THE COALITION FOR HEMOPHILIA B

HEMOPHILIA B NEWS

A QUARTERLY NEWS PUBLICATION FALL 2021

THE BEATS GO ON

THE ART OF PIVOTING

THE POWER OF SELF ADVOCACY FOR WOMEN BLEEDERS: LAUREN'S STORY

EMERGING THERAPIES

NOTHING IS STOPPING TEEN NICK! HIGH SCHOOL & HEMOPHILIA

HEMOPHILIA B NEWS FALL 2021

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THE COALITION FOR HEMOPHILIA B

MISSION

TO MAKE QUALITY OF LIFE THE FOCAL POINT OF TREATMENT FOR PEOPLE WITH HEMOPHILIA B AND THEIR FAMILIES THROUGH EDUCATION, EMPOWERMENT, ADVOCACY, AND OUTREACH.

THE BEATS GOES ON!

BY RENAE BAKER

Kim Phelan reflects, “When the program first began, the concept was good, but what actually happened exceeded my wildest expectations. Community members from all walks of life with unique talents playing different types of music styles totally merged. It flowed effortlessly, and everyone celebrated and cheered each other on.” She was enriched to see how this program brings together people who may not attend other events.

“A week later you can still feel the energy from this program. It’s not just music; it’s collaborating, sharing, bonding and finding a support system of like-minded people. It also helps with depression. The support, love and energy this program shines on all the positives.” Kim found the final performance very moving. “I was sitting in the audience just admiring each participant’s unique song genres and styles, and I was crying tears of joy. Some even wrote their own songs.” Already thinking about how to improve The Beats, Phelan exclaims, “We need a bigger stage and a bigger room! It has grown!”

Kim is always mindful and appreciative of our sponsors and has this message for them: “Thank you for believing in us and this program. We knew it was going to fill a void in the community. We knew it was good for depression and would further bring more in the community together. We knew it would not be easy to put together but we did it, and we are so thankful to our sponsors – who also bring in valuable programs during this event – for helping us bring our vision to reality, especially for those who we do not normally reach.” It’s wonderful to see how participants become more active in community events after attending this program!”

Of all the hats I wear within this wonderful organization, my favorite participation happens at The Beats music program.

Leaning into the science behind the power of music to improve quality of life, Kim Phelan and Coalition president Wayne Cook envisioned a program that would serve people in the hemophilia B community who have interests not addressed in other programs. Wayne, who has severe hemophilia B, knows firsthand how effective therapy music can be for depression and other chronic illnesses. He felt that The Beats music program would open doors for people with hemophilia B, to express themselves and form bonds.

I remember arriving at The Gaylord Opryland Resort Hotel in July of 2019. After being warmly greeted, I sat down to lunch at a table of enthusiastic Beats participants and sponsors of the event. Throughout the next four days, I would have my eyes opened to what it means to live with hemophilia B. I would hear how challenging the lives of people with this bleeding disorder have been. I would also learn how life-affirming and joy-filled the Coalition events are that bring this ever-expanding family together! The Beats 2019 was such a resounding success that leadership confirmed that it would become an annual Coalition program. Soon, I became part of The Beats 2020 planning committee.

2020 – as they say in Minnesota – “Oofda!” The Coalition leadership and staff rode the “Corona Coaster” through uncertain months of postponing multiple live events, canceling and rescheduling flights, accommodations, speakers and more. They went into overdrive purchasing equipment, software, and training to be able to conduct programs remotely. I don’t need to tell anyone reading this newsletter that The Coalition for Hemophilia B is no stranger to overcoming adversity, and The Beats 2020 program was no exception. Naturally, we missed being together, but we still found our way to loads of laughs, meaningful connections and comforting musical vibes through Zoom.

We began 2021 cautiously optimistic about resuming live events as we tracked our nation's vaccination trends. In May, happy dances took place across the country, as Kim announced that Beats 2021 would be a live event in July. Once again, we would join together, in music, at The Gaylord Opryland Resort and Convention Center in Nashville! The participation sign-ups came in swiftly with many returnees and some newcomers as well. The ages of the participants spanned five decades, with the youngest being 17, and the oldest being of the set who call themselves "The Old Farts Band."

Adding to the group's diversity were musical tastes and experience levels. But what we all had in common were hearts full of song, love for our hemo B family and proof that we had been fully vaccinated against COVID-19, thanks to the strong Coalition leadership.

There was electricity in the air on July 14th, as we reunited with our friends, and made new ones. Wayne gave a welcome presentation followed by Robert Friedman, who joined us via Zoom. Friedman, an internationally recognized speaker and author in the world of health, gave a presentation called *What's So Funny? The Rhythm is Going to Get You*, which launched us into animated group participation and spotlighted how rhythm and laughter are two activities that benefit us mentally, emotionally and physically.

After dinner, Dezarae Tate, RN and Tim Ringgold, MT-BC presented *Common Connection and Music Therapy for Stress Management*, with Ringgold via Zoom and Tate in the room with us. Between the two, they discussed bleed protection, factor levels, dosing, how managing stress impacts managing a bleeding disorder and how music can create sustainable benefits to your body and mind.

As each day of programming wound down, there were opportunities to deepen connections with fellow Coalition members by going to the designated Beats hangout and jam room and collaborate on music. Sheer musical magic has happened in that space!

The next morning, Elec Simon and his fellow drummer Ben, led us all in what was modestly billed as *Percussion Session*, and yes – we drummed our hearts out – but as anyone who was present will tell you, it was so much more.

Simon, a former NYC street busker and subway platform musician-turned-professional performer in the Off Broadway hit *STOMP*, now performs all over the world, delivering life lessons while conducting rhythmic group participation with drumsticks on five-gallon, plastic paint buckets. He says it's a rhythm based on the heartbeat. I can't imagine a more perfect guest for this program! We loved him in 2019, and after suffering through the devastating blows the pandemic dealt professional performers, Simon had new perspectives to impart to us. He shared how he, as an entertainer, had struggled with a lack of work during the pandemic, which led to depression.

Like so many of us in showbiz, Elec had to find other means of work. Then he brought down the house when he related a story of how he had started driving a school bus to make ends meet. "A little boy gets on the bus says, 'Me and my dad saw you on TNT last night. What are you doing driving a bus?' I said, 'I'm driving you to school, boy, go get in your seat!'"

Elec shared his honest story about his recent depression and loss of faith. "You never see the people who motivate people get down. I'm a motivational speaker. I'm always the one saying, 'Never give up!' And I'm lookin' in the mirror, and I'm like, 'Bro – you broke!' I was trying to speak to myself, but I broke down." Months into his dark period, while lying in his bed one morning, he felt electricity coursing through his body. He heard his voice inside of him saying "Here I am! I'm back!"

Simon wanted to encourage the hemo B family with his story and added his sentiments about how he is learning more and more about hemophilia B. He opened his heart; told us he cares about us and feels like part of the family. He also created a safe space in which others were able to share their own challenges.

This crowd wasn't shy about telling him that he is, indeed, a treasured member of this family. Coalition staff and committee team member Rocky Williams remembers Elec as a highlight of the program. "He blew me away!" He exclaims, adding, "The program exceeded my expectations. Everything fell together without much difficulty. It just flowed. The sessions were really great. I loved seeing the talent from our teachers and our speakers."

Speaking of talented speakers, up next was Michelle Leona Cecil, a Novo Nordisk Hemophilia Community Liaison, who had already been making a positive impact with her exuberant presence among us. In her presentation titled, *Stop Waiting to Thrive*, Michelle showed us six principles of empowerment we can use every day to help us thrive. Her informative talk was followed by Maxwell (Max) Feistein's talk on critical listening.

Max is a touring musician, songwriter, producer, and comedian with hemophilia. He is an outspoken advocate representing the bleeding disorders community and educates people about hemophilia and mental health through a variety of creative means. Max recently released a solo album called *Redefine*, which he wrote to shine a light on the challenges of life with a rare bleeding disorder. Max's contributions to The Beats '21 were plenteous! In addition to his talk on critical listening, he wowed a class with a guitar riffing workshop and demonstration, and he performed a solo in the concert and jumped into a group number at the last minute.

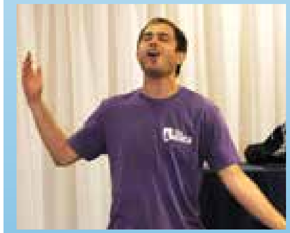
The group music classes began on day two with the drumming workshop presented by Richard Adams, the guitar workshop by William "Tiger" Fitzhugh and, as previously mentioned, the *Express Yourself Through Song,* masterclass, which I was delighted to lead with the amazing Joe Turley joining us on the piano and chiming in with his musical intuition and experience.

For the drumming workshop, Adams instructed the drumming participants in how to work with other musicians and use timing and the metronome to bring music in sync. He also worked with the class on how to use stick and feet control, even with joint issues, to add to their repertoire of drum licks.

Tiger worked with the guitar participants on using the guitar as their unique "voice" and also worked with them on songwriting and how to write unique guitar riffs. Bryant, a participant in the class said, "As a guitar teacher, Tiger can quickly figure out his students' level of ability and then provide lessons and exercises that are difficult enough to be challenging, but not so difficult as to be frustrating. As a result, I came away from his sessions feeling I'd learned some things I could really apply to my playing."

Obviously, I had a front row seat to the vocalists' class where we jumped into songs ranging from Billie Eilish to Stevie Nicks, vintage to modern, blues to gospel, and two performers, (Dylan and Andrew,) performed songs they had penned themselves! "Ivory" Joe Turley, an accomplished award-winning composer, bandleader, pianist, saxophonist, and harmonica player, worked with each singer to ascertain the best key, tempo and other nuances, and helped each singer feel comfortable enough to step outside of their safety zone into the performance directions I suggested to them. Joe, who wrote the recent Ringo Starr hit, *Zoom In Zoom Out*, said, "We had a seriously talented, fun and diverse group of brothers and sisters all pulling for each other. It was an oasis of togetherness and positivity and a healing break from all the isolation."

Belle, our youngest vocalist, said of the whole program, "What I loved was the immense amount of support and love from each and every individual. The instant feeling of home and of family is what I always look forward to in these events












and am never disappointed. I learned that the butterflies in our stomach are not your enemy, and that if you don't have butterflies, your performance isn't going to be that great. My inspiration to grow and to become better at singing came from the support that each and every one gave me." The butterflies to which Belle is referring are otherwise known as performance nerves. I addressed those in a new talk called, *Befriending the Butterflies – Harness the Power of Performance Nerves*, helping the performers to give stronger, more purposeful performances.

On day three, singer-songwriter Trevor Martin who has hemophilia, impressed us all when he sang and shared the story of two of his original songs and songwriting process. He was "amazing" and ran into overtime. Also on day three, we had the opportunity to take a tour of *The Robot Factory*, a recording studio in East Nashville, run by producers Jeremy Bose and the Coalition's own Adam B. Smith. Adam, who has a young son with severe hemophilia B, was new to the Coalition when he jumped in with both feet and lent his talents to the inaugural Beats program in 2019.

The very moving *Silver Linings* music video which resulted from the 2019 Beats was mastered by Adam. He was a major key to the success of the remote 2020 Beats as he created rehearsal tracks, helped the singers find their groove, collected home recordings and mastered them into videos we could all be proud of, including the group number, *That's What Friends Are For*. Smith was part of the 2021 Beats planning committee and ran the sound and lights for the guest speakers and the final performance, adding a new level of production values to showcase the participants' talent and growth!

One of the thrills of The Beats programs held in Nashville is taking in The Grand Ole Opry Show. It's not just a show, it's a historic country music tradition that dates back almost one hundred years! Some Beats participants showed their spirit by dressing in their county-western duds, and the electric energy from the special night was still buzzing at the breakfast tables on day four.

Day four on Saturday was performance day. After one more rehearsal with the teachers, the singers, drummers, and guitar players

went to their rooms to make themselves stage-ready for the culmination of their brave work of stretching themselves and furthering their musical craft. As curtain time drew near, the audience seats filled with Coalition members, including some non-Beats members who traveled to Nashville to show support for their hemo B family.

Also present were The Beats sponsor volunteers from CSL Behring, CVS, Medexus and Novo Nordisk. Photographer, Lindsay Goats, who took such stunning photos of the program participants in 2019, was joined by Eliza and Baxter Linney to photograph and video the four days and captured the musicians and singers on stage and audience members as they cheered on their tribe. Everybody joined in the closing number, *Lean on Me*, and then the kind of celebration that stems from personal triumph ensued.

Looking back, Milinda raved, "The performances really surprised me. Who knew we had so much talent in this community?!" One of those performances was by Kendall, a specialty nurse and mother to a son with hemophilia B. She had never sung a solo in public before and came to the program with an open mind and a willing spirit. She worked on her chosen song in the masterclass and then took advantage of music jam times with other musicians in the evenings to have an even fuller experience.

As one of those musicians, returning Beats participant, Rick, said, "As a veteran of The Beats program, I found it inspiring to watch others grow with the guidance they received, especially Kendall. To see her, a person who has never sung before, challenge herself, then to have another song thrown at her in the last minutes leading up to the performance made my heart sing!" That's right, Kendall said "Yes," when Rick asked her to sing another song with them from the stage, with no rehearsal

time! It was roundly agreed that she is a natural performer.

Ron, who led the whole audience singing *Right Here, Right Now*, called it a wonderful experience to have enjoyed the connection and memories made. Stephen, who took part in the drumming clinic, said, “I really enjoyed everything about this program. I liked seeing everyone, increase my drumming skills and meet great musicians.”

“This was my first time attending this program live,” Fel relates. “Last year was virtual, but as always, I really love the connection with my fellow brothers and sisters, and to be connected by music is even greater.” Fel felt that he learned a lot from his time spent with the coaches and teachers. “To get those one–on–one experiences with Renae, Elec, and Richard was new and inspired me to let go of my fear of singing in public. It helped to have amazing pianist, Joe Turley, and my amazing coach, Renae, giving me all the tools to succeed in my performance.”

Bryant, who took part in the guitar clinic, wanted to highlight the many opportunities The Beats program offers Coalition members to play with other musicians. “I’m a bit of an introvert and a homebody, and I really have not made much of an effort over the years to seek out other folks to play with. So being able to rehearse and perform with a really competent bunch of guys, (Ray, Rick and Wayne) was a great experience for me. The other thing I’ll mention is

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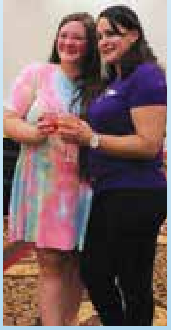
COMMON CONNECTIONS & MUSIC THERAPY

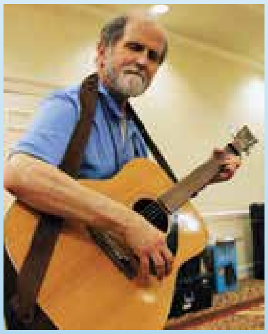
DEZRAE TATE, RN
& TIM RINGGOLD MT-BC

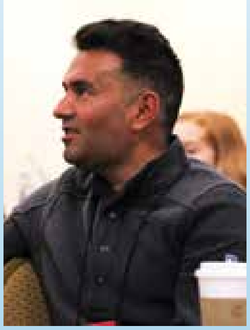
RYMAN STUDIO L

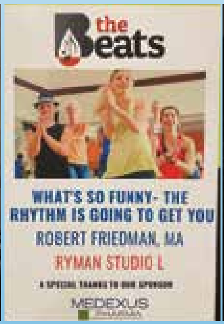
A SPECIAL THANKS TO OUR SPONSOR

CSL Behring









the Beats

WHAT'S SO FUNNY- THE RHYTHM IS GOING TO GET YOU

ROBERT FRIEDMAN, MA

RYMAN STUDIO L

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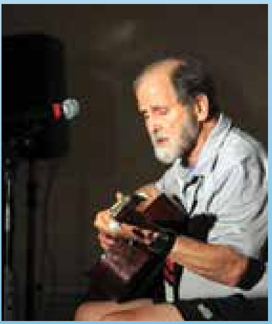
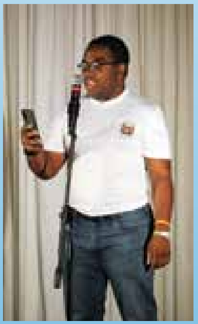
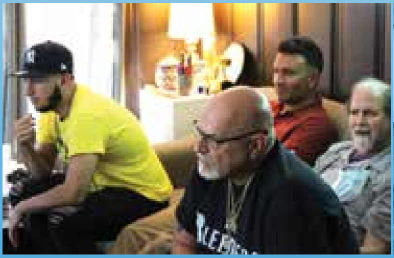
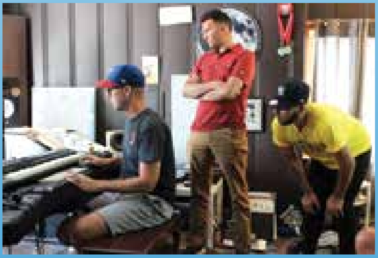
MEDEXUS
PHARMA

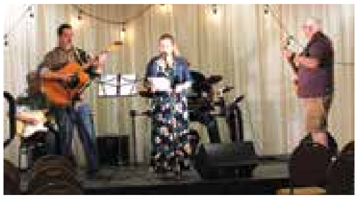








that by having a program centered on music, I found it a lot easier to strike up conversation and get to know the other participants than it would have been at a regular (medical/educational) hemophilia event. For example, I had a nice, long chat with Max Feinstein on the final night that I'm fairly certain wouldn't have happened if we hadn't had music as a conversational launching pad. It's a great program. I hope I have the chance to participate in it again." Bryant also influenced a young audience attendee with hemophilia to begin playing guitar. He spent some time with him after the final night and now this young new guitar player cannot wait to attend this program. Connections are so powerful!



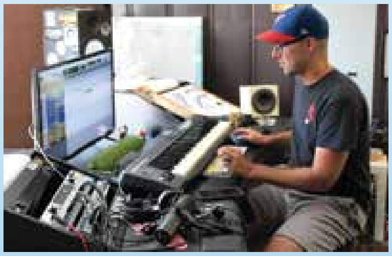
Max had some thoughts about the program, "Anthony Kiedis refers to music as *The Great Communicator*, and during my time at The Beats program, I was as aware and appreciative of that sentiment as I have ever been. In a community that often prizes activity because it represents a functioning body, the arts can seem neglected. This program is proof-positive how vital and valuable a connection through the arts can be."

Milinda raves, "Let me tell you! The Beats program couldn't have gone any better! The programs by the professionals who taught us were so awesome! The talent they have for teaching us new things really lit my curiosity. All the music sessions and the fabulous Joe Turley on piano and harmonica

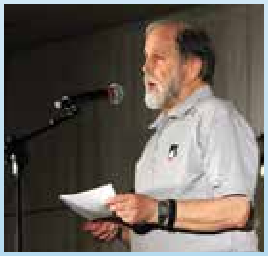


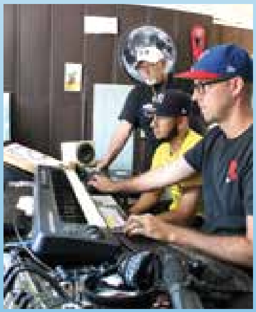




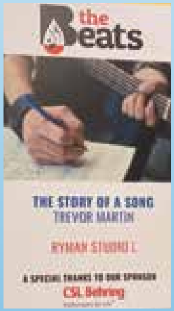



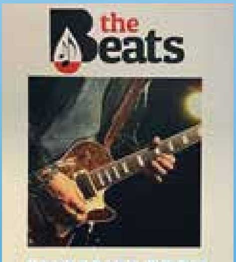






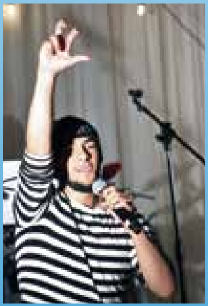












were such amazing experiences." She credits the production team. "Everything was put together so nicely! The hard work they put in really paid off!" It inspired me to remember we all have friends we can lean on. We have music we can count on to bring us joy, and that connection we have together will last a lifetime. Music is happiness. It's therapy. It's love! I look forward to seeing what the future holds for The Beat. It keeps getting better!

Kim Phelan reflects, "When the program first began, the concept was good, but what actually happened exceeded my wildest expectations. Community members from all walks of life with unique talents playing different types of music styles totally merged. It flowed effortlessly, and everyone celebrated and cheered each other on." She was enriched to see how this program brings together people who may not attend other events. "A week later you can still feel the energy from this program. It's not just music; it's collaborating, sharing, bonding and finding a support system of like minded people. It also helps with depression. The support, love and energy this program shines on all the positives."

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"Thank you for believing in us and this program. We knew it was going to fill a void in the community. We knew it was good for depression and would further bring more in the community together. We knew it would not be easy to put together but we did it, and we are so thankful to our sponsors – who also bring in valuable programs during this event – for helping us bring our vision to reality, especially for those who we do not normally reach." To prospective sponsors, Kim states, "Sponsor this program. You will not regret it! Come once and you will see why!"

Transcending pain and achieving solid gold relationships through music. Does it get any better than that? I cherish my time witnessing and participating in musical magic. If you have a desire to express yourself through music, I hope you'll join us next year!

More photos from the Beats Music Program can be found on our Facebook Page.

the Beats

THANK YOU, SPONSORS!
For Your Generous Support of
The Coalition For Hemophilia B
3rd Annual Music Program

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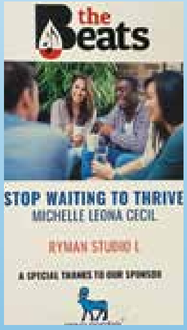
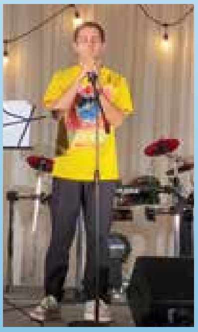
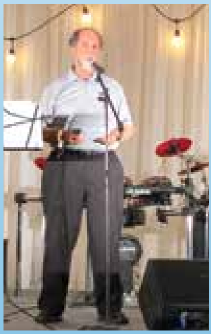
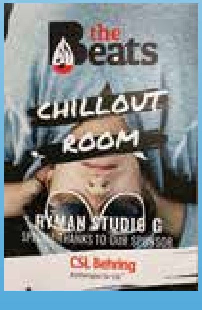
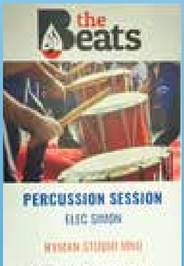
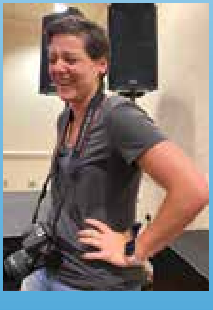












A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.

HOW DOES THIS FACTOR IN?

To find out about a prescription option, talk to your doctor or visit **OnceWeeklyForHemophiliaB.com**

February 2021

BEHIND THE HEMOPHILIA B DIAGNOSIS

BY TIFFANI P.

"Is his cheek swollen?" my mother asked when my son Aleks and I visited on a random Friday night. I told her his cheeks have always been chubby. She asked me to come into the next room and look. It was obviously swollen. I had no idea how I had missed it all day or how long it had been like that. I immediately got on the phone with our pediatric center to see what I should do. My son's cheek was not warm or flush, just big. She told me to keep an eye on it and if it did not get any bigger, to hold out until Monday when the office opens. So, I did.

Come Monday morning, I called the office and they scheduled me in right away. The nurse practitioner was as confused as I was. She started noticing other small bruises on Aleks, such as on his ankle. This raised concerns, I could tell, but I knew nothing bad was happening to him. I stayed home with him all the time. She sent us to Toledo Hospital emergency room right away to get MRIs and X-rays. I was met in the hospital room by children services whose first line of introduction was, "I'm gonna be straight with you, your kid probably isn't going home with you today."

My worst nightmare was coming true right before my eyes. I could not comprehend what was happening. Luckily moments later, the doctor came into the room, ushered the children's services representative out, and informed us that blood results had come back with some type of hemophilia. "Hema-what? What is that?" I was lost and it was all just the beginning.

As we rolled our six-month-old up to the children's floor of the hospital, I cannot tell you the relief that was lifted off my shoulders knowing there was an explanation for the bruises. I did not know where our life was going or what was going to happen to our baby boy in the next 24 hours, but he was still with us, in our care. I will never blame the nurse practitioner or the hospital for calling children's services. I would want them to do that a million times again. I would never want a medical professional to second guess if a child is a victim of abuse. I am grateful they did what they did because my son was able to get the help he needed.

Days go by as we sit in the hospital with our son and with each passing minute, it seems as though we learn something new about his diagnosis, severe hemophilia B. Although, I probably couldn't even say it once from the top of my head at that time. All the unfamiliar terms and lingo were so confusing. It was A LOT to take in, to say the least. Did I mention I was already four months pregnant with our youngest son during all of this? So, we had genetics done right away (or as soon as insurance approved it) on myself to see if I was a carrier. It turns out I am a carrier, but we will save that for another time.

When we were finally discharged from the hospital, we were still scared as to where this life was going to take us now, but we felt relief knowing our child was well cared for at the Toledo Hospital. I got home and realized I did not even know the terminology. I could not differentiate between really anything! Luckily, a

sweet soul named Tara reached out to me not long after we got home from the hospital. Her son was just diagnosed about a year earlier and she really helped guide me through my early days of hemophilia. She was truly an angel in disguise, as any hemo mama is! I knew I could call or text her whenever I had any questions or if I just needed to vent. Tara helped me sign up with The Coalition for Hemophilia B and I applied for events right away because she said they were great at helping her in the beginning of her journey.

Months go by and we are doing our regular visits with the hemophilia treatment center, but Aleks gets a little chunky and his veins are starting to get harder to find. I was near the end of my pregnancy when we had to poke him seven times. SEVEN. TIMES. He was just under one year old and had blood spots on his onesie now and we had turned him and cradled him every way we could, but he NEEDS his factor. After what seemed to be hours, we finally were able to infuse his factor. It felt great knowing we finally got it, but I broke down and cried. I called my husband and said, “I can’t do this every week,” knowing Aleks was the one that had to go through the torture, not me. So, after careful consideration, we decided to get Aleks a port.

Aleks had his port placed on August 5, 2019, just a couple of weeks after his first birthday. The whole procedure went well and Aleks was taking his infusions wonderfully now. Another huge weight was lifted. We were learning the process of accessing Aleks’ port through our clinic and I ran into another roadblock: accessing his port myself. I had never been a fan of needles, or you know, poking my own child with needles. It was something I struggled with for weeks. I could do everything else except do the poking. Maybe that’s a normal feeling for a parent, but it was just so hard for me, and I could not even envision it. I did not know when I would get over that hurdle.

The Coalition for Hemophilia B held a women’s retreat that September in Phoenix, Arizona. I felt so blessed and was so excited to be able to meet not only Tara, but other women from the community. I learned about their fears, their struggles, and what has helped them cope. I made lifelong friends and I have a whole community of women that can help me whenever I may need it. So many of these women has endured struggles worse than mine and their tears and laughter gave me strength. I knew if they were still standing tall, right in front of me, and telling me their stories, I could do anything. I was capable of leaping over any hurdle that was in front of me, because these women did it too. I have never felt more empowered in my entire life. I was not afraid of hemophilia anymore. I was not afraid of what my son’s life was going to look like, because he has me, and I have these women.

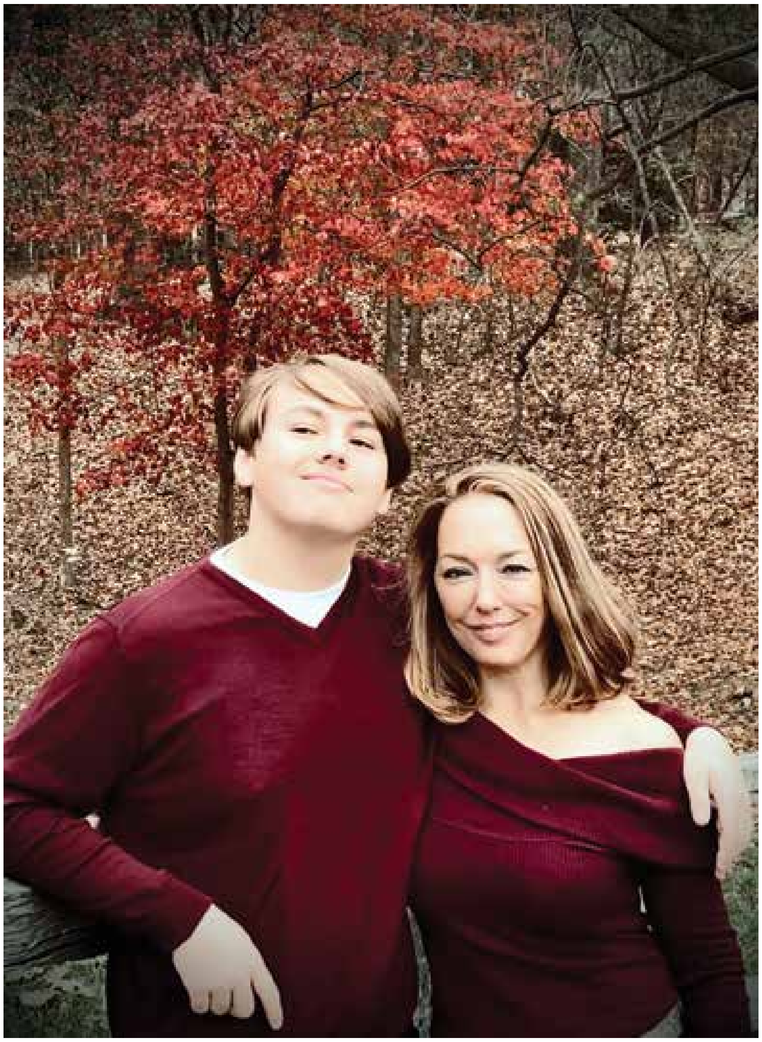
I accessed Aleks’ port for the next infusion after I got home from Phoenix. I knew as we drove to the clinic for his infusion the week after I got home from the women’s retreat, I was going to access his port. Nothing was going to stop me. The women I had the honor of meeting in Phoenix helped change my life, and Aleks’. I knew if ANYONE was going to access my baby, it was going to be me, and I did. By February of 2020 we were doing home infusions all by ourselves and the freedom of not having to go to a clinic every week is amazing. Knowing if something were to happen to Aleks and he needed factor right away and I could do it, made me feel higher than the clouds themselves.

When hemophilia came into our lives like a wrecking ball, I did not know what the future was going to look like, and I am sure that happens with a lot of unsuspecting families. I am forever grateful for Tara, The Coalition for Hemophilia B, and our Hemophilia Treatment Center in the Toledo Hospital, for always helping us and guiding us through our journey. It is only the beginning as Aleks is now three, but having the community that we do, and the support system we now have, I know we will be just fine. Thank you all so much.

Golf

GAVE ME BACK MY CHILD

BY LISA H.



"Golf gave me back the child that had been lost to imaging studies, doctor visits, surgeries, and years of chronic pain."

In 2017, my son, James, was active in middle school. He also has mild to moderate hemophilia. For most of his life, his hemophilia was well controlled. He swam, played soccer and, in elementary school, discovered volleyball. In the winter of 2017, he joined a competitive boys' travel volleyball club.

Easter Sunday of that year, he was at a trampoline park jumping. He said he landed, and his right knee popped and swelled. At the direction of the hematologist on call, I took him to our local emergency room who later transported him to John Hopkins Hospital. After 13 hours, two emergency rooms, an ambulance ride, and an infusion of factor, he was discharged on crutches.

We spent the next several months bouncing between hematology and orthopedics. This wasn't the first time his knee had popped and swelled. By default, he was started on a prophylactic dosing of factor. His volleyball season and the summer season were effectively over.

In 2018, he was back to playing volleyball again but he started to complain of swelling and pain in both knees. An imaging study of his right knee, the one that had popped, revealed a large bucket handle tear of the medial meniscus and at least two areas of erosion into the bone. Despite swelling being noted in both knees, no imaging studies or follow up were done on the left knee. The entire focus became the right knee.

We consulted with multiple orthopedists and settled on Dr. Leigh Curl in Baltimore. She was the orthopedist for the Ravens and James appreciated her middle-of-the-road approach. At his age, the goal was to attempt to save as much of the meniscus as possible and give the joint time to heal. The need for bone grafts or cadaver replacements should wait.

Eight weeks after surgery, James began rehab. Post-operatively and during physical therapy, it was noted there was swelling in the left leg. The belief was that it was the result of him favoring this leg. When his physical therapist noted that she would have guessed he had surgery on the left leg and not the right leg, I was finally able to convince his medical team to do an imaging study of that leg, just to be sure we hadn't missed anything.

It was during that scan that they noted a lesion in the left femur. The diagnosis from his care team bounced from tumor to cancer, to infection, back to tumor, and finally settled on a hemophilic pseudotumor. James was

placed into a chronic pain clinic and was told that pain shouldn't be that bad and he should be able to work through it.

In the midst of this health crisis, we had received an email from The Coalition for Hemophilia B that James had won a scholarship for golf clubs and lessons. He was not enthusiastic about winning the scholarship. He was upset because he had lost the sport he loved, volleyball. He was frustrated none of the doctors seemed to believe that he was in pain and that this was just going to be his life. The knee that had been repaired was still causing pain and not healing, and now he had a lesion in the other leg.

I convinced James to just try golf. If nothing else, maybe he could play golf instead of partaking in PE, if the lessons went well. I reached out to the high school who recommended a local golf pro. Instantly he and James connected. James started to smile and show an interest in doing something again.

However, he still struggled with pain. It was a challenge for him to golf more than a hole or two, but he was learning the game. He started to smile again. It was at the end of the lessons, almost 10 months after the lesion was first diagnosed, and over two and a half years of complaints about knee pain and swelling that he was seen for a second opinion at Georgetown University Hospital.

He was diagnosed with a chondroblastoma, a rare bone tumor. Despite never having treated this type of tumor in a person with a bleeding disorder, within a month the teams at Georgetown and the Washington Cancer Institute had diagnosed, developed a plan, and treated the tumor. To my son, who had been told for years that his pain wasn't real or was neurological, the oncologist said, "Of course you are in pain, these types of tumors are incredibly painful."

Over a period of two years, my son had gone from travel-level athletics to not being able to walk for more than 10 minutes without needing a break. His weight increased and, for the most part, he gave up any hope of sports. A sadness crept into our lives.

With winter and the removal of the tumor, golf went on hold for a few months. This past spring, James returned to golf, used the scholarship and competed on his high school team. I had alerted his high school coach to James' history and that he was nervous he wouldn't be able to walk far enough to play. He didn't want to commit to the team and let his teammates or the coach down. The coach told James they would take it one day, one hole at a time. If he needed a break, they would take one.

Golf and athletics was about more than winning; it was about building character and friendships. James finished the season, earning a varsity letter and even completing 18 holes on foot. He lost over 20 pounds. His earlier golf instructor pulled me aside to tell me how happy and full of life he seemed on the course. Our close family friends told me how nice it was to see James smiling and joking around again.

As a parent, watching your child endure pain that cannot be relieved, seeing the joy and hope fade from their life is heartbreaking. Golf gave James a new door. It has provided a lifelong sport, a chance to make new friends and a varsity letter. For me, golf gave me back the child who had been lost to imaging studies, doctor visits, surgeries and years of chronic pain.

I look back and I am not sure we would have made it through the last several years without the support of the community. I never would have gotten James on the golf course had it not been for the scholarship from The Coalition for Hemophilia B. I am eternally grateful for the scholarship and the unwavering support of the community and bringing light back into our lives.

TAKE CONTROL TO A HIGH LEVEL

WITH REBINYN®

IN HEMOPHILIA B

Rebinyn® elevates factor levels above your normal levels[a]

+94% Factor IX (FIX) levels achieved after an infusion[b]

83-hr (3.5 day) average half-life in adults[a]

With a single dose of Rebinyn® 40 IU/kg in adults with ≤2% FIX levels[a]

Clayton, 34 years old, is a pilot and enjoys hiking and camping in his spare time. Clayton lives with hemophilia B.

Achieve higher factor levels for longer

Compared with Alprolix®[c], Rebinyn® provides

4x greater factor coverage

6x higher factor levels at 7 days

Image of hemophilia patient shown is for illustrative purposes only.

[a] In a phase 3 study of adults, single dose pharmacokinetics were tested during the first Rebinyn® 40 IU/kg dose in 6 adults.

[b] Based upon a 2.34% increase in factor levels per IU/kg infused in adults.

[c] Based upon a phase 1 study comparing a single 50 IU/kg dose of Rebinyn® to a single 50 IU/kg dose of extended half-life rFIXFc in 15 adults. To allow for direct comparison between products, all patients received the Alprolix standard 50 IU/kg dose.

INDICATIONS AND USAGE

What is Rebinyn® Coagulation Factor IX (Recombinant), GlycoPEGylated?

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyn® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used for routine prophylaxis or for immune tolerance therapy.

IMPORTANT SAFETY INFORMATION

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

- **Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.** Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn®.

Who should not use Rebinyn®?

Do not use Rebinyn® if you:

- are allergic to Factor IX or any of the other ingredients of Rebinyn®.
- are allergic to hamster proteins.

What should I tell my health care provider before using Rebinyn®?

Tell your health care provider if you:

- have or have had any medical conditions.
- take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

How should I use Rebinyn®?

- Rebinyn® is given as an infusion into the vein.
- **Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.**
- Do not stop using Rebinyn® without consulting your healthcare provider.

What are the possible side effects of Rebinyn®?

- **Common side effects include** swelling, pain, rash or redness at the location of the infusion, and itching.
- **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- **Tell your healthcare provider about any side effect that bothers you or that does not go away.**
- Animals given repeat doses of Rebinyn® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

Please see Brief Summary of Prescribing Information on the following page.

Rebinyn® is a prescription medication.

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

Learn more at rebinyn.com and connect with your local HCL

novo nordisk®

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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rebinyn®
Coagulation Factor IX (Recombinant), GlycoPEGylated

rebinyn®

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Brief Summary Information about:

REBINYN® Coagulation Factor IX (Recombinant), GlycoPEGylated

Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/REBINYN.pdf to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

Read the Patient Product Information and the Instructions For Use that come with REBINYN® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about REBINYN® after reading this information, ask your healthcare provider.

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

Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing REBINYN® so that your treatment will work best for you.

What is REBINYN®?

REBINYN® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Hemophilia B is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

REBINYN® is used to treat and control bleeding in people with hemophilia B.

Your healthcare provider may give you REBINYN® when you have surgery.

REBINYN® is not used for routine prophylaxis or for immune tolerance therapy.

Who should not use REBINYN®?

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

What should I tell my healthcare provider before I use REBINYN®?

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor IX.

How should I use REBINYN®?

Treatment with REBINYN® should be started by a healthcare provider who is experienced in the care of patients with hemophilia B.

REBINYN® is given as an infusion into the vein.

You may infuse REBINYN® at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

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

If your bleeding is not adequately controlled, it could be due to the development of Factor IX inhibitors. This should be checked by your healthcare provider. You might need a higher dose of REBINYN® or even a different product to control bleeding. Do not increase the total dose of REBINYN® to control your bleeding without consulting your healthcare provider.

Use in children

REBINYN® can be used in children. Your healthcare provider will decide the dose of REBINYN® you will receive.

If you forget to use REBINYN®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using REBINYN®

Do not stop using REBINYN® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much REBINYN®?

Always take REBINYN® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more REBINYN® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of REBINYN®?

Common Side Effects Include:

- swelling, pain, rash or redness at the location of infusion
- itching

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor IX products. **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against REBINYN®, which may stop REBINYN® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

Animals given repeat doses of REBINYN® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

These are not all of the possible side effects from REBINYN®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

What are the REBINYN® dosage strengths?

REBINYN® comes in three different dosage strengths. The actual number of international units (IU) of Factor IX in the vial will be imprinted on the label and on the box. The three different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store REBINYN®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Store in original package in order to protect from light. Do not freeze REBINYN®.

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) REBINYN® should appear clear without visible particles.

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 86ºF (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about REBINYN® and hemophilia B?

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

More detailed information is available upon request.

Available by prescription only.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 11/2017

REBINYN® is a trademark of Novo Nordisk A/S.

For Patent Information, refer to: http://novonordisk-us.com/patients/products/product-patents.html

Manufactured by:
Novo Nordisk A/S
Novo Allé, DK-2880 Bagsværd, Denmark

For information about REBINYN® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

USA17BIO03951 12/2017

novo nordisk®

ADVOCACY UPDATE

NHF'S VIRTUAL WASHINGTON DAYS

NHF's Washington Days will take place *virtually* on March 1-2, 2022.

This is your opportunity to share personal stories about living with a bleeding disorder with your elected members of Congress and their staff. Participants will focus on several important issues including the passage of H. R. 5801, the bipartisan HELP Copays Act (HR 5801). This bill aims to support the 133MM+ Americans living with a chronic condition, by ensuring that all payments, whether they come directly out of a patient's pocket, or with the help of a copay assistance program, will count towards their out-of-pocket cost-sharing requirements.

All members of the hemophilia community are encouraged to participate.

EMERGING THERAPIES

BY DR. DAVID CLARK

We have just a few updates in this issue. Many organizations wait until the American Society for Hematology (ASH) meeting in December to announce their latest results. We should have a lot more updates in the next issue.

As Catalyst Biosciences to Discontinue Hemophilia Product Development

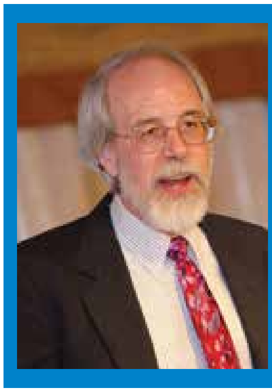
11/12/21 Catalyst Biosciences has been developing three hemophilia treatment products, DalcA, a subcutaneous factor IX with longer half-life and higher activity, MarzAA, a subcutaneous activated factor VII product for inhibitor treatment, and a gene therapy for hemophilia B using their DalcA factor IX. The company is trying to reduce costs to better support their other products under development. They are looking to license or sell their hemophilia portfolio to another company. [Catalyst Biosciences press release 11/12/21]

GeneVentiv Developing Factor Va Gene Therapy for Inhibitor Treatment

11/2/21 GeneVentiv announced that FDA has granted Orphan Drug Designation (ODD) for their GENV-HEM gene therapy for hemophilia A or B inhibitor patients. ODD gives a company tax credits and other incentives to develop a medication of orphan diseases. GENV-HEM uses AAV vectors to produce activated factor V (FVa). Much like factor VIIa, which is currently used for inhibitor treatment, FVa increases the activity of factor X to improve clottability in the absence of factors VIII or IX. [GeneVentiv Thgerapeutics press release 11/2/21]

Pfizer Gene Therapy Delays

11/2/21 Pfizer is currently developing gene therapies for hemophilia A and hemophilia B, among others. They recently revised their development timeline based on feedback from FDA, which is requiring longer-term data for gene therapies. Their hemophilia A gene therapy also recently resulted in a few new patients developing higher than normal levels of factor VIII, which can be thrombogenic(cause dangerous unwanted clotting). Their gene therapies for hemophilia A and B are completely unrelated products, and the extreme levels have not been seen for factor IX. Pfizer is now expecting to have complete data for their hemophilia B gene therapy in early 2023. [Pfizer 3rd Quarter Earnings Call 11/2/21]



HEMOPHILIA HEALTH NEWS

BY DR. DAVID CLARK

ATHN Study on Bleeding in Carriers and Women with Hemophilia

9/29/21 A study of hemophilia carriers who are seen at U.S. HTCs was conducted using the ATHNdataset. Among 922 women in the dataset, 74% had normal bleeding scores, including 59% of those with factor VIII or IX levels less than 40%, which is the WFH cutoff for normal factor levels. Interestingly, 24% of the women who had factor levels above 40% did have bleeding problems. That is, about a quarter of carriers with factor levels in the normal range still bleed, while over half of those below the normal range do not bleed. This finding is consistent with other studies and suggests that more than just factor level is at work in carriers.
[Puetz J and Cheng D, *Haemophilia,* 27(6), 1045-1050, 2021]

Prophylaxis with Alprolix Produces Long-Term Improvements in Pain and Quality of Life

11/10/21 It has been an open question whether long-term prophylaxis with extended half-life products and/or continued factor IX production via gene therapy would heal already-damaged joints and improve pain scores in hemophilia B. Two recent studies of prophylaxis with Alprolix have shown reason for hope. A European study looked at patients in the Alprolix clinical studies who had been treated for up to 6.5 years. They found significant decreases in pain and improvements in physical functioning over the course of the study. They also found an increased ability to participate in sports, from walking to football (soccer) among the participants.
[Astermark et al., *Haemophilia*, online ahead of print 11/10/21]

10/11/21 The other study comes from Ireland where essentially all hemophilia B patients have been placed on Alprolix because of a government contract. Although the media have touted this study as not showing much improvement in pain, the study did in fact show a significant 9% improvement over the course of two years, but the rate remained high with 74% of patients still reporting pain. This suggests that although pain decreases, it is a slow process.
[O'Donovan et al., Res *Pract Thromb Haemost*, online ahead of print 10/11/21]

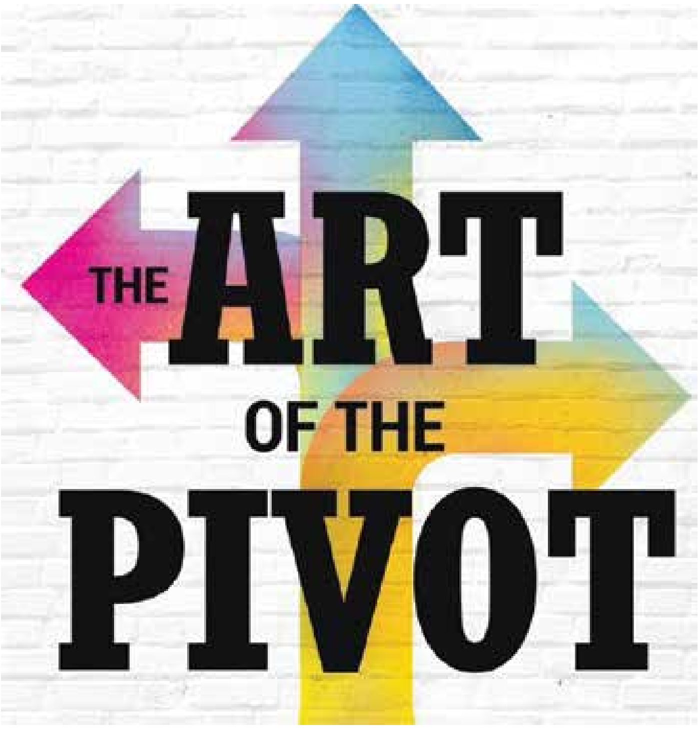
Factor IX Affects Bone Mass and Strength

6/12/21 In addition to clotting, factor IX also appears to affect wound healing and bone strength. A group from Oregon looked at the effect on bone density and strength in hemophilic mice. In mice that have been genetically engineered either to not produce factor VIII (FVIII-knockout), or to not produce factor IX (FIX knockout), they found that either deficiency leads to skeletal issues that are apparent long before adulthood.

There is some evidence that thrombin (activated factor II), which is produced downstream of FVIII/FIX in the clotting system, is the culprit. Thrombin stimulates bone cells called osteoblasts that form new bone. This all suggests that it is the low level of clotting activity, and thus the low level of thrombin, that affects bone strength, and not some other property of factors VIII or IX.
[Larson et al., *Calcified Tissue International*, online ahead of print 6/12/21]

THE ART OF PIVOTING:
ADJUSTING TO AN UNPREDICTABLE WORLD

BY MATTHEW D. BARKDULL, MS, MBA, LMFT, MEDFT



Is it just me or are world circumstances becoming more uncertain, unpredictable, and unstable? Don't get me wrong, I consider myself to be a naturally optimistic person. However, when I read or watch the news constantly highlighting pandemic variants, bomb cyclones, civil unrest, political infighting, and any other number of problems, I want to throw my arms up in dismay and tune out of reality.

At times I feel like Wile E. Coyote, the Looney Tunes character always in pursuit of the elusive roadrunner, pulling down the shades while knowing that a train is about to pummel him. That which is out of sight does not change the trajectory of emerging threats. In such circumstances, we often employ one of three survival instincts: fight against it, run away from it, or freeze in fear or denial. As much as we hope these tactics will prove successful, they rarely amount to much, especially when we're up against a speeding locomotive. In the end, trains always win!

So denial is not only a river in Africa but also doesn't work well when it comes to coping and adjusting to an unpredictable world. So, what's to be done? More and more social scientists continue to research and report on what is becoming known as "Pivoting." A pivot is known in engineering but has been adopted several other places including the social and behavioral sciences. In business, pivot means to change some aspect of services or strategy due to changing client, financial, or societal circumstances that are outside of its control. In other words, a business doesn't wait for outside circumstances to change; the business adjusts or "pivots" itself in order to thrive and meet changing demands. If not, the business can quickly die. The same principle is seen in sailing and oceanic navigation.

An American religious leader stated the following, "A very large ship is benefited very much by a very small helm in the time of a storm, by being kept workways with the wind and the waves. Let us, therefore, cheerfully do all things that lie in our power." Winds and waves regularly shift in storms; therefore, the navigator is constantly "pivoting" and adjusting to these variations so as not to capsize the ship.

So, let's talk turkey and have a blunt conversation about our future. Frankly, I'm getting tired of the naysayers and those continuing to promote the status quo. The world seems bent on marginalizing and downplaying the merits, accomplishments, and capabilities of individuals, especially those that face the specter of chronic or even acute health conditions. This leads me to emphasize the first of three suggestions on the fine art of pivoting despite the storms that may be raging around us.

PIVOT PRINCIPLE #1: PAY ATTENTION

Any good business is going to have professionals whose sole purpose is paying attention to, tracking, and reporting trends to senior management. Like the sailing analogy, these skilled employees are analyzing the shifting patterns of the winds and waves that, if caught unawares, could capsize, or put the business at a serious disadvantage. We're no different. All too often, changes and shifting patterns are more subtle than obvious. This subtlety requires that we're vigilant and paying attention. Like a riptide, it's not altogether apparent that there's danger until the current traps the unaware and pulls them steadily out to sea. Part of paying attention is listening to trusted sources. In the bleeding disorder community, people trained to see the riptides give us important information about what may be coming so we feel more prepared and act early before we find ourselves in harm's way. The art of pivoting is dulled when we are caught off guard. If possible, the more we pay attention and act upon information given to us, the more effective our pivoting will be. As stated in a scriptural passage, "But if ye are prepared ye shall not fear."

PIVOT PRINCIPLE #2: Remember Our Value

Remembering our value is often sidestepped as a relatively unimportant, even misunderstood idea. Most find it too "Mr. Rogersy" or simplistic but I'm here to tell you, as a licensed mental health counseling professional, that seeing value in self is one of the most important components of health living including healthy brain function and mental health. When one discredits the value of self, a part of our brain (within the limbic system) takes this belief and often unconsciously forms a warped identity that is parading around as you while burying the real you in a shroud of misaligned beliefs and thinking errors. What's the consequence? To name a few: depression, hopelessness, anxiety, fear, unwillingness to advocate for self, ruined relationships, living defensively not offensively, and surviving without thriving.

Professional counselors or coaches are often highly skilled at helping you challenge these beliefs and working with you to realign your life to true principles that constitute your authentic and wonderful identity. In order to properly pivot during the storm means that you have energy and "umph" to have the gumption to call out the lies and embrace who you really are. And I guarantee, you'll like who you find!

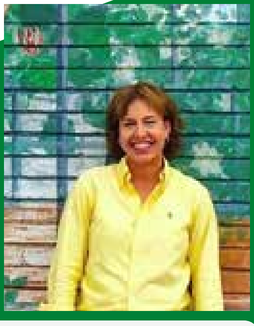
PIVOT PRINCIPLE #3: React Objectively, Not Emotionally…Eventually!

Here's a little something to think about. Reflect upon a time that you were absolutely blown away by some new piece of information that took you completely by surprise….in a strongly negative way. Do you have something in mind? If you're struggling here are a few ideas: the 9/11 attacks, a COVID-19 variant being discovered, reaction to any election, a loved-one passing away suddenly, the loss of a job, being the victim of a crime, being betrayed, diagnosed with a health issue, and so forth. Choose one of these difficult moments. Now that you have identified something, consider how you immediately felt. Fear? Anger? Disbelief? Shock? Disgust? Bewilderment? Sadness? Denial? Choose one or more emotions. As you remember this hard moment with its accompanying emotions, recall what you actually did as a result. How did you behave? Identify your behavior.

Now, let's make a few things clear. "Feeling is not bleeding.". It's okay to feel, express emotion, and go through a process of healing, mourning, and adjusting to what happened. I have worked with many that feel bad about how they reacted to an emotionally power-packed punch to the gut and normalize the reaction. That being said, could you imagine yourself feeling like this all the time—constantly in a state of emotional upheaval? You may be surprised how many people live in this constant state of emotional shackling. All the sadder is that the more they struggle, like quicksand, the faster they sink deeper into their problems.

How do we go about reacting objectively (or thoughtfully) to challenges and new information? There is a buzz word that is common in today's vernacular—mindfulness. Take the information that you've received, react emotionally as needed given the circumstances (sometimes this takes a great deal of support given the difficulty), but allow yourself time and space to consider what the change means. Mindfulness can be done multiple different ways: yoga, meditation, journaling, prayer, counseling, progressive muscle relaxation, deep breathing, really anything that brings a greater sense of grounding, objectivity, and clarity of thought. As we grow accustomed to coping in this type of fashion, the result often increases our ability to see things as they really are and act upon well thought out strategies to help us pivot based upon these discoveries.

These are just the core basics of what professionals have found helpful in pivoting and adjusting to the unpredictable circumstances that we may find ourselves. As stated above, extra support may be needed to fully comprehend and work through these challenges. The true key to mastering the pivot involves not burying our heads in the sand but to be aware, informed, and proactive to gain the information needed to make clear decisions. By doing so, although difficult and often emotional, we'll greatly increase our capacity to adjust and act upon solutions faster than fighting, fleeing, or freezing.



4 REASONS TO BECOME A MENTAL HEALTH FIRST AIDER

- ☑ Preparedness
- Help
- Mental Illness Is Common
- Care

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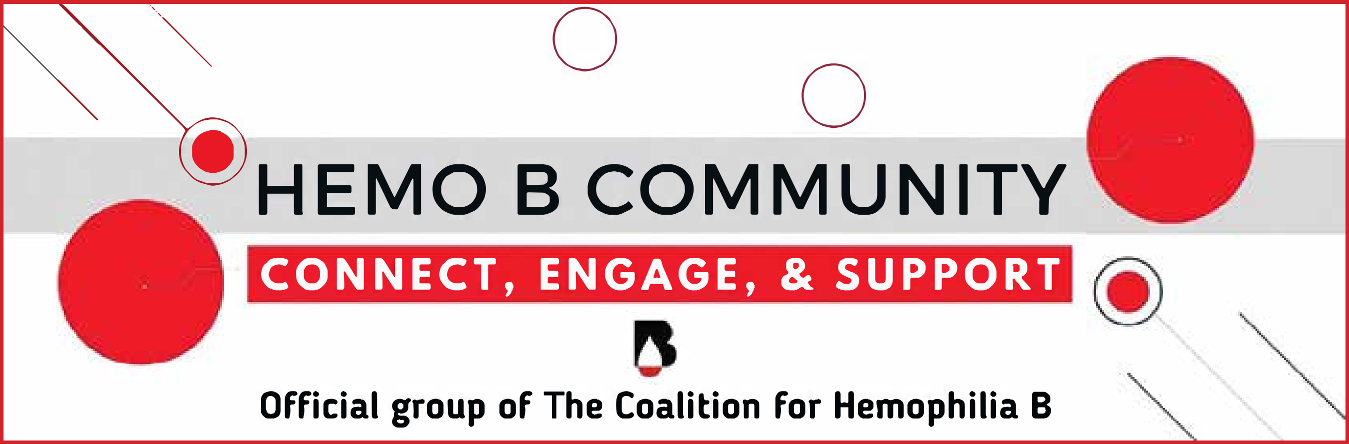


HEMO B COMMUNITY

CONNECT, ENGAGE, & SUPPORT

Official group of The Coalition for Hemophilia B

Join Our Facebook Group! You may already know about The Coalition For Hemophilia B Facebook PAGE, but we have also have a private Hemophilia B GROUP as an opportunity for families to connect, engage, and support each other. We encourage you to share photos from special events, celebrate milestones, and most importantly, build genuine relationships. Please join our GROUP today by searching for "Hemo B Community" on Facebook.

THE COVID PILL

BY DR. LISA HENSLEY

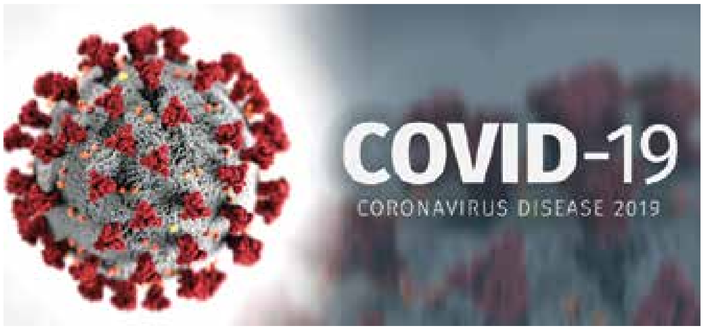
Recently the results of a phase III clinical trial evaluating a new treatment for COVID-19, Molnupiravir, was released through the media. The interim analysis of the study data reported that the drug reduced hospitalization or death by ~ 50%. Many hailed these initial results as a game changer. However a review of the complete data set failed to show a demonstrated benefit in the second half of the study and the final study analysis reported the reduction of hospitalization or death to be 30%. The experiments excluded persons who had been vaccinated and no benefit could be detected among the very small number of individuals that were seropositive at enrollment.

On November 30th an expert panel for the FDA voted 13 to 10 in favor of an emergency use authorization for the treatment of COVID-19 in persons over the age of 18. The drug has yet to be tested in persons younger. If an emergency use authorization is received, Molnupiravir will be the first oral antiviral treatment of mild to moderate COVID-19.

Molnupiravir is a broad-spectrum antiviral produced by Merk and Ridgeback Biotherapeutics. The drug was originally discovered at Emory University in 2013 and tested against a variety of different viruses including other coronaviruses, Ebola virus, and respiratory syncytial virus. The drug works by what is termed lethal mutagenesis. Molnupiravir is a nucleotide analog or more simply put, when broken down it looks like one of the building blocks the virus needs for replication.

When the virus uses the look a like building block it accumulates errors that eventually prevents the virus from replicating. This same mechanism of action has raised concerns regarding the safety of the drug in particular for pregnant women. Safety concerns were raised by the FDA advisory panel and the potential need for additional studies before the drug was used in those under 18 or in other populations not evaluated in the trial.

Currently there are limited options for treatment of COVID during the early stages of disease. There are antibody products, but these require infusions or injections and can only be received in medical centers. Mulnupavir is a pill and must be started within the first five days after the onset of symptoms. Patients taking mulnupavir take four pills two times a day for five days. Ongoing studies are evaluating the potential for this drug to prevent development of COVID after exposure to the virus. In addition data from another oral antiviral, Paxlovid, in clinical trials was submitted to FDA.



Approval and widespread availability of a drug that can significantly reduce morbidity and mortality is the penultimate goal for the scientific community. This type of breakthrough would slow if not stop the rising cost of this pandemic. The potential that such an intervention could also be used to even prevent disease in persons exposed would bring us even closer to a return to normalcy. The question remains if such a drug has or can be identified. A careful review of the trial designs and data from the Mulnupavir and Paxlovid studies as well as additional studies in larger population is needed to better determine how close we are to identifying the breakthrough intervention for COVID-19 we are all hoping for.

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women bleeders

A NEW FEATURE SECTION

ARTICLES TO SUPPORT WOMEN WITH HEMOPHILIA B

Lauren's Story

BY RENAE BAKER

On November 19, 2020, the World Federation of Hemophilia (WFH) hosted its first ever global summit focusing on girls and women with bleeding disorders. It launched the WFH's new Initiative on Women. A second global summit was held from 8-10 July 2021. National Member Organizations around the globe are now beginning to focus more than ever on the experiences of girls and women with bleedings disorders. Lauren Phillips, a board member of the Haemophilia Foundation of New Zealand, shares her experience and talks about the importance of self-advocacy for women. She has made a career in advocacy as an environmental lawyer in New Zealand. Lauren is also a member of the WFH Youth Committee and the Women with Inherited Bleeding Disorders Committee and has recently been involved in the WFH Youth Twinning Pilot Project between New Zealand and Nepal.

"I learned a long time ago the wisest thing I can do is be on my own side, be an advocate for myself and others like me" - Dr. Maya Angelou

I was diagnosed with Type 1 moderately-severe Von Willebrands at the age of eight. My childhood and teen years seemed to be largely unencumbered by my bleeding disorder. However, from the age of 12 I experienced crippling abdominal pains which landed me in the emergency department on numerous occasions. I had very heavy periods and was prescribed hormone therapy (the contraceptive pill) to help manage this. It was always explained to me that as a woman with a bleeding disorder, pain and heavy bleeding were part in parcel of my life experience. As a young teenager with little knowledge or the ability to question things, I accepted this.

As I got older these issues became progressively worse. I became anemic, passing golf ball size clots and unable to leave my bed on some days. Outings with friends became impossible near the time of my period as I couldn't eat or drink without pain or needing to vomit. I struggled to attend university and work as the pain was combined with crippling fatigue. This meant that usually two weeks out of each month I was out of action. I was prescribed iron, tranexamic acid, strong opioids and more contraceptive pills. This was when I began to start asking questions. Due to attending university in a new city I switched HTC's and for the first time I was referred to a gynecologist within the hospital, seven years after the onset of symptoms. There was some reluctance from the gynecology team to accept that my experience of periods was caused by anything other than my bleeding disorder. However, I continued to advocate for myself.

I researched, connected with others with similar symptoms and pushed my medical team to consider another diagnosis, endometriosis. I learned as much as I could about the disease and learned that in the majority of cases laparoscopic diagnosis was required. I felt empowered with the information that I had researched to ask that further investigations to be done. I didn't pretend to know all about the disease or tell the gynecologist they were wrong but having general information about it helped me to understand and discuss my options. After two surgeries in the public system failed, I was incredibly fortunate to have private medical cover and the final surgery was successful.

It took eleven years from the onset of symptoms to finally finding a "cure". As I matured and changed over that time, so too did the self-advocacy tools that I employed. As my confidence grew I was able to be more direct in the conversations that I had with healthcare professionals and escalate my response when needed. The decision to self-advocate in this situation was an easy one as the cost of not doing so was a life half lived with chronic pain, fatigue and

potential infertility. I want to acknowledge that I live in a relatively progressive country where women, by and large, are not restricted by culture or religion from actively participating in decisions regarding their medical treatment, and I recognize that this is not the same for all women globally.

The discourse around women's experiences of bleeding disorders is changing globally. But for many this change will not happen quickly enough to create real impact in their lifetime. Currently, women have a relative health disadvantage when compared to men of the same age, socio-economic conditions and ethnicity. This means that self-advocacy is an incredibly important tool for women to improve health outcomes and realize their potential.

As women we are incredible at advocating for others. We fight for our partners, our children, our parents and our friends, yet when it comes to our own wellbeing or our own progression, we struggle. There are a lot of theories as to why this is, most centered around the socialization of young girls and the messages that we receive. Young girls who express their opinion are deemed "bossy" or are considered too opinionated, whereas young boys who behave similarly are described as having leadership qualities. When these girls grow into women, they struggle to self-advocate as the message is internalized that they should remain quiet. Though the world has progressed in terms of equality in the way women are treated there can still be an underlying discomfort when women challenge those in positions of authority, such as medical professionals, or where we try to make space for ourselves at the table.

Patient self-advocacy is defined as "representing one's own interests within the health care decision-making process." However it can be much wider than this and include education, participating in discussions with other women or asking questions. These other tools of self-advocacy can be particularly important for women who are not able to take as active a role in their own treatment for either cultural or religious reasons.

Research regarding female cancer survivorship shows that self-advocacy is proven to lead to better individual health outcomes. Further, self –advocating, whether it be through seeking health information or through doctor-patient interactions can increase patient satisfaction. Anecdotally I found this to be true in relation to my pregnancy where an induction was

recommended due to VWD, my geographic location and my levels not increasing markedly in pregnancy as expected. While the decision to induce remained the same, asking questions, seeking the opinion of another obstetrician and working through the process with my treatment team helped me to feel comfortable in that decision and allowed me a sense of ownership. Not only is self-advocacy essential to improving individual health outcomes, but the value that women add when they do self-advocate and step into leadership roles is exponential. An analysis of the S&P Composite 1500 undertaken by Ernst & Young found that firms with women at the top were worth on average $40m more than those without.

Women need to advocate for themselves to improve their own wellbeing and health outcomes as quite simply, no-one else will do this for us. There are allies and champions of women's rights that we can lean on and draw energy from, but the real potential for change lies within us. For those of us who are comfortable self-advocating or are in positions of leadership, we have a duty to act as mentors to other women. It is our responsibility to empower all women to build the necessary skills, courage and confidence to self-advocate. Even those who do not necessarily have self-advocacy experience can help to foster a sense of independence and confidence in women by encouraging them to take an active role in their healthcare, to step into leadership roles and to ask questions about decisions that affect them in all areas of life. As women we need to champion ourselves – we create meaningful impact for those around us in our personal and professional life, now it is time we do something for ourselves.

SHARE YOUR STORY

Are you ready to share your story and help others? Whether you have an incredible career, an extraordinary family, or a tale of triumph, we want to hear from YOU! You will collaborate with an in-house writer to help you communicate your story in a compelling and meaningful way. The best part is that no previous writing experience is necessary! To add your voice and share your insights with The Coalition for Hemophilia B, please contact us at contact@hemob.org.

LET'S PLAY NINE:
A GREAT GAME FOR A GREAT CAUSE!

BY GLENN MONES

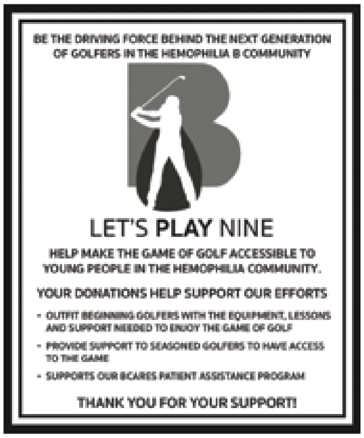
On October 19, 2021, members and friends of the hemophilia B community gathered for the *Let's Play Nine* Golf Fundraiser! The setting for our beautiful fall day was the Town of Oyster Bay Golf Course & Mansion in Woodbury, NY.

The course features an 18-hole, par 70 championship course situated on 121 perfectly manicured acres with narrow fairways, water holes, sand and grass bunkers, putting green, and the turn-of-the-century Mansion at Oyster. The entire event was held outdoors with COVID-19 testing requirements, social distancing, and other safety measures strictly enforced.

Our special guest was Perry Parker, a community member, professional PGA golfer, teaching pro, and motivational speaker who shared his own knowledge and experience and provided over the award ceremony.

The event generates funding for the *Let's Play Nine* Scholarship Fund which arranges golf education and equipment for deserving young members of the community. Proceeds also benefit the B Cares Emergency Assistance Fund, helping community members and families deal with a short-term crisis. As a program, the *Let's Play Nine* program highlights the benefits of gentle physical activity for people with hemophilia while raising funds for a variety of important needs.

We want to thank our generous sponsors including CSL Behring, Medexus Pharma and Novo Nordisk (Gold Level), CVS Specialty (Silver Level), and Wingmen Foundation (Bronze Level). Thanks also to *Let's Play Nine* Committee Chairs Wayne Cook, Matt Sclafani and Hope Woodcock-Ross, and all our participants and staff.



BE THE DRIVING FORCE BEHIND THE NEXT GENERATION
OF GOLFERS IN THE HEMOPHILIA B COMMUNITY

LET'S PLAY NINE

HELP MAKE THE GAME OF GOLF ACCESSIBLE TO
YOUNG PEOPLE IN THE HEMOPHILIA COMMUNITY.

YOUR DONATIONS HELP SUPPORT OUR EFFORTS

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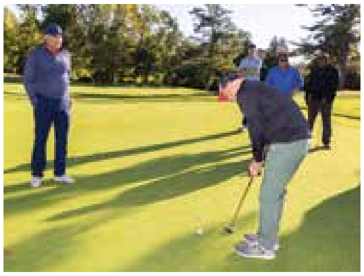
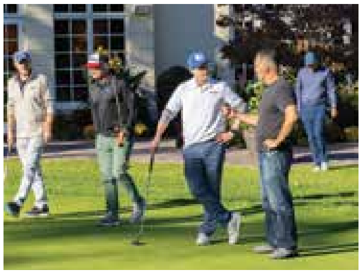
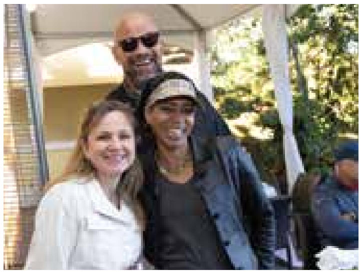
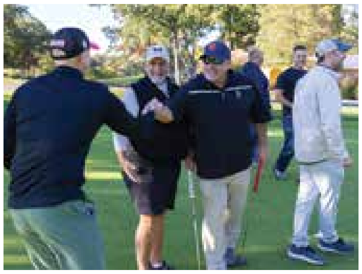
- PROVIDE SUPPORT TO SEASONED GOLFERS TO HAVE ACCESS TO THE GAME
- SUPPORTS OUR BCARES PATIENT ASSISTANCE PROGRAM

THANK YOU FOR YOUR SUPPORT!









LET'S **PLAY** NINE

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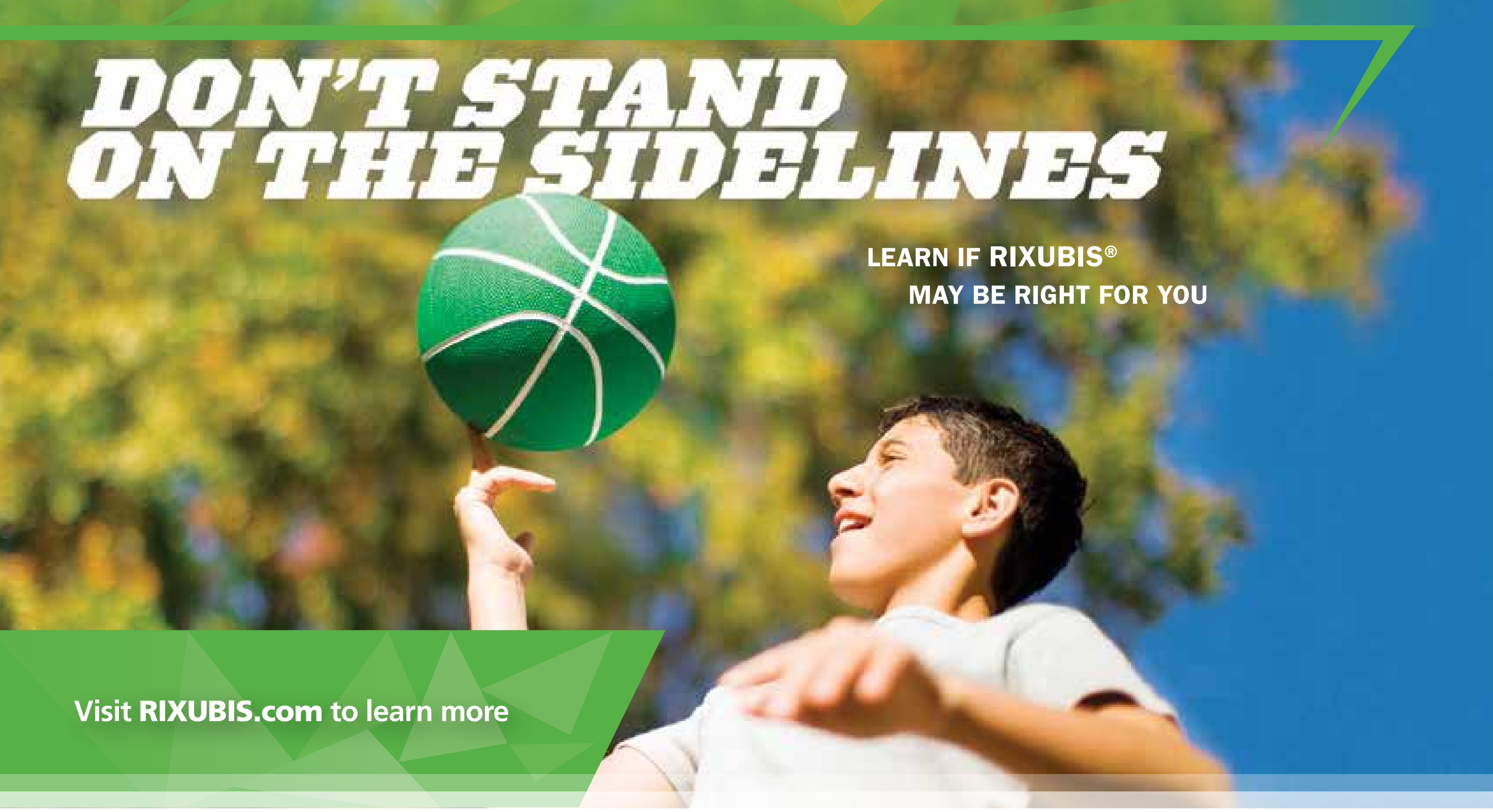

RIXUBIS® [Coagulation Factor IX (Recombinant)] Important Information

What is RIXUBIS?

RIXUBIS is an injectable medicine used to replace clotting factor IX that is missing in adults and children with hemophilia B (also called congenital factor IX deficiency or Christmas disease).

RIXUBIS is used to control and prevent bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Detailed Important Risk Information for RIXUBIS® [Coagulation Factor IX (Recombinant)]

Who should not use RIXUBIS?

You should not use RIXUBIS if you

- are allergic to hamsters
- are allergic to any ingredients in RIXUBIS.

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

What should I tell my healthcare provider before using RIXUBIS?

You should tell your healthcare provider if you

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

What should I tell my healthcare provider before using RIXUBIS? (cont'd)

- are breastfeeding. It is not known if RIXUBIS passes into your milk and if it can harm your baby
- are pregnant or planning to become pregnant. It is not known if RIXUBIS may harm your unborn baby
- have been told that you have inhibitors to factor IX (because RIXUBIS may not work for you).

What are the possible side effects of RIXUBIS?

Allergic reactions may occur with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.
Some common side effects of RIXUBIS were unusual taste in the mouth and limb pain.

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

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

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

Please see RIXUBIS Important Facts on the following page and discuss with your healthcare provider.

RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]
MOVING FORWARD

Important facts about RIXUBIS®:

RIXUBIS
[COAGULATION FACTOR IX
(RECOMBINANT)]

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

What is RIXUBIS used for?

RIXUBIS is a medicine used to replace clotting factor (Factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents blood from clotting normally. RIXUBIS is used to prevent and control bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use RIXUBIS?

You should not use RIXUBIS if you

- are allergic to hamsters
- are allergic to any ingredients in RIXUBIS

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

What should I tell my healthcare provider before using RIXUBIS?

You should tell your healthcare provider if you

- have or have had any medical problems
- take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies
- have any allergies, including allergies to hamsters
- are breastfeeding. It is not known if RIXUBIS passes into your milk and if it can harm your baby
- are pregnant or planning to become pregnant. It is not known if RIXUBIS may harm your unborn baby
- have been told that you have inhibitors to factor IX (because RIXUBIS may not work for you).

What is the most important information I should know about RIXUBIS?

Allergic reactions have been reported with RIXUBIS. Stop using the product and call your healthcare provider or get emergency treatment right away if you get a rash or hives; rapid swelling of the skin or mucous membranes; itching; tightness of the throat; chest pain or tightness; wheezing; difficulty breathing; low blood pressure; lightheadedness; dizziness; nausea; vomiting; tingling, prickling, burning, or numbness of the skin; restlessness; or fainting.

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

The use of factor IX containing products has been associated with the development of blood clots. Talk to your doctor about your risk for potential complications and whether RIXUBIS is right for you.

What are the possible side effects of RIXUBIS?

Some common side effects of RIXUBIS were unusual taste in the mouth, limb pain, and atypical blood test results. Tell your healthcare provider about any side effects that bother you or do not go away. These are not all the side effects possible with RIXUBIS. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about RIXUBIS?

Consult with your healthcare provider to make sure your factor IX activity blood levels are monitored so they are right for you.

You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their RIXUBIS by themselves or with the help of a family member.

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

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

The risk information provided here is not comprehensive. To learn more, talk about RIXUBIS with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at https://www.shirecontent.com/PI/PDFs/RIXUBIS_USA_ENG.pdf or by calling 1-877-825-3327.

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

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Takeda

A WEEKEND OF EMPOWERMENT AND EDUCATION: MEN RECONNECT VIRTUALLY

BY GLENN MONES

From October 29-31, 2021, a group of men from throughout the community came together over Zoom for The Coalition for Hemophilia B's ***Fall 2021 Men's Education & Empowerment Retreat***. This program has become a treasured part of CHB's annual calendar as it provides men in the community with a unique opportunity for education, powerful tools and to share feelings and experiences creating a strong connection with each other on a deep level. Although the event had to be held virtually because of the ongoing pandemic, CHB was able to offer engaging, interactive activities that, based on participant feedback, successfully replicated much of the warmth and camaraderie that continues to make this program a draw.

The program opened Friday evening with welcoming remarks by CHB President Wayne Cook followed by rap sessions and icebreakers led by Wayne, fellow community members Carl Weixler, Fel Echandi and Rocky Williams. Also participating was psychotherapist and author Robert Friedman, MA who led the next session entitled *Being the Best You Can Be – Staying Motivated*. Robert is a popular presenter at many CHB programs who uses humor, and other modalities to learn about each other and themselves. Robert's session showed participants how to maintain a positive attitude when working to overcome life's challenges.

The men closed the first night by joining in their choice of fun, interactive games that were all a big hit. Some of the games helped encourage teamwork and promoted cohesiveness in the group. Others, were just a fun way for participants to relax and hang out together. Saturday morning started with the "feeding" of mind, body and soul." Community member and Rick Starks led participants in a session of tai chi and meditation designed to promote physical fitness and a sense of calm and mental well-being. Tai chi has been described as meditation in motion, tai chi promotes relaxation and stress reduction through gentle, flowing movements. As you move you find yourself breathing deeply and more naturally. Tai chi also addressed other key components of fitness including, muscle strengthening, flexibility, and balance.

Well-known, Chef Mike Hargett led the attendees in preparing – and then enjoying – their own unique breakfast sandwiches. As an accomplished chef and the only person with hemophilia to have received a double organ transplant, Mike's positive attitude towards his own life and health has inspired many in the community to make their own life changes.

The afternoon opened with a session on using the techniques offered by cognitive behavioral therapy (CBT) to effectively deal with emotional situations. The powerful discussion was led by Dr. Joel Minden, a licensed clinical psychologist and author of the book Show Your Anxiety Who's Boss. The session went overtime as the participants became very engaged and had many questions.

After a short break, the men divided into two groups for breakout sessions. The first, geared towards men with hemophilia B, was led by Mike Sager of Pfizer. Mike covered a range of topics including communicating with your health care team, financial considerations of health care through life stages, and the importance of staying physically active. The other breakout was targeted to the fathers and spouses of individuals with hemophilia B. It was led by Joseph Schuch who is also part of the Pfizer team. Joe is dedicated to empowering

families through sharing knowledge and support.

Later in the afternoon, the attendees engaged in a session of art therapy, which has been proven to improve communication, concentration, and can help reduce feelings of isolation. This session was specifically painting on canvas to explore one's creativity and manifest positive change in every area of life. Participants had a chance to create and share their own small works of art. The session was conducted by Jessica Carlisle, LPC, LTR, a Licensed Professional Counselor and Art Therapist at the Dandelion Therapeutic Art Center. This was followed by two more targeted breakout sessions. The first, led by attorney and popular CHB speaker Donnie Akers, Esq., was geared towards dads and spouses and focused on tools and techniques for maintaining crucial legal and government benefits. The second session, geared towards men with hemophilia B, focused on "five secrets" to overcoming fear, depression and despair. The talk was led by Matthew Barkdull, MS, MBA, LMFT, MedF. Matt is a member of the hemophilia community and a certified medical family therapist with more than twenty years of experience.

In the afternoon, the men came back together for a session on the "mechanics of physical intimacy" led by Alice Anderson PT, DPT, MS, PCS, a physical therapist with long-term experience in the hemophilia community. Alice went over some of the challenges presented during physical intimacy for individuals with joint damage or chronic pain. She handled what many consider a very difficult subject with great openness and sensitivity. The day ended with a fun, interactive murder mystery game called "Murder on the Titanic!" with more opportunities to share, interact, renew friendships and create new bonds.

Sunday's program opened with another great tai chi and meditation session led by Rick Starks and a rap session led by Wayne Cook. These were followed by a session called "Getting Back on Track "focusing on forming positive habits and sticking with them. The session was led by Debbie de la Riva, LPC, a community member, mental health first aid instructor and founder of Mental Health Matters Too. The program concluded with a session called "Finding Happiness with Stress Management Tools" led by Catherine Canadeo, CHHC, AADP. Catherine is a Certified Holistic Health and Life Coach who helps promote healing behaviors and happy, healthy lifestyles.

The feedback we have been given from many of the participants has been extremely enthusiastic. These are just small samples of the many comments we have received:

"It has been a great experience to connect with some old friends and make new friends at the retreat. These programs are great occasions to connect with fathers who have already gone through similar situations!"

"Every time I get the opportunity to participate in one of the Coalition B retreats it brings so many emotions to me. It really helps me from going into depression. It helps me see that I'm not alone and creates a family bonding community experience."

"The CHB retreats are an extremely vital component of my health and well-being! They are well designed with a great balance of educational sessions and time for peer support and networking. They also have a very comfortable atmosphere that makes it easy for the participants to open and honestly deal with the tough issues of life living with hemophilia B. The Coalition for Hemophilia B is an organization that truly puts the needs of their constituents above all else and we recognize it."

"I really enjoyed this retreat. It was my first time, and I was able to communicate with people who are having the same day to day struggles as myself. I think that everyone in the community needs these retreats to be able to learn and communicate with one another as they go through similar struggles in life. It's life changing."

The Coalition for Hemophilia B expresses our deep gratitude to Pfizer, the sole sponsor of this amazing program. We also send our thanks to the speakers, the staff and everyone who did so much to make the event possible.

Pfizer

A WEEKEND OF EMPOWERMENT AND EDUCATION

BY JENIFER FRAKER

The Fall Virtual Women's Educational and Empowerment Retreat was a great success! During the first week of November, women with hemophilia, caregivers, and spouses from all over the country connected together for a weekend of learning and fun.

The Coalition's COO Kim Phelan kicked off the weekend as she called out different stressors and instructed the women to blow air into balloons each time they identified with one of them. All at once when almost every balloon was about to burst, the women released the balloons into the air to symbolize letting go of the daily stress that was holding them back from growing and learning. You could see the delight and relief in the faces of the women as they all shifted their focus from everyday stressors to the retreat and the learning opportunities it would offer.

The first session led by Matt Barkdull, a licensed marital and family therapist. Speaking on *The Art of Boundary Making: Shunning Perfectionism and Embracing Joyful, Balanced Living*, this session provided attendees with a look at how the social trend of comparing yourself to others can lead to depression, despair, doubt and stress. Matt shared steps the participants need to incorporate into their lives in order to embrace who they really are and shift from preconceived ideas of perfection. These steps include seeking support and sharing yourself with those around you.

During the session, a lively discussion was held and attendees opened up and shared with others as they moved toward shunning perfectionism and embracing the tools learned for more joyful present living. We look forward to checking in on their progress.

Art Therapy was next on the agenda. This session was led by Alicia Gattis, who is a licensed professional counselor from Dandelion Therapeutic Art. Art therapy has been proven to improve communication, concentration, and can help reduce feelings of isolation. The session was interactive, allowing the participants to reflect on their feelings and create art expressing them. Later the beautiful masterpieces, each unique, were shared with the other women in the community allowing them to bond and grow together during this transformative, healing art session.

The Saturday morning session began with Cassandra Starks, community member and expert in mindfulness, leading a session in *Tai Chi and Meditation*. Tai chi has been described as meditation in motion, promoting relaxation and stress reduction through gentle, flowing movements. As you move you find yourself breathing deeply and more naturally. Tai chi also addressed other key components of fitness including muscle strengthening, flexibility, and balance. Cassandra's direction and guidance helped the ladies to flow in movement as stress was decreased and moods were improved

Women's Fall Retreat:
Warmed Hearts and Ignited a Passion for Learning

with this tai chi session.

Gratitude and Goals, two very important topics that often get pushed aside in our crazy-busy lives. Natalie J. Sayer, a renowned certified coach with clients worldwide, helped the women in our community reflect and set goals for ten aspects of their lives, as she presented the session, *2022: A Yearlong Vision for You*.

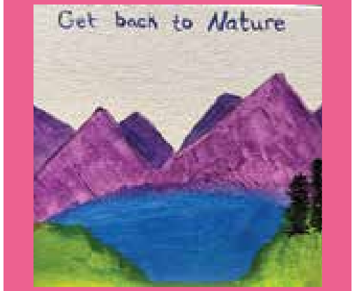
The first visualization identified things they were grateful for in each of these areas. The value of this exercise was to acknowledge what is going well and to build on those successes when setting goals for 2022. Gratitude helps to shift the mind to what is possible. For the second part of the presentation, participants visualized possibilities for 2022, once again exploring ten areas of life. From that visualization they set a vivid intention to better their lives in 2022. Some of the participants shared some of the steps they planned on taking to help them achieve their goals. We look forward to checking in on them to see how they are progressing toward their goals.

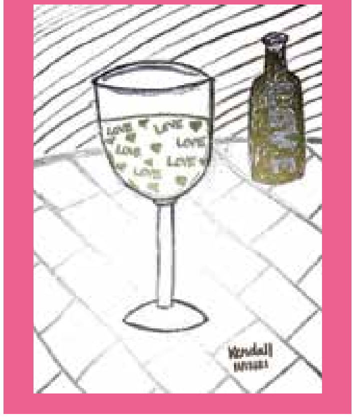
Psychologist Dr. Joel Minden educated attendees on the benefits of cognitive behavioral therapy (CBT), which is an evidence-based treatment for depression and anxiety. *The Power of Cognitive Behavior Skills to Work Through Depression and Anxiety* was a session that empowered attendees how to understand and relate differently to difficult emotions when they appear. This powerful session provided strategies for tackling feelings head on and allowing our authentic feelings and thoughts to exist.

Following, Claire Louise Clifton from Ireland brought us into *Mindful Movement and Dance*, which has many benefits, including the power of movement and checking in with your body in a way that can help you lower stress levels, release negative energy, and strengthen your mind-body connection.

Saturday afternoon continued with two powerful advocacy sessions including one session specifically for women with hemophilia, *Women with Hemophilia Empowered: Tools for Self-Advocacy* facilitated by B. Patty Eastin, Rare Disease Patient Affairs Liaison from Pfizer, and Eva Felix, MSA-HCM. Participants in this session were given practical tips to help learn self-advocacy, including self-assessment, setting goals, communication, and building a support network. Participants looked at the benefits of open communication and self-advocacy in the treatment of hemophilia for themselves and their loved ones. Simultaneously, caregivers and spouses attended *Balancing Emotional Wellness* with Jackie Mosca, MBA. In this session participants were given an overview of how emotional health impacts the hemophilia community, what signs/symptoms to look for, and how to encourage dialogue with health care providers for better health outcomes.

The day was packed with relevant, timely content, as Attorney Donnie Akers, ESQ shared valuable legal advice to help participants learn how to secure their futures and the futures of their children, during the session *Legal Tools Tips To Avoiding Poverty & Maintaining Your Child's Benefits*. This was a great question-and-answer workshop that covered topics like medical powers of attorney, estate planning, and





WOMEN'S FALL RETREAT:

preventing the loss of Medicaid.

Late afternoon, attendees were offered two sessions on the topic of financial health with Ellen Kachalsky, LMSW, ACSW, speaking on *Navigating Finances and Disability Issues*. In this session participants learned about the differences between SSDI and SSI and discussed financial considerations one must have when living with a disability or potentially limited income. In the other session the topic was on *Relationship Challenges During the Daily Grind: Let's Talk About It* with David Rushlow, LMSW, and Karen Boyd, LMSW, facilitating a highly interactive session where participants had the opportunity to explore effective communication skills and navigate intimacy during challenging times.

As the evening drew to a close, the women enjoyed the well-known *Chit Chat and Chocolate* session. One of our most intense sessions, moderated by psychologist Dr. Mina Nguyen-Driver, as Aamina, Milinda, and Tiffani shared their stories of strength and resilience. The attendees also shared their stories and created deep bonds over their common experiences living with hemophilia B.

The last session of the day was *Game Night*. This provided an opportunity for community members to play and laugh together while strengthening their bonds as hemophilia B community members.

The last day of the retreat began with a relaxing round of Tai Chi with Cassandra, followed by a workshop led by Shellye Horowitz. Shelly presented, *Partnering with Providers for Care*, a workshop that empowers women with tools and information which help them improve their health outcomes with providers treating bleeding issues.

Afterwards, Dr. Amber Federizo presented, Menstruation and Intimate Health, a session that allowed women to enter the "no embarrassment zone" and discuss important issues and learn more about their bodies and empower them to ask questions when seeing their doctors.

In the last session of the weekend, Catherine Canadeo, CHHC, AADP led the women on their journey to finding happiness by "Focusing on how emotional wellbeing is tied to your physical health. Catherine expertly guided the women on their journey by educating on how your emotional well-being, proper self-care, and nutrition are tied to your overall physical well-being.

Participants shared many positive reflections about the on the weekend program including:
"The Coalition for Hemophilia B Women's retreat has changed my life forever. Getting together with all these women from the hemophilia B community who are dealing with the same issues as I am, has always given me a sense of relief that I'm not alone. I know I can count on CHB and all the ladies I have connected with. Coming to this retreat allowed me to learn about new topics, create bonds with new women in our community and helped me strengthen my friendships with my Hemo B sisters. This retreat gave me an escape from everyday madness! What an Amazing Experience!"

"And again, The Coalition did not disappoint! What a wonderful women's retreat from start to finish. Although we couldn't be in person, they made it just as special as though we were! Connecting us with speakers and giving us tools to better our lives I want to thank everyone at The Coalition for making it such a wonderful event!"

"First of all, I want to thank the Coalition for Hemophilia B for the women's retreat. For me, it is spectacular, we learn about our bleeding disorder and the many different important issues for women and that can really help you in different areas of your life, such as mental, emotional, and physical health. Another important part of the retreat is the opportunity to feel so warm and welcomed with all the wonderful women who attend. These women, including myself, share our experience so we can help each other with current issues and to strengthen bonds. When I return to my home life, I feel renewed and I take the good vibes and great experiences with me as I face my everyday. Thank you to the sponsors. This is a very much needed program!"

"I had such a nice time connecting with all the ladies. Everyone is so helpful, especially during this transitional time (starting prophy after 5 years of on-demand treatment). I'm so thankful to have The Coalition and women I've met and connected with at the retreat to lean on and learn from. These bonds are so important and special to me. Virtually or in-person, being able to express my concerns with others who have had such similar experiences with B has been so wonderful."

We are so thankful to Pfizer for sponsoring our Fall Women's Retreat 2021 as it allowed our community to have a unique experience of empowerment and education. We are also thankful to our speakers, participants, and team for making it a weekend to always remember!

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GENERATION IX PROJECT

BY ROCKY WILLIAMS

GEN IX ADVOCACY

While we wait for an opportunity to gather for the next Gen IX Advocacy program in person, we came together virtually on Monday, November 15 and Wednesday, November 17 to celebrate community and the powerful advocacy work we accomplish as a group.

In advocacy work, your stories matter. Our Gen IX Advocacy program invites members of the Hemophilia B community to come together to raise social awareness and strengthen relationships through meaningful discourse and engaging, fun team challenges. It's only when we share our stories that we learn to advocate for ourselves and learn from examples of how others advocate for themselves. That's why building a strong community and culture of advocacy starts with connecting with one another, building relationships, and having some fun!

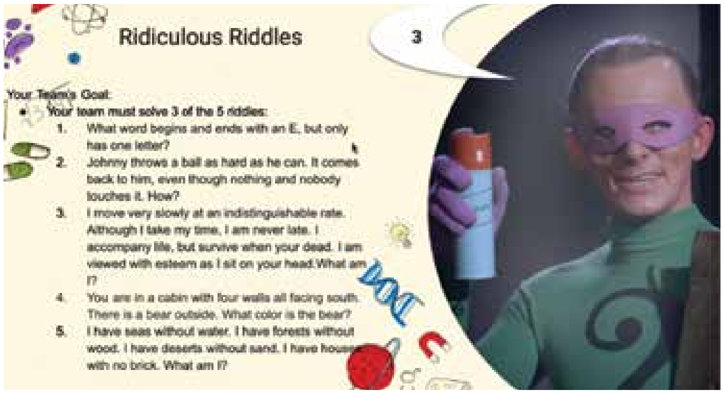
Across the two evenings, Gen IX Advocacy participants had loads of fun hanging out and playing games with GutMonkey. They shared their Wall-O-Stuff Game inspired by Nickelodeon's What Would You Do, and it was hilarious! We tackled riddles, came up with team mascots, and went scavenger hunting. We battled in TV Themed trivia, and we mastered GeoGuessr with a guess less than 5 miles from our clue. We even created our own song to the melody of "Leaving on a Jet Plane." Both nights were an absolute delight!

Throughout each activity, we invited participants to problem solve, work together, actively listen, and take initiative. Despite the overall program being just a few hours long, the laughter and memories will continue to build the relationships that will strengthen our community and, as a result, our advocacy efforts.

We'd like to give a special thank you to Medexus for sponsoring this program, and to GutMonkey, our programming partner, for their incredible session development and facilitation.

Stay tuned for upcoming opportunities to be involved with Gen IX.

MEDEXUS
PHARMA



Ridiculous Riddles

3

Your Team's Goal:
- Your team must solve 3 of the 5 riddles:
  1. What word begins and ends with an E, but only has one letter?
  2. Johnny throws a ball as hard as he can. It comes back to him, even though nothing and nobody touches it. How?
  3. I move very slowly at an indistinguishable rate. Although I take my time, I am never late. I accompany life, but survive when your dead. I am viewed with esteem as I sit on your head.What am I?
  4. You are in a cabin with four walls all facing south. There is a bear outside. What color is the bear?
  5. I have seas without water. I have forests without wood. I have deserts without sand. I have hous with no brick. What am I?

WHEELS FOR THE WORLD

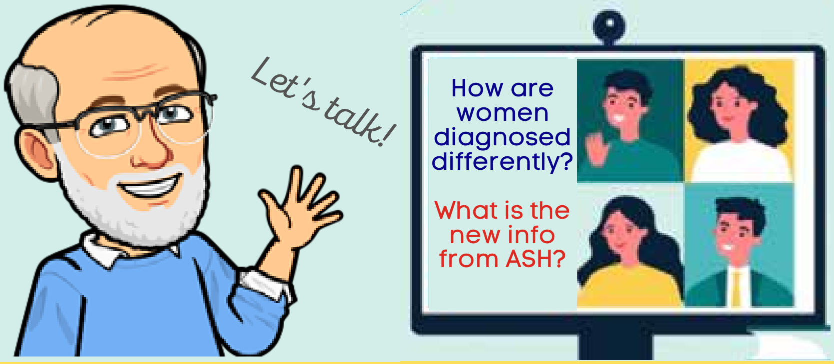
Our team members Kim and April, and their spouses rode bikes for ***Wheels for the World 2021 Virtual Biking Event***! This event ran from August 1st to September 30th and all proceeds benefited *Save One Life*, which improves the quality of life and future for people with bleeding disorders in developing countries through direct financial assistance.

This virtual biking event is a result of community member Barry Haarde who inspired individuals with and without bleeding disorders when he cycled across the country six times and raised over $250,000 for *Save One Life*. When Barry passed away suddenly in 2018, Save One Life wanted to honor his memory. This annual event recognizes Barry's contribution to the bleeding disorder community and encourages healthy and active living.

EMERGING THERAPIES 101

VIRTUAL ZOOM MEETING | FEB 9, 7:30–9:00PM ET

REGISTER TODAY: HEMOB.ORG/UPCOMING-EVENTS



LET'S GET CASUAL AND HAVE A DISCUSSION ABOUT EMERGING THERAPIES WITH DR. DAVE. THERE'S A LOT GOING ON IN OUR HEMOPHILIA B WORLD AND A WHOLE NEW VOCABULARY!

LET'S PLAY OUR NEW GAME! RAFFLE PRIZES AND MEAL VOUCHERS!

THE COALITION FOR HEMOPHILIA B

CSL Behring
Biotherapies for Life™

First 50 registrations by January 24 will receive a decorating kit

Kahoot & Raffles

Daniela's Little Wish

Love Bug Cupcake Decorating

Saturday, February 12 from 3:00-4:30 pm est

Register today: hemob.org/upcoming-events/cc-decorating

The Coalition for Hemophilia B

In Partnership with

MEDEXUS PHARMA

TEEN PROGRAM

RAFFLES!

MEAL VOUCHERS!

SEE WHAT THIS TEEN HAS IN STORE FOR YOU!

WEDNESDAY, FEBRUARY 16
7:00- 8:30PM ET

A SPECIAL THANKS TO OUR SPONSOR

SANOFI GENZYME

The Coalition for Hemophilia B

EXTRA, EXTRA READ ALL ABOUT IT!

KEEPING CONNECTIONS STRONG THOUGH THE WINTER MONTHS

2022 VIRTUAL MEETINGS ON THE ROAD

CSL Behring
Biotherapies for Life
FEBRUARY 5
IL, MO, MN, IA, NE
2:00 – 6:00 PM CST

CSL Behring
Biotherapies for Life
FEBRUARY 19
AZ, CO, ID, MT, ND, NV,
NM, SD, UT, WY
2:00 – 6:00 PM MST

CSL Behring
Biotherapies for Life
MARCH 5
KY, MI, WI
2:00 – 6:00 PM EST

CSL Behring
Biotherapies for Life
MARCH 12
DC, DE, MD, NC,
SC, TN, VA
2:00 – 6:00 PM EST

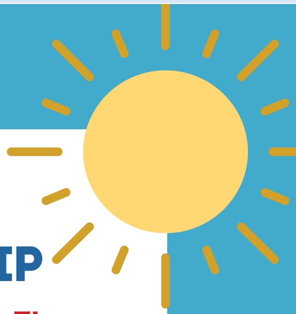
novo nordisk
MARCH 19
AK, CA, HI, OR, WA
2:00 – 6:00 PM PST

CSL Behring
Biotherapies for Life
MARCH 26
AR, KS, OH,
IN, OK
2:00 – 6:00 PM EST

If unable to attend the designated date, choose another!

LET'S GATHER ON ZOOM! REGISTER NOW AND WE'LL SEE YOU SOON!

hemob.org
(212) 520-8272



The Coalition for Hemophilia B

NEW MEMBER/FIRST TIME ATTENDEE SCHOLARSHIP

2022 COALITION FOR HEMOPHILIA B ANNUAL SYMPOSIUM MAY 19-22 IN ORLANDO, FL

The scholarship will pay for airfare, hotel, and transportation to and from the airport.

THE APPLICATION DEADLINE IS FEBRUARY 28, 2022

APPLY TODAY: bit.ly/Symp2022

IN THIS TOGETHER

NAVIGATING HEMOPHILIA B AS PARTNERS

April 7-10, 2022

Atlanta, GA

Register at:

https://bit.ly/hemobinthistogether2022

THE COALITION FOR HEMOPHILIA B

Let's Play IX

The wonderful and popular game of golf is one of the few sports those living with hemophilia can safely enjoy. Through your generous donations, we are able to provide golf access and education to children within our hemophilia community so they can experience this fun social activity and its many healthy benefits. Funds raised also benefit the B Cares patient assistance program.

Highlights:

- Clinic with professional golfer ***Perry Parker***
- 18 Hole Scramble!
- Contests! Closest to the Pin, Longest Drive, Hole in One
- Breakfast and Awards Luncheon
- Dry-FIT Polo Shirt!
- Goodie Bags!
- Raffle Prizes!

LET'S PLAY IX

LET'S PLAY IX GOLF OUTING

MAY 18, 2022

Kissimmee, Florida

8 am Registration & Breakfast
9 am Clinic with Perry Parker
10 am Tee Off
Luncheon & Raffles

18-hole tournament to benefit
The Coalition for Hemophilia B programs

Join the fun and support a great cause!

Contact Kim Phelan
kimp@hemob.org or call (212) 520-8272

B.EMPOWERED

B.AMAZING

SAVE THE DATE SYMPOSIUM 2022

MAY 19-22 2022
IN
ORLANDO, FL

NOTES ARE
AVAILABLE
FOR STUDENTS
MISSING SCHOOL

B.TOGETHER

MORE
INFORMATION
COMING SOON!

THE COALITION FOR
HEMOPHILIA B

FAMILY RATE $159
TRAVEL & HOTEL
GRANTS AVAILABLE

HEMOB.ORG

save
the
date

The Coalition for
Hemophilia B

ETERNAL SPIRIT
AWARD GALA
Thursday, August 11, 2022

Honoring
Ellen Kachalsky, LCSW
&
Roshni Kulkarni, MD

The Coalition for Hemophilia B
757 Third Avenue, 20th Floor; New York, New York 10017
Phone: 212-520-8272 Fax: 212-520-8501 contact@hemob.org

SCAN ME

VISIT OUR SOCIAL MEDIA SITES:

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For information, contact Kim Phelan
kimp@hemob.org or call 917-582-9077

The Game Is Afoot!

BY ROCKY WILLIAMS

Their mission, if they chose to accept it, was to come prepared to be wowed and help make "the impossible possible!"

That was the call to teens participating in a unique interactive program held virtually on Sunday, November 21, 2021.

Attendees arrived to find their hosts Cassandra, Rocky and Nick (a teen in the community) already dressed as the legendary characters Sherlock Holmes, Enola Holmes, and Watson who led the teens through the hilarious process of "going undercover."

Teens watched short video clips of old English accents and practiced their own best Sherlock Holmes with iconic phrases like "Elementary, my dear Watson," "To a great mind, nothing is little," and of course, "The game is afoot!"

The teens' deductive skills were put to the test as they immersed themselves in a Sherlock Holmes escape room and to choose their own adventure. After narrowly escaping, they tackled the game "Keep Talking and Nobody Explodes." Teens worked as one cohesive unit to help diffuse a virtual bomb puzzle. They accomplished their task with a mere 21 seconds to spare before it would have blown everything to smithereens.

The evening was capped with a "dynamite discussion" led by facilitator and community member Matt Barkdull. It was a great way to spend a Sunday evening with other teens engaged in thoughtful games and the opportunity to hang out with friends in the hemo B community.

We'd like to thank Sanofi Genzyme for sponsoring this awesome event. Stay tuned for more teen programs coming soon!

SANOFI GENZYME

NOTHING IS STOPPING NICK

BY ALICIA COOK

Nick, almost 16, is currently taking driver's ed courses and cannot wait to get behind the wheel. Born and raised in Maryland, about 30 minutes outside Baltimore, Nick is a self-proclaimed "typical teenager." He loves video games, soccer, the Dallas Cowboys, Cartoon Network, Lego Modular Buildings, and golf.

"I enjoy a lot of things. My favorite sport is football. I am going to see the Cowboys play in New York next month! I am not able to play football due to my hemophilia B. I love golf and I am on the high school golf team! The season just recently ended. Actually, The Coalition for Hemophilia B gifted me clubs and lessons. So, I have them to thank for that!"

Nick might not be the standard "typical" teen, but he says he doesn't allow hemophilia to take over his entire identity. "I bring up hemophilia if it comes up. I usually don't lead with that. I don't want my identity to be hemophilia. I want to be myself, with hemophilia."

One time Nick recalls having to bring up his hemophilia was when he was in fourth grade and he hit his head against the hard floor of the gym, while the class was doing sit ups. He knew he had to explain his condition to the school nurse, because even at a young age, Nick knew he needed special care when it came to certain injuries.

"I knew even back then that the nurse had little understanding of hemophilia B. The nurse just gave me an icepack and sent me back to class."

He was in pain, he knew he needed more help, but being a child, he pushed through the pain and made it to the end of the school day. "I went to the couch at home, sat in complete darkness, until my mom came home and immediately took me to the hospital."

Nick's head injury turned out to be a concussion and he needed factor. Nick, thinking back to that moment says, "A lot of people, even school nurses, don't know what it means for a student to have hemophilia B. I wish more people would know about this."

As it turns out, he is not your average teen with hemophilia either! One thing that sets him apart is that he has a really rare form of hemophilia B. He was born with severe hemophilia B, but his factor level has risen over the years, and now he lives with mild hemophilia B. Nick says that the severity level of hemophilia declining is quite rare, and he doesn't take that for granted.

"Maybe one day I will have the opportunity to do some things in life I couldn't do earlier in my life," he says, hopefully. In fact, he has already experienced this with football.

"A couple of years ago, I couldn't play any form of football, but now I can play flag football!"

In his family, his mother is a carrier and his mother's brother (his uncle) died at three-weeks-old many years ago due to hemophilia complications and little being known about the condition at that time. He was introduced to The Coalition for Hemophilia B through his mother, who is active within the hemophilia community.

Nick's favorite event the Coalition runs is its annual Symposium in Orlando.

"I really like attending the symposiums. I love interacting with the community in person, it's so special," he says, pointing out that he is even more excited to regroup in person with the community after the pandemic moved everything to a virtual setting.

Nick is the youngest sibling in his family, with three older sisters. His entire family is very close and loves taking trips together. One of his sisters has Williams syndrome, a developmental disorder that affects many parts of the body. This condition is characterized by mild to moderate intellectual disability or learning problems. He says that he relates to her a lot in the sense of sometimes there are limitations on what they can both do. Nick's overall outlook on life is quite positive and upbeat, on days he finds himself down, he reminds himself that there is a whole community behind him.

"Sometimes I see my friends doing things that I know I can't. That general feeling of being held back from something I would love to do can be disappointing. But I realize I am not alone here. Other people feel this way and I connect with them, and we can all do things together." He adds, "The community is always there. If you are ever feeling bummed, there are always people out there – any time, any day. People all over the USA and world!"

Nick takes great pride in how well he has performed academically throughout his schooling so far (he hopes to join the Honor Society soon!) and has big plans for his future. His ultimate goal is to become a lawyer. He has no plans on letting hemophilia B stand in his way.

Nick's advice to other teens with hemophilia B is straight to the point. "Keep your head up! Don't let hemophilia take over your life. Be yourself. You are in control yourself, don't let hemophilia B control you."

FANTINE: THE YOUNG ADVOCATE

BY ALICIA COOK

Fantine (pronounced fahn-teen) is turning 10 soon, and she is excited. To celebrate, her and her mother Delphine, grandparents, and 15-year-old brother Tristan are traveling from their home in Birmingham, Alabama to the beach.

Fantine adores her older brother Tristan. "We are very close. I love to play Minecraft with him, and tag and hide and seek," she says. "At the beach, he always digs big holes and buries me!" She is also his built-in protector. "I tell him all the time to be cautious! I don't want him to get hurt."

Tristan and Fantine are the first two members of Delphine's family to be born in the United States. While their father is American, Delphine is French, and the two children have dual citizenship.

"I'm half French!" Fantine says, proudly. "I've visited there! My favorite memory about France is visiting my great-grandmother, being in her very old house in her little village. I was four when I visited and I remember being amazed that the village had two playgrounds!"

At just 10, Fantine knows more about hemophilia B than the average adult. Delphine has made sure to answer her daughter's questions about hemophilia and to keep her involved in the community and with The Coalition for Hemophilia B. Through her everyday exposure to hemophilia B, Fantine has become an advocate in her own right.

"Hemophilia B is a rare bleeding disorder. We need to careful that my brother gets enough medicine, but not too much. We are very cautious with what Tristan does with his friends," explains Fantine, confidently.

And with that knowledge, comes worry. Fantine does not want anything bad to happen to her brother.

"When my brother went to the hospital in January because of a port infection, I felt very scared that he was going to die," she says. "I don't want him to die because he's my only brother. I was really spooked because I couldn't go see him because of COVID-19 restrictions. I cried at school and my teacher and classmates made a 'get well soon' card for him."

"I am so happy he is okay now. I felt relieved. I would have cried rivers," she adds.

For any siblings worrying about their brother or sister with hemophilia B, Fantine says, "It is okay to worry about them, but trust the doctors and nurses too!"

While she is obviously wiser than her years, Fantine finds joy in what many young "tweens" enjoy. She loves playing video games, like Minecraft and Roblox. Her favorite subject in school is reading. She really likes to draw and is a talented gymnast and is currently working on back handspring and ariel. She has taken proper lessons for about a year and, within the first month, her gymnastics teacher moved her up a level, the one right before competition level.

Gymnastics is likely something the fourth grader wouldn't be able to fully participate in at this level if she had hemophilia. Having one child with hemophilia B and one without does lead to some big differences. For one, Fantine had her first blood test recently at nine years old. Tristan was two days old when he had his first.

"When I grow up, I want to be gymnast in the Olympics and then a kindergarten teacher," Fantine shares. "I would make sure anyone in my class who had hemophilia was taken care of."

Fantine is promoting awareness, whether she truly realizes that yet or not. She says that as a teacher, if a student of hers had hemophilia and got hurt, she would know exactly how to apply gauze and pressure so that the bleeding didn't go too long. She also knows just what to do with an ice pack if they get a bruise.

This awareness and attention to care is thanks to her mother including Fantine into the daily practices that come along with having someone with hemophilia B in your family.

Fantine would help with the infusions, especially when she was younger. She would help prep the items, hand her mother the syringe. Her mother always made sure Fantine was included in the process and did not feel like an outsider.

Delphine also includes both of her children in hemophilia B community events.

"I go to Camp Harvest," Fantine says, excitedly. Held each October at Children's Harbor on Lake Martin in Alexander City, Alabama, Camp Harvest provides a haven for learning, exploring, and bonding. It also provides Fantine with the opportunity to make friends with kids that have similar experiences as hers.

The family also attends the Symposium hosted by The Coalition for Hemophilia B in Orlando.

When she attends these events, Fantine asks everyone she meets, "Do you have hemophilia B or know someone who does?" Most of those she asks do not have it but have siblings who do. Fantine has a support circle of young people around her who know exactly how she feels.

"When we were in Orlando, I fell in the bathtub and Tristan yelled, 'ice pack!'" Fantine laughs, at the inside joke within the community.

"Sometimes I joke and ask if she needs factor when she gets hurts," adds Delphine with a smile.

Including EVERYONE is one thing Delphine wants to stress to other parents. "Even if there is a non-affected sibling, try to make them part of the infusions, the meetings, the Coalition, the jokes, the vocabulary...it really helps and brings the whole family together."

At the end of the conversation, Fantine shares some of the birthday gifts she is hoping to receive - Pop Its and other fidget toys, stress balls, and Prismacolor pencil set.

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Fall 2021

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FANTINE: THE 10-YEAR-OLD ADVOCATE

WANTED: TEEN CONTENT CREATORS!

Calling all content creators! If you have a heart for tweens/teens and a drive for content creation, then we would love for you to volunteer your time and talents with us. The Coalition for Hemophilia B is currently accepting volunteers to collaborate on a new section of the newsletter just for those special 11-18 year olds in our community.

No experience required as we have a team ready to polish your brilliant ideas for publication. If you have ideas for topics, events, and new sections, let's work on this together- reach out to rockyw@hemob.org for your next steps!