and communities will shoulder the burden of what reopening looks like, and it will differ from person to person, store to store, community to community. Make choices that keep you safe, even if those decisions are not universally adopted in the place where you live.



WE WILL GET THROUGH THIS.

This is absolutely certain. Nobody can say what the other side of this looks like, but all can agree we will get there. History and our survival of so many terrible things are our examples here. I will turn to the plague of the 1660s and an author I admire, Samuel Pepys, who kept a diary of his experience of that time. He lived in London when the plague struck in 1665. It is estimated that as many as 1000 people were dying daily in The Great Plague of London – a death toll that is sadly, but eerily equal to the current number of daily deaths in the U.S. due to COVID-19.^v

Out of fear, Pepys left London for a cottage in the countryside. While that is a luxury most of us do not have, it certainly highlights the sage advice of social distancing because Pepys survived and returned to London the following year. He found the businesses reopened, church members gathering, and the community filled again with life. London had survived. Life was returned and the city reopened.^{vi} The United States will as well.



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2020 BLEEDING DISORDERS CAMPS



Summer 2020 has found bleeding disorders camps on hold – most have been canceled for the year, a few postponed with the hopes there will still be a chance to meet in person come fall. Though gathering physically at various campgrounds have, for the most part been canceled, many organizations are holding “virtual” camps to encourage and uplift the children who would have attended.

We have been attempting to keep track of such meetings on our online Camp Directory; however, please be sure to check with your camp host to find more information.

To view the 2020 Camp Directory, please visit: <https://www.biomatrixsprx.com/bleeding-disorders-camp-directory>

As we have previously proclaimed, the bleeding disorders community is resilient. We are experienced with facing and overcoming adversity and together we will see this through.

Let's keep our eyes, hearts and minds toward the future and look forward to the days where children with bleeding disorders across the country can once again spend magical time away from home with their “other” family!



Summer 2020



Assisting Educating Advocating For The Bleeding Disorders Community.



www.hemophiliafed.org

FRUSTRATED?

YOU'RE NOT ALONE.

FEEL FREE TO

Vent!

BY: GARY MCCLAIN, MS, PHD, LMHC

The COVID-19 threat continues. Recovery has been painfully slow. We're all feeling frustrated.

Self-isolation has been key to staying healthy, but human beings are social by nature. We're all feeling the loneliness, along with the uncertainty about when we can safely return to some kind of normalcy.

Did I say uncertainty? That's something else humans don't do well with. We want to know!



How are you feeling? If you're anything like the people I talk with every day – as a mental health professional, as a friend, as a family member – you're most likely feeling all sorts of emotions as you cope with life as we currently experience it. Frustration, fear, anger, sadness, disappointment... and more frustration.

For families living with a chronic condition like a bleeding disorder, the isolation has resulted in additional concerns. Access to physicians and treatment centers has been much more complicated, with the need to take additional precautions to prevent bleeding episodes. Any changes to healthcare routines can be scary, as well as disruptive to established regimens. Of course, the need for home-schooling and other changes to family routines is also challenging. And frustrating...

All these emotions need somewhere to go. Sometimes you just want to vent.

A GOOD VENT CAN PROMOTE EMOTIONAL WELLNESS

Here are the potential benefits of a good vent: Venting helps you work through your feelings which, in turn, is a step toward accepting the challenges you and your family members are facing. It's a way to let out all those feelings that have been building up in your mind, taking up valuable space that could be better used for thinking and decision-making. Fighting your feelings is fighting yourself. When you stop the fight, you're in a better position to find solutions.



A caution: venting can turn into ranting, which is a lot of angry words that go on and on and don't accomplish anything except to drive everyone else away in the process. Venting helps you to release feelings, while ranting is a way of hanging on to them.

“...ask yourself, what is it you need to vent about, and why?”

NOT SURE HOW TO VENT IN A WAY THAT PROMOTES YOUR EMOTIONAL WELLNESS? HERE'S HOW:

Give yourself permission to express strong emotions
Human beings experience a whole wide range of emotions from the emotions we label as “good,” like happiness, to the ones we label as “bad,” like anger. Instead of labeling emotions as good or bad, let's label them as human. And then tell the positive thinking brain cells to take a break while we feel how we feel. Look at it this way: Not getting bogged down with trying to “swallow” your emotions can help you to maintain your optimism.

Find a willing listener

Not everybody in your life is able to listen while you vent about a challenge you're facing. Some may be uncomfortable with strong feelings or think they should do something to help you and, as a result, feel helpless, or they have too many of their own problems to deal with. Avoid choosing someone who wants to run for the hills as soon as you open your mouth, those who will judge you for not “staying positive,” or who will try to fix you in some way instead of *just listening*.

Be mindful of your intentions

Ever had a political discussion you realized later was really all about how angry you are at the other person and not about politics? A vent can be just that – a way of indirectly expressing anger at someone, or again, turn into a rant. Take a step back and ask yourself, what is it you need to vent about, and why?

Keep in mind that venting has consequences. A positive consequence is giving voice to your feelings. Doing this can take away their power to do harm or to keep you stuck. However, venting that is directed toward someone else can have the consequence of alienating other people.

Start by asking if the other person is willing to listen

Say something like, “I just need to talk to someone about how I'm feeling. Would you mind listening?” It might help to add: “I don't expect you to have any answers for me. I just need a listener.”

State what you want to vent about

“I am dealing with _____.” This accomplishes two purposes. First, it provides the opportunity for the other person to decide whether this is something they can hear. It will also help you stay focused and help avoid drifting into a rant about everything that has frustrated you for the past 20 years.

Be mindful of how the other person is reacting

Body language says it all. Nodding, leaning forward, eye contact – these are signs of involvement. Looking away, moving away, interrupting you with comments like “You’ll be fine” are signs the other person has heard enough. It can help to ask, “Is this hard for you to listen to? If so, I understand.” Don’t take it personally. Not everyone can sit with uncomfortable emotions – their own, or someone else’s.

Say what you need to get out

Set limits on your vent by being mindful of what you need to say. Signal you’re done by expressing appreciation, “Thanks a lot for listening. It helps to have a listening ear.”

Be realistic about your expectations

Your listener may have a few words of support, a few suggestions, or nothing to say at all. Remember, people do the best they can and all you asked was for them to listen. If your listener does respond with a whole list of solutions or orders, you have a choice as to whether you want to receive this information. Who knows? They may have a perspective you haven’t thought about, but you can also say, “You’ve been very helpful by just listening. I don’t expect you to make it better.”

HEALTHY VENTING CAN BE A WAY OF CONNECTING

Starting with your partner – you may both be walking around your home stepping around the elephant that keeps getting in the way of your communication. What’s the name of that elephant? Something like frustration, disappointment or fear? Address the elephant by name.



Talk to each other about feelings, beginning with encouraging each other to vent as needed.

Offer to be a listener, too

Remember that your listener, whether your partner or another listening ear, may have some of their own challenges and frustrations and need a listening ear, as well. Be willing to return the favor.

Parents, give your kids a chance to vent

Make your home a safe space for talking about emotions. Talk about your feelings and encourage your kids to talk about theirs. Let your children know you are open to hearing about how they’re dealing with life as we currently know it. They also are feeling a lot of emotions.

By the way, there is no greater way to connect with another person, your partner, your children, a family member, a friend, a co-worker than by listening. *Really* listening... with an open mind.

If you need a good vent, have at it. Then give somebody else a turn. We’re all in this together!

About Gary McClain

Gary McClain, MS, PhD, LMHC, is a therapist, patient advocate, blogger and author, specializing in helping clients deal with the emotional impact of chronic and life-threatening illness, as well as their families and professional caregivers. He works with clients to understand and cope with their emotions, learn about their lifestyle and treatment options, maintain compliance with medical regimens, communicate effectively with the medical establishment, and listen to their own inner voice as they make decisions about the future. Gary welcomes your questions and comments.

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SEAN'S FACTOR

BY: LEANN WILSON

"I would not be the same individual if I did not have camp. My experiences in the community have helped shape who I am today," shares Sean Noel.

Sean is not a typical 18-year-old. He was diagnosed with hemophilia A at the age of two, and when he was old enough, Sean attended a summer camp program for children with bleeding disorders. Camp Wounded Knee (now Camp Globeclotters) changed his life. "I learned so much about my condition, like the science behind it and self-infusing. It was such a great experience. The staff was amazing, and I made so many new friends," Sean recalls. His experience was so impactful, he decided to give something back in return.

Determined to provide for the community that made such a difference for him, Sean formed *Sean's Factor*, a non-profit organization with a primary objective of raising funds to help other children attend bleeding disorders camp. Crowdsourcing services have been instrumental in helping Sean raise funds with proceeds going to the Louisiana Hemophilia Foundation so they can send children with bleeding disorders to summer camp for free.

Sean also uses his platform to advocate, educate, and inform others about bleeding disorders. His efforts have

not gone unnoticed. Sean's Factor has been featured in the media and Sean has earned numerous awards including the 2015 Heroes of the LHF Award, 2017 Ryan White Youth Award, and 2018 National Teen Impact Award.

Sean is not slowing down anytime soon and looks forward to engaging future community leaders. "Camp helped develop me into the young man I am today," he shares. "I want to continue my part helping kids go to camp and raising awareness about bleeding disorders. One day I hope to pass the torch along to the next generation."

To learn more, search for *Sean's Factor* on Facebook.



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STRESS, BLEEDING DISORDERS, AND WAYS TO COPE

BY: JUSTIN LINDHORST

What day is it? When was the last time I showered? Did I eat breakfast? Is today my infusion day? This year, all of us are dealing with additional stress that can leave us unsure of even the day-to-day basics. COVID-19, political and social unrest on top of the daily challenges of life with a chronic health condition can stack up quickly, leaving even the most resilient among us feeling overwhelmed. For members of the bleeding disorder community, it's important to understand the influence stress can have on managing health. This article explores some of the negative consequences of stress and provides helpful tips on how to manage it.

Stress can negatively impact health. It can cloud our judgment, make us forgetful, and if left unchecked, chronic stress can lead to depression. Stress causes physical changes in our bodies. There is a significant amount of research connecting chronic stress with poor health outcomes.ⁱ Stress can be especially challenging for members of the bleeding disorder community. Research has found connections between bleeding episodes and stress.ⁱⁱ

Many patients and caregivers can confirm this correlation through their own experiences. Ask almost any bleeding disorder community member and they'll recount stories of spontaneous bleeding episodes happening just before or after periods of tension or heightened emotion. For

me, this meant bleeds on the first day of school, over the holidays, on my birthday and prior to summer camp.

Stress challenges each of us in unique ways. Check out the tips below to help manage feelings of stress during times of uncertainty.

STAY ENGAGED WITH THE BLEEDING DISORDERS COMMUNITY

It's more important than ever to activate or establish a support system to manage your bleeding disorder and help deal with the stress of living with a chronic health condition. Your hemophilia treatment center and specialty pharmacy are resources you can always leverage in times of need. COVID-19 may prevent you from attending your



annual HTC visit in-person, but telehealth visits are a great way to maintain contact with your healthcare team and receive the clinical support you need to effectively manage your condition.

Sometimes we just need to connect with another person who understands what it's like living with a bleeding disorder. Connecting with your peers in the community can help decrease stress and feelings of isolation.

Chapters, specialty pharmacies and manufacturers are providing virtual engagement opportunities to entertain, educate and connect the community during a time when it's safer to remain physically apart. Reach out to your local chapter or BioMatrix Regional Care Coordinator who can help connect you to resources and bleeding disorder focused virtual programming.



FOCUS ON SELF-CARE

During times of heightened stress, don't lose sight of self-care. It's okay to take a break and focus on your own well-being. Establish a routine that includes some time dedicated just for you to relax, recharge and center yourself. Include exercise and a healthy diet – these lifestyle factors have a tremendous impact on both physical and mental health. Take a little time each day to turn off the TV, log out from social media and focus on whatever recharges you!

It can be challenging to focus on yourself during times of stress and uncertainty. The Mental Health Foundation offers three tips for coping with the uncertainty of the



world we're living in today, "Focus on the present, bring things that are certain back into focus, and talk to people you trust."ⁱⁱⁱ If you need a hand learning to practice mindfulness, try downloading and using a self-care app. Since the start of the pandemic, the use of such apps has increased by 60%.^{iv} Some top apps that focus on self-care and mindfulness include *Calm*, *Headspace* and *Reflectly*. Explore the App Store for an option that suits your preference and start making time for self-care today.

STAY ON TOP OF THERAPY

Staying on top of any routine during periods of stress can be challenging. For those living with a chronic health condition, emotional distress can lead to decreased treatment adherence.^v Effectively managing your bleeding disorder is always important – but even more so in today's environment. Keeping our bodies bleed free is of critical importance and will help reduce your short- and long-term stress levels.



In the short-term, avoiding bleeding episodes will ensure you don't have to deal with unnecessary hospital visits that could put you and your family at risk. In the long-term, avoiding bleeding episodes will help protect joints, prevent arthritis and help you avoid chronic pain. Just as apps help to promote self-care and mindfulness, there are apps and digital tools that can help you stay on top of therapy. *MicroHealth Hemophilia*, *HemoTool* and other mobile-based apps offer treatment reminders and tools to track infusions and bleeding episodes.

During these challenging times we are all dealing with a lot of additional stress. Over time stress can impact health, lead to depression and could potentially negatively impact the way you manage your bleeding disorder. Make a commitment to effectively manage stress during these difficult times by engaging your support system, focusing on self-care and staying on top of your bleeding disorder therapy routine.

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My *Chronic* Life is *Not* a Lifeless Life!

BY: JACEY GONZALEZ



*Chronic...
Lifelong...
Everlasting...*

These are words that have been used to describe my bleeding disorder especially when explaining what I couldn't do, where I couldn't go, or what I was limited to. However, looking back on my life, I have realized through the highs and lows of living with a bleeding disorder, I have been given a *chronic* life, *not a lifeless* life.

Growing up, my mother and I planned everything around what was going on with my health. Where I would go to school, what sports I would play, where and with whom I could travel. It seemed we always had everything planned to a tee. My life revolved around my health – first leukemia, with which I was diagnosed at age 3, then on my platelet disorder, and then around my von Willebrand Disease. I was hyper-aware that while I was an average child, medically, I was different.

I was always inspired to do the absolute most with my life and to curse anyone who thought otherwise. I was strong, I was resilient, but by the ripe age of 16, I was completely done caring about my medical needs. This was the only time I lashed out against my health issues.

Call it teen angst, call it independence – no matter what you call it, I wanted nothing to do with managing my bleeding disorder. I grew up as the “cancer kid” and I wanted nothing more than to spite that moniker for the rest of my life. It defined me, almost too much.

Kids are mean and they notice when you're different. There is something almost cruel about the innocence and ignorance of children who don't have to worry about their medical limitations. The impact of this didn't quite dawn on me until my junior year of high school.

Junior year – my first chance to go to prom, the year I took my SATs, the year I fell in love for the first time. We lost our insurance that year and got stuck with the worst state-monitored HMO plan we could have possibly imagined. So much was going on all at once and with all that change, this was the year I decided I wanted to be normal. I didn't even want to worry or think about my bleeding disorder.



Isn't that what every person with a chronic illness wants? To be normal, to not question if basic things are safe, to go with the flow and not inconvenience the people around you. I was a varsity athlete, I had the best friends, and I thought to myself, "If I believe I am normal enough, everyone else will too."

I made mistakes. I took my (very fragile) health into my own hands and decided I was going to live an unencumbered life and pretend my bleeding disorder didn't exist. Come what may! To save you the trouble of rehashing all of my mistakes, I'll leave you with my final thought after that turbulent year.

I'm not normal, and I was never meant to be.

People with chronic illnesses aren't normal. We aren't meant to be. We are a tenacious bunch who for whatever genetic reason, have an ailment that impacts our lives. We are stronger than most, we persevere more than anyone should ever have to, and we are brave.

We put a smile on our face and have Emmy-worthy acting skills making everyone believe we are okay. Even if we may not always feel like it, we make sure everyone knows we are just fine. Every time I have to take a butterfly needle and find a vein, I am filled with melancholy. But I do it – we have to. We weren't given a choice in the matter.

Having a chronic illness is not only physically exhausting but mentally as well. It's almost as if my brain wants to give up but my body won't let it. Then as soon as my body fails me, my mind compensates. It's a constant teeter-totter of what will cause you duress on any given day – my brain or my body. Sometimes it takes you to the deepest darkest places and there's almost no semblance of light to cling to.

But where we don't have light, we have hope. We are so fortunate to live in an age where effective medications are available for us. Where we have competent doctors helping us manage our lives. Where our diagnosis doesn't mean impending death. We can call our friends we met at camp or through conferences and ask for help during our difficult times. We are only a Facebook message away from contacting someone who is going through the same thing. We are the lucky ones. Not everyone in other chronic illness communities is as lucky. We are fortunate to be part of a community where we are loved, understood, accepted, and supported.

Chronic illnesses aren't easy. I've changed some of my life goals to be able to work with what I am physically able to do. I have come to terms with the way my bleeding disorder has shaped my life. I have also come to terms that I am not the same carefree kid I once was, but those losses have been replaced with a responsibility that I am part of a changing medical landscape. Hoping that it will one day help other people, I am contributing to advocacy and research. My efforts are making a change not only in my small rare disease community but in the greater population of rare diseases.



“But where we don't have light, we have hope.”

We are so fortunate to have the opportunity to be directly involved in the issues that impact us regularly. Whether the issues are regarding new medications, new legislation, or new insurance regulations, we have the power to better our own life as well as the lives of others in our community.

We, as a community, are not normal. We were never meant to be. Normalcy is a construct with expectations that are inherently out of reach. Our version of normal though – our chronic life – is so full of color and hope and perseverance, it's better than any version of “normal” ever described. We are history, we are the future, and we are living amazing lives full of challenges and triumphs and growth of character. Even with a disorder where something is missing, we are whole.

I am a Star Wars nerd, an avid reader, and a proud mom to many succulent plants. I'm a sister, a daughter, an advocate.

I am not my disorder. I am not normal.
My chronic life is *not* lifeless.



SLEEP

WHAT IS IT GOOD FOR? ABSOLUTELY EVERYTHING!

BY: SARAH HENDERSON and JUSTIN LINDHORST

Most of us love crawling into bed to drift off into dreamland...only for the alarm to go off before getting a full night's sleep. The National Sleep Awareness Roundtable reports that 50–70 million Americans aren't getting the rest they need. Sleep deficiency can wreak havoc on our bodies and minds. The *Huffington Post* reports, "After just seven nights of too little sleep, researchers observed more than 700 genetic changes that could play a role in consequences including heart problems and obesity." Anybody can suffer from lack of sleep, but those living with a bleeding disorder need to be aware of how this can aggravate the condition.

Over the last few months a common complaint heard from friends and family members is that they have been having trouble falling asleep, staying asleep, or both. There is little doubt the events of 2020 have been weighing heavily on everyone's minds. Fear of contracting a virus or spreading it to loved ones, possible loss of income, isolation and staying home, compulsively washing hands, wearing masks, wiping down groceries... these changes have been taking a toll on most of us. Just as things began to lighten slightly, our country faced another outpour of emotion as we watched civil unrest explode against deep and recurring societal injustices. It is not surprising we're having a difficult time shutting down our brains at night. But how is this lack of sleep affecting us?

Chronic pain and lack of sleep

Chronic pain is common in the bleeding disorder community. Unfortunately, pain can be especially disruptive to a person's sleep cycle. Lack of sleep can escalate feelings of pain, which again results in more interrupted sleep. Painkillers are meant to relieve pain but can also have the negative effect of fragmenting sleep.ⁱ This adds to the sleep deficiency cycle. An occasional sleepless night is quite normal; however, losing sleep on

a more consistent basis can negatively impact health and pain levels.

During sleep, growth hormones and cytokines are released by the pituitary gland. Cytokines, small secreted proteins, when released, send signals to the immune system. Hormones help the body heal damaged muscles and joints while cytokines activate the immune system to help battle inflammation, infection and trauma. Lack of sleep and the depression that it may cause can amplify the pain, especially at night, creating a vicious cycle.

Additional negative effects of too little sleep or lack of quality sleep can range from a decrease in immune function, an increased risk of heart disease, and raised blood pressure. Too many sleepless nights can also exacerbate conditions such as Parkinson's, Alzheimer's, gastrointestinal tract disorders, kidney disease, multiple sclerosis, and behavioral problems in children.ⁱⁱ

For the body to function at its best, it's imperative to find ways to get sufficient sleep.





Solutions for a better night sleep:

Everyone requires a different amount of sleep; however, age can be a guideline. Most infants require 16 hours, while teenagers need an average of 9 hours, and adults need 7 to 8 hours of sleep. This amount varies based on each individual.ⁱⁱⁱ



Set a routine. Go to bed and wake up on a set schedule. Try to keep the schedule consistent even on weekends. During the day, expose yourself to natural light or bright lights. This helps the body regulate one's circadian rhythm, an internal 24 clock that serves as a sleep/wake cycle.

Another issue which greatly impacts a person's circadian rhythm is spending too much time in front of a computer monitor or TV screen. Not only does the content of television and social media not allow our brains to relax, light emitting from these devices interrupt the sleep/wake cycle. For an hour or two before bed, avoid watching a screen and read a book instead. The bedroom should be kept dark, quiet and cool. Draw the shades and run a fan if needed.

Eating heavily just before or going to bed hungry can disrupt sleep. Avoid eating within a couple hours before bedtime and pay attention to which foods cause problems at night. Caffeine, nicotine and sugar, especially later in the day, can throw sleep into turmoil. Sleep comes easier if a person is sleepy so avoid taking afternoon naps. Include exercise in daily routines, though it is not advisable exercise too late in the day.

Do something to relax – a warm bath, listening to soft music, practicing deep breathing as a relaxation technique.

Paying attention to your bedtime routines and making necessary adjustments may be the key to sleeping better. Good night!



References:

- i. Lavigne, Gilles. "Pain and Sleep." <https://www.sleepfoundation.org/articles/pain-and-sleep>
- ii. Mercola, Joseph. "New Insights into Links Between Immune Function and Sleep." <http://articles.mercola.com/sites/articles/archive/2012/08/04/immune-system-and-sleep-deprivation.aspx> (08/04/2012)
- iii. Nazario, Brunilda. "Are You Getting Enough Sleep?" <http://www.webmd.com/sleep-disorders/guide/sleep-requirements> (11/29/2011)

The National Sleep Foundation offers ten tips to get the most out of your sleep each night:

1. Maintain a regular bed and wake time schedule, including weekends
2. Establish a regular, relaxing bedtime routine such as soaking in a hot bath, reading a book or listening to soothing music
3. Create a sleep-conducive environment that is dark, quiet, cool and comfortable
4. Sleep on a comfortable mattress and pillows
5. Use your bedroom only for sleep
6. Finish eating at least 2-3 hours before your regular bedtime. Avoid sugar, spicy foods or other foods you find to which you are sensitive
7. Exercise regularly, but not too late in the day
8. Avoid caffeine (e.g. coffee, tea, sodas, chocolate) close to bedtime
9. Avoid consuming alcohol near bedtime
10. Avoid nicotine – cigarettes and other tobacco products. Used close to bedtime can lead to poor sleep

BIOMATRIX

ON THE *Virtual* MOVE!

With many aspects of our great country still shut down, the opportunity for members of the bleeding disorders community to gather and mingle has come to a stand still. To keep us unified and engaged during this most unusual time, we at BioMatrix have designed and released a series of virtual meetings across the land! So rather than listing the many places our Regional Care Coordinators typically travel to as exhibit booths are staffed, educational dinners are held and fundraising efforts ensue, this section of our newsletter will feature when and what topics we've been able to bring virtually to the community. Admittedly, the photos in this collection aren't as high-res as usual, but we still wanted to share the familiar faces of our community!

At the request of our Regional Care Coordinators, our Education Team consisting of Terry Rice, Kelly Gonzalez and Shelby Smoak, Ph.D. have been readily on hand to lead discussions on many topics. Following the learning

portion of the sessions, our Education Team presenters have emceed plenty of BioMatrix Games – Family Feud, Jeopardy and Trivia sessions have been especially fun! The competition among our community members is hilarious! Game player names are entered into a raffle for a gift card with more chances entered for the winner of the game. Competition is high! Attendees also receive an awesome gift box with an exclusive BioMatrix ceramic cup, hand sanitizer, band-aids and lip balm – everything you need while Zooming!

If you have a group – large or small – of folks who would benefit from one of our sessions or just want to gather a few community friends for a game night, please contact us and we'll do the rest! Reach out to your local BioMatrix Regional Care Coordinator or email us at: education@biomatrixsprx.com. Let's stay connected!



Meet Our Education Team!



Terry Rice

Director of Advocacy and Education

Terry Rice has been a lifelong advocate within the bleeding disorder community. He has served on the Board of Directors for local and national bleeding disorder advocacy organizations, and was one of the original founders of the Hemophilia Federation of America (HFA) in 1994.

Throughout the 1990s, Terry spent significant time educating members of Congress in Washington DC regarding legislative initiatives furthering the interests of persons with bleeding disorders. Terry also served a two-year appointment as the community voting member on FDA's Blood Products Advisory Committee. He has held various management and executive positions within the healthcare industry for over 20 years.

Terry is a person with a bleeding disorder and his passion is to empower people with a chronic illness. Terry earned his bachelor's in chemistry and has studied master's level economics concentrating in health economics.



Kelly Lynn Gonzalez

Sr. Education Specialist and Regional Care Coordinator

Kelly Gonzalez is a patient, the parent of patients, and the spouse in the rare disease community. Having personal experience in bleeding disorders, autoimmune diseases, PID, epilepsy, and cancer, Kelly presents education drawn from a lifetime of personal and professional experiences.

Kelly has traveled nationwide presenting for various non-profit organizations within the bleeding disorders community.

Her educational presentation style shares her journey and educates and empowers the audience. She channels her past experience as a teacher and infuses her passion for persons with chronic illness into heartfelt and dynamic programs. Kelly holds an MBA and MA in Education.



Shelby Smoak, Ph.D.

Education Specialist and Advocate

Shelby Smoak is a tireless advocate for patients with chronic health conditions. In the 90s, his experience living with a bleeding disorder and HIV led him to become actively involved in advocacy, especially as it pertains to the ever-changing dynamics of healthcare.

Shelby helps others understand complicated health policy and serves as a voice for patients with rare conditions across the nation. He's been featured on TV and radio, including NPR. Shelby served on the board for Hemophilia Association of the Capitol Area and currently serves on the Pfizer B2B board.

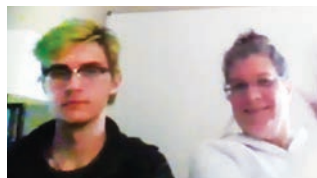
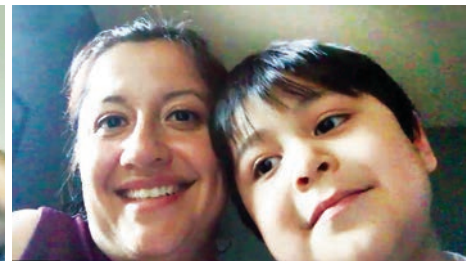
A former literature professor, Shelby is also a writer and a musician. Awarded a Pen/American grant for writers living with HIV, Smoak holds a Ph.D. in Literature and an MA in English. His book, *Bleeder: A Memoir* received praise from sources as diverse as *The Minneapolis Star Tribune*, *Library Journal*, and *Glamour*, and has won several awards, including Best of the Best by the American Library Association.



Singing-^{to}HEAL

Music can make everything a little more manageable and a little sweeter too. In this session, fellow musician and resident Ph.D. Shelby Smoak discussed the history of music including interesting information about the oldest artifact of a musical instrument. He also covered how music creates an emotional response and the way it affects our brain when we listen to or play music. The brain changes in a way that can help us deal better with pain or to simply relax and let go.

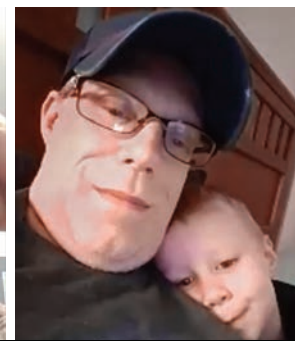
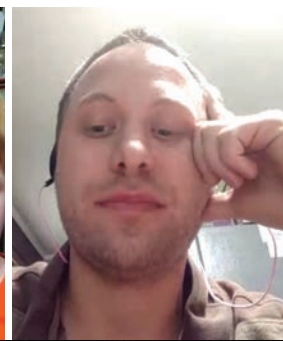
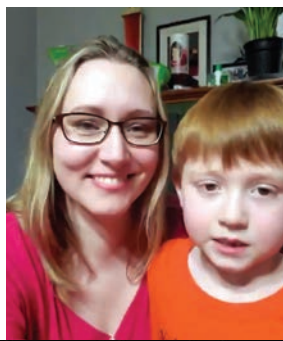
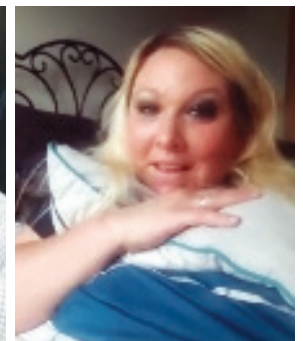
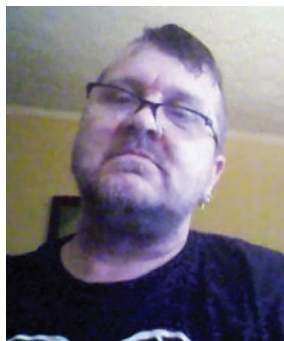
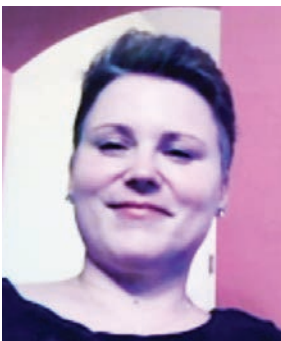
During the session on May 27th, CSL Behring's Jim Hurster was on hand to play guitar along with Shelby. On the June 18th Zoom, a group of Tennessee blood brothers made introductions and shared which instruments they play. The groups also discussed how influential and therapeutic music is to them. We were all in consensus on how important music is in our lives especially when living with a bleeding disorder. These sessions provided a great way to offer support to one another and listen to some really good music!



May 20, 2020
 Presenter: Shelby Smoak
 RCC: LeAnn Wilson

May 27, 2020
 Presenter: Shelby Smoak
 RCC: Eva Kraemer
 Sponsor: CSL Behring

June 18, 2020
 Presenter: Shelby Smoak
 RCC: David Tignor



HEALTH INSURANCE BASICS

Everything

You Didn't Know — You Need To Know

Many will agree that insurance is not always the very most exciting topic, yet this session provided a great amount of useful and important information. Every day there seems to be some change with insurance – at times, it is increasingly challenging to know where to turn for answers. This session offers guidance when looking for an insurance policy and helps clarify co-pay accumulators and how they may affect you, along with many other interesting pointers.

May 28, 2020

Presenter: Shelby Smoak, Ph.D.
Communications Manager: Maria Vetter
Host: The Coalition for Hemophilia B
Sponsor: Medexus



May 31, 2020

Presenter: Shelby Smoak, Ph.D.
Communications Manager: Maria Vetter
Host: The Coalition for Hemophilia B
Sponsor: Medexus



**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



Awareness for - Advocacy -

Many often think you have to do something big to make a difference. The truth is there are small things that can be done that will leave a big impact on your life.

This engaging and informative presentation is a great reminder of the things you can do that can become huge assets should you ever be faced with issues such as insurance problems, desire to change treatment regimen, communications with providers, etc.

March 28, 2020

Presenter: Kelly Gonzalez

RCC: Kelly Gonzalez

Host: Nevada Chapter of NHF

June 11, 2020

Presenter: Shelby Smoak

RCC: Terry Stone

Host: Virginia Hemophilia Foundation

June 11, 2020 ¡En español!

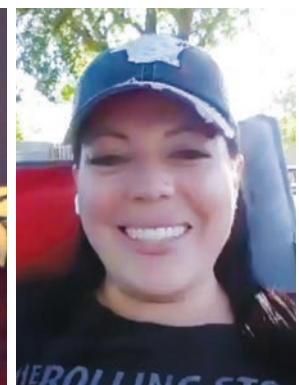
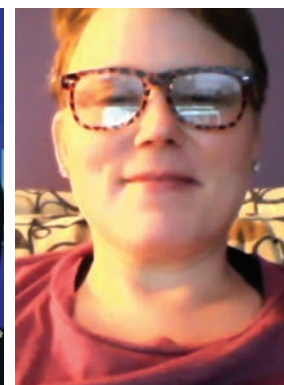
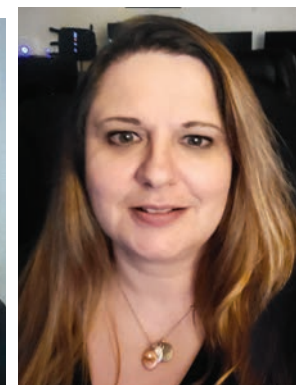
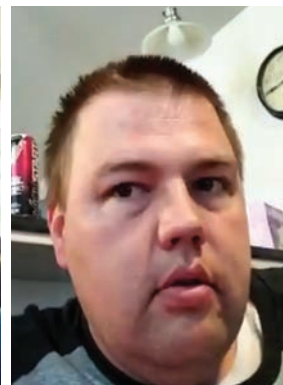
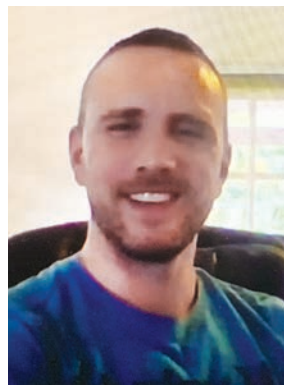
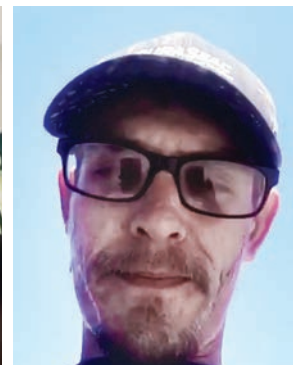
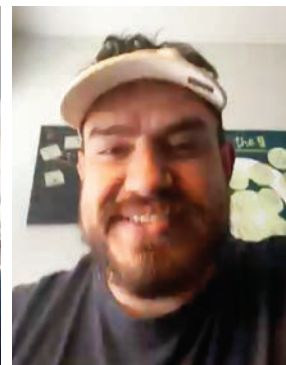
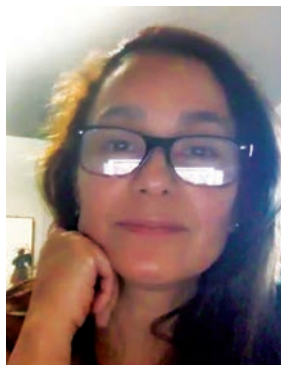
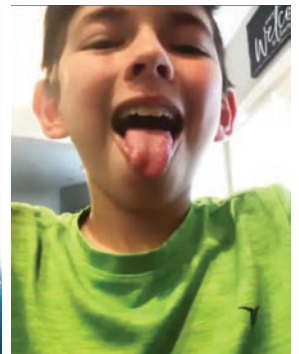
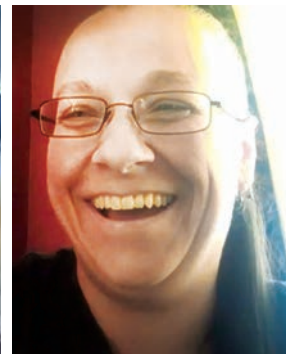
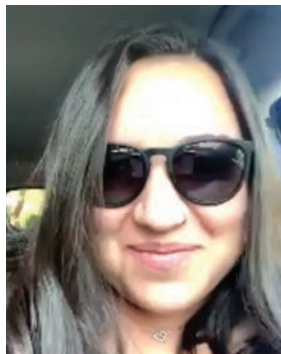
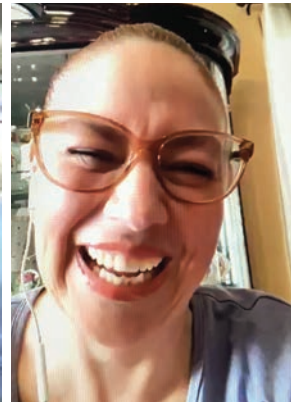
Presenter: Kelly Gonzalez

RCC: Eva Kraemer

June 18, 2020

Presenter: Kelly Gonzalez

RCC: Jeff Johnson

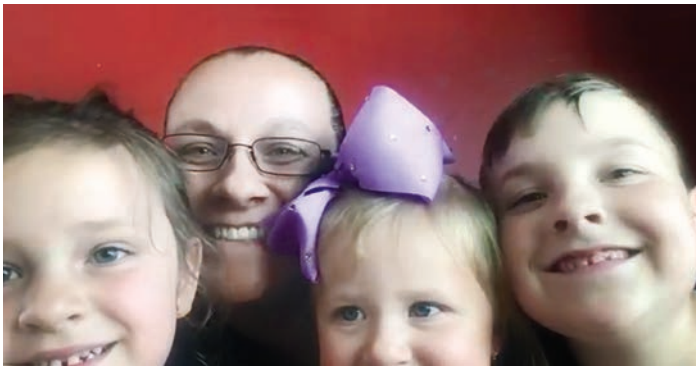
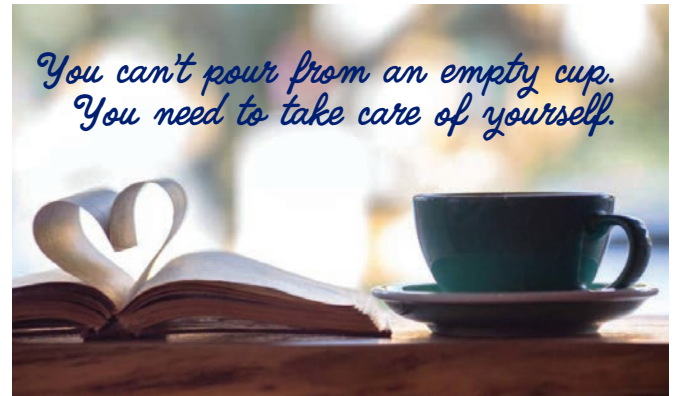


Putting The Mask On — First —

In these sessions, Kelly Gonzalez talked about the importance of caring for yourself as you care for those you love. So often caretakers put the needs of everyone before them, never taking a moment for themselves to regroup and replenish.

Kelly shared intimate details of her family's health challenges, how she tried to be strong for everyone, and how in the process, failed to care for herself. Speaking from the heart, Kelly shared the lessons she learned and inspires caretakers to understand their value.

These were very moving presentations, reminding us to take care of ourselves when caring for someone with chronic illness. Especially with the added stress of today's COVID-19 issues, this program was well-received by all.



April 17, 2020

Presenter: Kelly Gonzalez
RCC: Rich Vogel
Host: Hemophilia Alliance of Maine

May 28, 2020 ¡En español!

Presenter: Kelly Gonzalez
RCC: John Martinez

April 17, 2020

Presenter: Kelly Gonzalez
RCC: Jeff Johnson
Host: Idaho Chapter NHF

June 12, 2020

Presenter: Kelly Gonzalez
Communications Manager:
Maria Santucci Vetter
Host: The Coalition For
Hemophilia B
Sponsor: Medexus

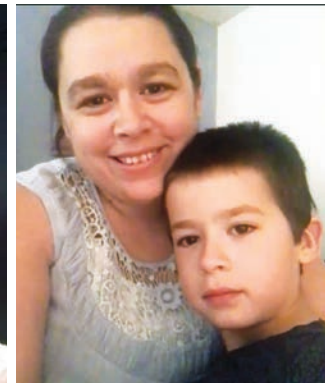
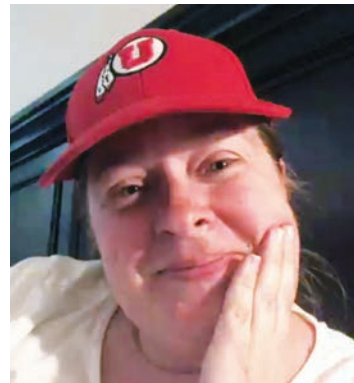
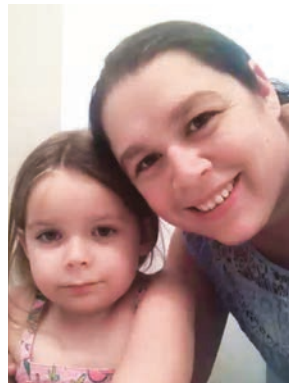
May 28, 2020

Presenter: Kelly Gonzalez
RCC: LeAnn Wilson
Host: Louisiana Hemophilia
Foundation
Sponsor: CSL Behring



May 28, 2020

Presenter and RCC:
Kelly Gonzalez



Transition to College

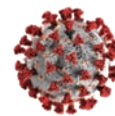


College should be an exciting time for new students; however, when living with a bleeding disorder, it may also be more concerning. This insightful session offers students and their parents many tips and tricks for navigating successfully as they prepare to live on campus.

June 25, 2020
Presenter: Kelly Gonzalez
RCC: Jeff Johnson

June 25, 2020 ¡En español!
Presenter: Kelly Gonzalez
RCC: Gabriela Griffin

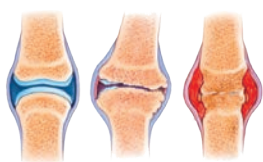
COVID-19 Crisis:



This intriguing session helped sort through all the information presented daily by various news sources. Being in this for the long haul, this session helped us understand the ways COVID-19 may affect those with a bleeding disorder.

June 11, 2020
Presenter: Terry Rice
RCC: Hector Heer

No Need To Bleed: Making Joints Last A Lifetime



This session concentrated on the negative effects of bleeding episodes on the joints and demonstrated the need for therapy adherence and access for all people with a bleeding disorder. Today, as patients with hemophilia live longer, it more important than ever to be proactive when it comes to joint care. This program offered hard hitting facts about the benefits of prophylactic treatment versus treating on demand.

June 16, 2020
Presenter: Kelly Gonzalez
PCS: Susan Moore and Sarah Henderson

MORE SESSION TOPICS AVAILABLE!

In addition to the sessions listed on page 26, we have even more topics to choose from! Email or call your Regional Care Coordinator, your Patient Care Specialist or contact the Education Team directly to book a session - free of charge - today! education@biomatrixsprx.com

AWARENESS FOR ADVOCACY

Highlights the need for record keeping, health literacy, and using tools for becoming an informed advocate when faced with challenges such as appeals, denials and access to care.

SINGING TO HEAL

Empowers participants to tap into the healing power of music and sharing the emotional experience with others.

WRITING TO HEAL

Explore the calming effect of writing while learning various approaches and word applications to channel journaling into a positive experience with valuable impact on their lives.

NAVIGATING MEDICARE

Provides and overview of Medicare and discusses important information in coverage options with a focus on those with chronic illnesses.

NAVIGATING TRICARE®

Offers an overview of the TRICARE® program with a special focus on persons with a chronic illness.

WOMEN BLEED TOO

Discusses signs and symptoms of a bleeding disorder, differences between *symptomatic carriers vs. women with a bleeding disorder*, and provides an avenue to document vital information and open dialogue with providers.

HILLBEAT ON THE ROAD

Covers a selection of policy issues, industry advances, insurance issues, and healthcare concerns in a guided forum.

SAFE TRAVELS FOR SUMMER

Offers valuable information on how to prepare for vacations while caring for someone with a bleeding disorder.

TRANSITION OF CARE TO ANOTHER

Helps prepare parents and caregivers to feel comfortable leaving their child with a bleeding disorder in the care of another (babysitter, daycare, etc.).

TRANSITION TO SELF-INFUSION

Addresses the benefits of self-infusion at home, school, or work, and helpful tips and tricks.

TRANSITION TO SCHOOL AND 504 PLANS

Provides guidance to parents and caregivers of school aged children. Includes extensive details about educational rights and establishing a 504 Accommodation Plan.

TRANSITION TO HIGH SCHOOL

Highlights the importance of keeping routines, making responsible decisions, adherence to medical protocols, and what to disclose and to whom while transitioning to high school.

TRANSITION TO COLLEGE

Includes valuable information a new college student with a chronic illness needs to know about preparing to leave for college.

SCHOLARSHIP 101

Workshop-style program designed to assist high school students identify available college scholarships, what items are needed, how to apply, and how to keep track of applications.

BIOMATRIX GAME NIGHT

Sometimes what we need instead of browsing social media, listening to the news, or going over PowerPoint presentations is just a time to relax, be with friends (even if virtually), have a few laughs, play some games, learn a little, and take on a little friendly competition! And thus, BioMatrix Game Night was established! Jeopardy, Family Feud, Wheel of Fortune and a Trivia Quiz are the featured games available to play! The struggle is real when you are trying to declare a win over your opponents! Games have been held from coast-to-coast with bragging rights ringing loudly!

May 19, 2020

Emcee: Shelby Smoak
RCC: Terry Stone

June 7, 2020

Emcee: Shelby Smoak
RCC: Felix Garcia

June 24, 2020

Emcee: Kelly Gonzalez
RCC: Eva Kraemer

May 20, 2020

Emcee: Shelby Smoak
RCC: Tina McMullen

June 17, 2020

Emcee: Shelby Smoak
RCC: Tina McMullen

June 24, 2020

Emcee: Shelby Smoak
RCC: Jeff Johnson

June 2, 2020

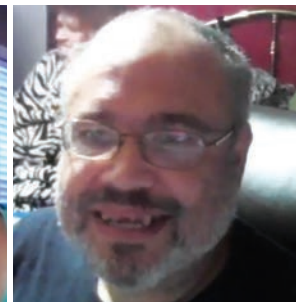
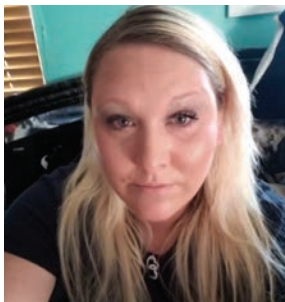
Emcee: Shelby Smoak
RCC: Terry Stone

June 23, 2020

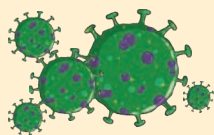
Emcee: Kelly Gonzalez
PCS: Susan Moore and Sarah Henderson

June 25, 2020

Emcee: Shelby Smoak
RCC: Cyndy Coors



Time for Fun!



1. b. A tiny germ that can make people sick
2. d. Wuhan, China
3. e. All of the above
4. a. 20 seconds
5. b. Maintaining distance between you and other people
6. c. Illness that coronavirus causes
7. a. Older people or people with certain health conditions
8. e. A vaccine

ANSWERS TO PUZZLES ON PAGE 27

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

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

Virtual Webinars Available From BioMatrix!

COVID-19 Crisis: The Impact on Bleeding Disorders

Get up-to-date facts on COVID-19. Understand how the crisis impacts bleeding disorders. Learn ways to keep you and your family safe. Be empowered to weather the crisis with confidence.

It's Ok to Not Be Ok

Hear about a community member's struggle with depression. Learn how they were able to overcome challenges by accepting their shortcomings and are pushing forward through the toughest times, including COVID-19.

No Need to Bleed: Making Joints Last a Lifetime

Review hard-hitting data that challenges bleeding disorder patients to invest in a lifetime of joint care. Understand what hemophilic arthropathy is, how it damages joints over time, and what happens if you don't take charge of your condition.

Health Insurance Basics: Everything You Didn't Know You Need to Know

If you've ever faced insurance challenges—dealt with prior authorizations, been denied a drug due to step therapy, told you have a copay accumulator adjustor, or had a claim denied for any reason—this program is for you. Learn about insurance policy-making and how to appeal decisions made by your health insurance plan.

Putting the Mask on First

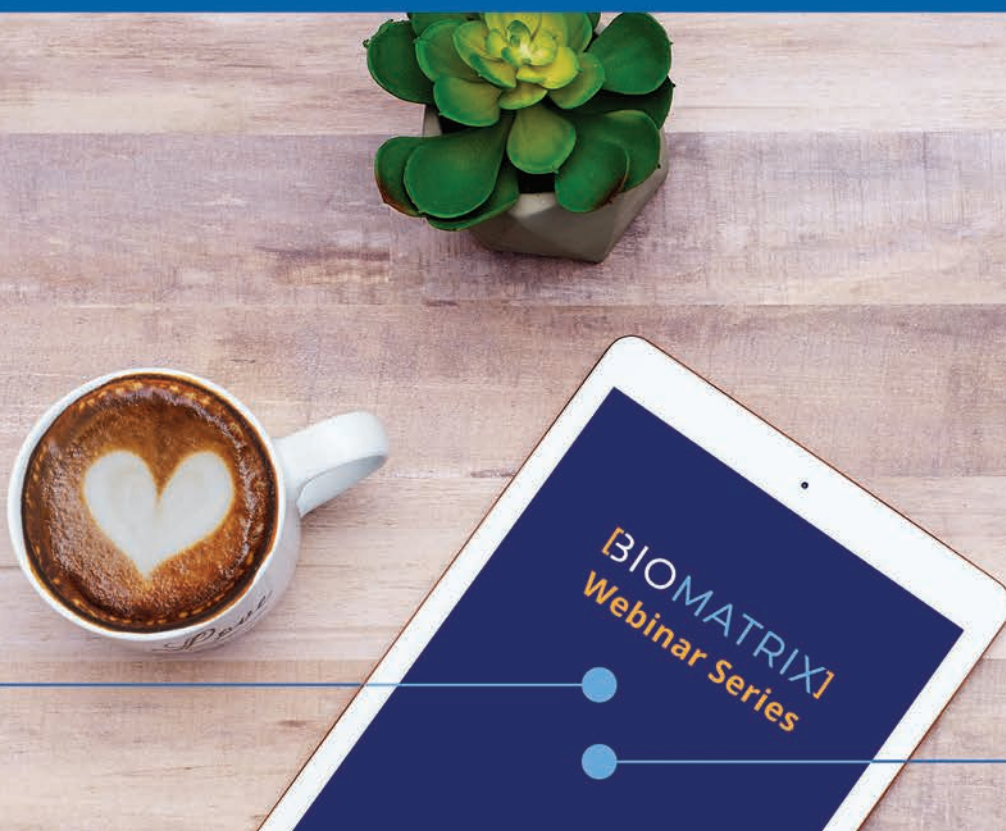
If you are a caregiver for someone with a bleeding disorder, this is your program. Learn how to take care of yourself while you take care of a loved one.

Bleeding Disorders Educational Games!

Play bleeding-disorders versions of Jeopardy, Wheel of Fortune, and Family Feud! Play these educational game versions with us individually or as an add-on to any our other programs! We have adult and kid versions! What are you waiting for?! Solve the puzzle! Spin the wheel! Win your daily double with BioMatrix!

To get set up with our virtual webinars, contact your RCC or email us at:

education@biomatrixsprx.com



Time for Fun!

HI KIDS!

Many kids across the country still may not know what school is going to be like this fall. Whether you will be in the classroom or learning virtually from home, it's a good time to brush up on your coronavirus knowledge. See how many of the questions below you can get correct. Good Luck! Answers are on page 25.

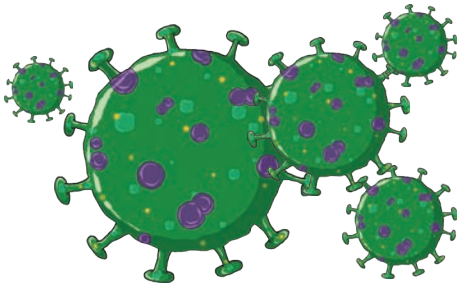


1. What is coronavirus?

- a. The name of my dog
- b. A tiny germ that can make people sick
- c. A yellow sunflower
- d. A type of cat
- e. Something growing in my garden

2. Where did this coronavirus come from?

- a. Chicago, Illinois
- b. Shanghai, China
- c. Venice, Italy
- d. Wuhan, China
- e. Hong Kong



3. What can you do to help slow the spread of coronavirus?

- a. Wear a mask
- b. Wash you hands or use hand sanitizer
- c. Avoid touching your face
- d. Practice social distancing
- e. All of the above

4. How long should you wash your hands?

- a. 20 seconds
- b. 10 seconds
- c. 5 seconds
- d. 4 minutes
- e. 20 minutes

5. What is meant by social distancing?

- a. Stop talking on the phone
- b. Maintaining distance between you and other people
- c. Stop all computer use
- d. Start ignoring your sibling
- e. Making sure to shake everyone's hand

6. What is COVID-19?

- a. A type of X-ray
- b. The name of a hospital
- c. Illness that coronavirus causes
- d. A kind of umbrella
- e. A modern piece of furniture

7. COVID-19 can be most serious for which group of people?

- a. Older people or people with certain health conditions
- b. Teenagers
- c. People that travel a lot
- d. Grade school children
- e. Pet owners

8. What are scientists working on to help keep people safe from the coronavirus?

- a. Antiviral hats
- b. Body bubbles
- c. Electronic watchbands
- d. Biohazard suits for everyone
- e. A vaccine

Corona VIRUS
Be aware of these **symptoms**

Fever

Cough

Headache

Runny Nose

Sore Throat

Fatigue

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

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

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

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