THE COALITION FOR HEMOPHILIA B

HEMOPHILIA B NEWS

A QUARTERLY NEWS PUBLICATION

SUMMER 2021

SEEING *double*

MEET TWO SETS OF TWINS

ETERNAL SPIRIT AWARD GALA

HEIDI'S STORY

CASSANDRA'S FAMILY

EMERGING THERAPIES

ADVOCACY UPDATE

30 YEAR ANNIVERSARY THE COALITION FOR HEMOPHILIA B

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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.

Crazy the Odds: Tabitha's Story of Twins

BY RENAE BAKER

Tabitha doesn't remember her father's hemophilia B affecting her while she was growing up. He had a mild diagnosis and was older when she was born, "so he wasn't doing crazy stuff." Nevertheless, she was aware that he had hemophilia and that it was a possibility that she might have children with hemophilia one day.

Tabitha doesn't remember her father's hemophilia B affecting her while she was growing up. He had a mild diagnosis and was older when she was born, "so he wasn't doing crazy stuff." Nevertheless, she was aware that he had hemophilia and that it was a possibility that she might have children with hemophilia one day.

Camden and Paxton

they gave the question about whether to circumcise the boys serious consideration. "Ultimately, we decided if the boys did have hemophilia, that wasn't the way we wanted to find out," she shared.

In fact, Tabitha and Travis don't want to green-light any permanent body changes to their

Tabitha and her husband Travis both working from home. It's a good year for remote work conditions because while the pandemic was turning the world upside down in March of 2020, their family was undergoing a big change! It turns out that hemophilia isn't the only thing that runs in Tabitha's family. Her father has a twin sister who has shown no signs of hemophilia in her seventy-two years.

You see where this is heading, right? Tabitha, Travis and daughter Mackenna, who will be four in May, have spent this past year in their little pandemic bubble adjusting to new family dynamic with baby twin brothers, Camden and Paxton. The parents knew there was a chance that they could be fraternal twins and that neither, or only one of them might have hemophilia, but Tabitha and Travis were blessed with fraternal twins, and both were diagnosed with mild hemophilia B. Although fraternal, their factor levels are only one percent shy of each other's.

During and following the birth there were no bleeding issues; just a little additional pressure applied after "heel sticks." Because they knew hemophilia was a possibility,


Lots of Bluey fans in household!

Camden, McKenna and Paxton

children. “I have an issue with piercing my daughter’s ears. I don’t want to because she can’t tell me if she’s ready for that. So, by the same token, I don’t want to circumcise the boys.” Tabitha sees it as a cosmetic issue. “It seems like body modification should be their own decision. That, plus the possibility of hemophilia made us say, ‘Let’s just hold off.’”

Tabitha lays out a bit of the prenatal experience, “When you have twins you have to go to a maternal fetal medicine doctor, but ours didn’t really know what to do. They checked my factor levels and said, ‘No, you’re not a carrier.’ I was like, ‘Wait, that’s not how it works!’”

She’s right. That’s not how it works. Dr. David Clark clarifies, “A woman’s carrier status cannot be determined by her factor levels. Hemophilia carriers can have factor levels ranging from less than 1% to over 100% of normal. A woman with very low levels will probably be a carrier, but women with higher levels may also be carriers. A woman whose father has hemophilia is called an obligate carrier. She will be a carrier because she inherits her father’s X-chromosome, which carries the defective factor gene. Even though she may have ‘normal’ factor levels herself, she still has the defective gene that she will pass on to her sons. She has a 50-50 chance of passing the gene on to her daughters and making them carriers.”

Tabitha has never had any bleeding issues beyond heavy menstrual cycles. Her father was not a part of The Coalition for Hemophilia B. Tabitha became connected to the organization through her own research. “I’m a ‘give-me-all-the-information’ kind of person, but my father wasn’t, so I was looking through Facebook, trying to find all the groups I could,” she shared

Tabitha has made several online connections with groups that have to do with everything from having twins to having hemophilia to having twins with hemophilia. “One day, I was looking at charities, because I was posting about Rare Disease Day, and the Coalition happened to come up. I thought ‘THAT’S interesting!’ because it was specific to hemophilia B.”

Rare Disease Day happens on February 29, during a leap year (a nice little nod to the day being rare). Outside of leap years, Rare Disease Day is observed on the last day of February.

Back to the boys. Camden and Paxton were diagnosed with mild hemophilia B after their six-month vaccinations when Camden’s injection created a “pocket” in his thigh, because they didn’t yet know the injection site needed to be held for five minutes after the shot.

“We were all just playing on the living room floor together, having a good time. We looked down and there was this green goo oozing out of Cammy,” she recalled. This resulted from a hematoma that formed at the injection site and prompted them to get the twins seen by a hematologist. “The first doctor we saw kind of freaked us out,” she admitted. “She acted like they were going to be little ‘bubble boys,’ and we were like, ‘Oh my gosh!’”

The family then went to their local hemophilia treatment center where she found relief and positivity. Here, they met Sarah, a physician’s assistant who has made all the difference in their lives. “She made us feel a lot better and assured us the twins were not going to be on medication every day of their lives, just when needed.”

Of the boys, born one minute apart, Camden has experienced quite a bit. “Cam is our kid where, if something wrong or bad can happen, it happens to him,” she said. At two months old, prior to the hemophilia B diagnosis, the doctor picked up on a heart murmur in Camden. “So, on top of everything else, we have had to go to a heart doctor. He had a hole in his heart. Luckily, it’s closed now, but he has a bicuspid aortic valve.” Tabitha continues, “Your heart is supposed to open in three’s, but his only opens in two’s. It’s not really a big issue. The hemophilia won’t affect it. It’s just an extra layer of complexity.”

Tabitha carried the twins to 38 weeks. “They were both so big they had torticollis, which is tight neck muscles,” or, as the Kennedy Krieger Institute’s Cranial Cervical Clinic describes, “asymmetrical posturing of the head or head tilt (otherwise known as “wry neck.”) “So, we’ve had to go to physical therapy to stretch the neck muscles, and it’s so miserable! Cammy actually ended up in a helmet, 23 out of 24 hours of the day, because he had what they call ‘brachycephaly’ due to the combination of sleeping on his back and not wanting to move his neck muscles caused the back of his head to flatten.” Tabitha is happy to report he is better and out of the helmet now.

Tabitha and Travis don’t let the stress of baby, hemophilia,

or any other obstacles overshadow the family fun. With McKenna, the parents were able to let her go pretty much wherever she wanted to explore, but with the twins, Tabitha and Travis realized it was different story. “We figured out pretty quickly if you’re on the floor with the two, you’re just constantly bringing them back to the middle of the floor because they want to go out and want to get the plug-ins and whatnot. So, we have a big fenced-in area in our living room with foam mats. We know the bumps are going to happen, but we just try to mitigate it as best as possible.”

Toddler McKenna wasn’t able to visit her brothers in the hospital when they were born due to COVID-19 restrictions. Tabitha confesses, “I had this romanticized picture of her coming to the hospital, seeing the boys and it being just this moment of ‘here we all are! We’re a family! Here are your brothers!’ and we couldn’t do that.” She takes a moment to pull the tears back, “It was fine. It was just rough because it was not what I had pictured. You’re so happy that you have these babies, but there is this grief over not having the first born you’ve never been away from for even a single night be a part of the first day of her brothers’ lives.”

Once the boys were home, McKenna became a big helper. She loves to fetch items for them and when Tabitha and Travis joke that they’re going to send her brothers to China when they’re acting up, she sweetly and protectively proclaims, “No! You can’t take my brothers!”

While McKenna may not yet have a complete understanding about her brothers’ hemophilia, Tabita says, “She understands that something is up, but she isn’t old enough to process it. She’s not one to play rough with them, so that isn’t a concern.” McKenna is learning from Tabitha how to be a loving mommy. “I was changing Cammy’s diaper yesterday and she had her little baby doll. As I was giving Cammy kisses, she was giving her little baby doll kisses!”

When asked what advice Tabitha has for other parents of children with hemophilia B, she shares, “Slow down and breathe. Know there are enough resources now. While our

Camden and Paxton

things we’re going to have to modify, it’s not an ‘end-all-be-all’ situation.”

“Give yourself grace,” she continued. “It’s not your fault. Stuff happens. Getting plugged into the community and getting as much information as you can is essential.” She also urges parents to find a doctor who is educated about hemophilia B and with whom you can have a good relationship. “Getting the right medical team in place is key.”

For someone just starting out who doesn’t know how to put together a great medical team, Tabitha suggests, “Facebook is one of best resources right now. Try key words like hemophilia, twins, birth, local and national. Just start there and search.”

Tabitha also uses Google, but she remembers it was Facebook that led her to Kim Phelan and The Coalition for Hemophilia B. “Kim is amazing and the Coalition is so open and helpful!” Tabitha exclaimed.

Since discovering the Coalition during the year of remote events, Tabitha and her family are looking forward to the days when they can attend in-person events hosted by The Coalition.

Photography by Taryn Starky
The Photo Doula

The Special Challenges of Having Twins with Hemophilia: One Mom's Story

BY MICHAEL PERLMAN

Having a child with hemophilia B presents parents and other family members with unique challenges. When they have twins who both have hemophilia B, those challenges can easily double.

Kaila and her husband, Wayne, are both corrections officers. When their twins, Karter and Kole, were diagnosed with severe hemophilia B, their treatment center connected them to The Coalition for Hemophilia B, where they have since found resources, warm friendships, and dedicated support.

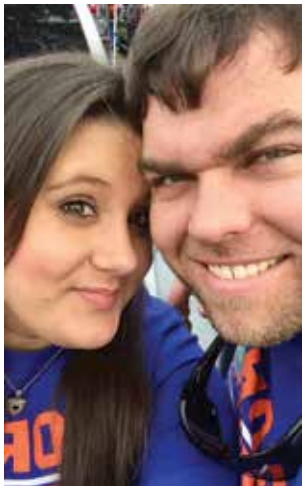
Karter and Kole

Kaila's delivery is one of the more rare cases where twins are both born with hemophilia B. "When the boys were born in 2019, underlying factors contributed to the belief there were greater challenges at hand," Kaila explained. "Being premature, Karter was in the NICU for 11 days due to not being able to breathe independently. During the first eight days, Karter's heel was stuck for blood work and it would not stop bleeding. He was transferred to another hospital where he was diagnosed with hemophilia B. The doctors then recommended Kole be tested as well. He was also diagnosed with severe hemophilia B."

"Our twins bring us joy and happiness. We do not look at them as though they have a condition," said Kaila. Kaila and Wayne's blended family includes eight-year-old daughter Shealynn, six-year-old daughter Kassidee, and four-year-old son Stetson. Kaila shared, "The girls call the twins their babies, and Stetson loves to smell and kiss them. They love their brothers!"

"When we first learned they have a condition, I blamed myself, since as a mother, anything that happens to your children, especially while pregnant, you think is your fault," Kaila said. She and her family asked many questions about hemophilia B. "I realized it is neither of our faults that our twins have hemophilia B and that God has a plan for all of us," she said. "We love our children, and we are very grateful God chose us to come together, fall in love, and produce two of the most precious twins in the world. I wouldn't change them or their condition for anything."


Kassidee, Karter, Stetson, Kole and Shealynn


Kaila and Wayne


Kole and Karter

Snuggle time with dad, Wayne

Kaila explained their dad's cousin had hemophilia A, but it was unrelated. He had passed away from blood-borne infections. Much of her husband's side of the family was well-informed about hemophilia, but her side was largely uninformed. She began conducting research and came across a few groups that help moms like her. She was grateful for the moral support and advice she received. "We all joined groups and attended sessions to be more knowledgeable."

The challenges Kaila faced have contributed to her strength as an individual and have helped to shape her family's values to this day. "I didn't have the greatest childhood - I had to grow up early and take care of my younger sister. I do not want that for my kids," Kaila explained.

An obstacle transpired when Kaila received a call from the daycare center telling her that Karter was hit in the head by a wooden toy. In the emergency room, Kaila learned the accident caused a brain bleed requiring surgery and a shunt. "Karter had multiple seizures in the middle of the night in the hospital – it was one of the scariest things I have ever witnessed," Kaila shared, "but he came out okay."

Kaila was there with him every single day and night until COVID-19 restrictions limited her. Then she was able to be at the hospital only at night when her husband got home from work to care for the other kids because the daycare had closed. Karter was in the hospital for eight long weeks. "56 days, 1,344 hours – 80,640 minutes – 4,838,400 seconds!"

Karter and Kole had surgery to insert infusion ports on May 4, 2020. They were doing well, especially Karter, "As if nothing had happened to the little guy!" Karter remained in good spirits even when he had to return to the hospital for a shunt malfunction due to another incident in daycare, which sadly resulted in another month in the ICU.

"Karter is doing so much better after therapy," Kaila reported. That time was especially rough on Kassidee.

Worrisome times in the hospital

She cried every night for him, and Kole had a difficult time sleeping while Karter was in the hospital."

"As parents, providing our children with a loving home is a priority," Kaila said. "God put us together with a plan. We may not understand everything and still ask why our twins have hemophilia, but God never gives you anything you cannot handle. For that, I am grateful."

Karter

Kole

Karter

Kole

Birth Announcements

Welcome to Our Coalition B Family!

Cody & Bobbi welcomed Baby Saige!

Chris & Jessica welcomed Baby Carter James!

Justin & Morgan welcomed Baby Tucker!

Patrick & Natalie welcomed Baby Vivian Bea!

Wayne & Kaila welcomed Twins Karter & Kole!

Travis & Tabitha welcomed Twins Paxton & Camden!

The 2021 Eternal Spirit Award Gala
A Nautical Delight

On Thursday, August 12, members and supporters of The Coalition for Hemophilia B gathered in festive celebration for the 2021 Eternal Spirit Award Gala. The event was held at the beautiful Mansion at Oyster Bay in Woodbury, NY, a 1918 estate that once belonged to industrialist Andrew Carnegie. The spacious venue and other precautions allowed us to share each other's company in safety and comfort.

The 2021 Eternal Spirit Award goes to two extraordinary women in the community, Debbie De La Riva, LPC and Heidi Ramsey Lynch

The event theme was "An Evening at Sea," reminiscent of an ocean voyage including guests in whimsical nautical attire. The entertainment included song selections by Renae Baker, who also acted as the master of ceremonies, and the piano stylings of our own Bill Gati.

The formal program included a special welcome by Coalition President Wayne Cook. This was followed by a screening of a new video featuring well-known members of our community reflecting on the past, present and future for people living with hemophilia B. Our thanks to Pfizer for their sponsorship of this special part of the program.

The highlight of the evening was the presentation of the Eternal Spirit Award which is given annually to two deserving individuals who have made significant contributions to the health and well-being of our members. This year's recipients were Debbie De La Riva, LPC and Heidi Ramsey Lynch.

Debbie De La Riva became active in the community when her son was born with severe hemophilia and served in numerous leadership positions at the local and national levels throughout the years. With a strong background in stress management and mental health and inspired by the loss of a deep friend to many in the community, Debbie founded *Mental Health Matters Too* in 2018. She is a certified Mental Health First Aid Instructor, providing training to community members, bleeding disorders organizations and Hemophilia Treatment Centers across the nation. Debbie's passion and dedication shine brightly in our community.

Heidi Ramsey-Lynch has served as a devoted volunteer with The Coalition for Hemophilia B for several years. She has dedicated her weekends to assist with *Meetings on the Road*, the *Annual Symposium*, and leading personal outreach to community families. Heidi is also a woman

with hemophilia B and a strong advocate for women with bleeding disorders. She has also volunteered at many bleeding disorders camps across the US. She is currently enrolled in North Mississippi College of Nursing and will graduate in December 2022.

The event also featured the presentation of the Dr. William N. Drohan Scholarship. The scholarship's namesake was a well-known microbiologist and educator who lost his battle with metastatic lung cancer at the age of 60. He was a pioneer in using molecular biology to produce recombinant proteins and a visionary scientist who dedicated his life to improving the safety of blood and blood products. Dr. Drohan also served as a member of the board of The Coalition for Hemophilia B and was instrumental in the Coalition's creation.

Each year, we award four or more scholarships to students with hemophilia B and/or their siblings. Over the past 12 years, we have distributed more than $300,000 in scholarships. The scholarships are funded in part through the proceeds of the gala, including the generous support of our wonderful sponsors. 2021 sponsors included Medexus, Pfizer and Sanofi Genzyme (Diamond), CSL Behring (Platinum), CVS Health, Hemophilia Alliance, Novo Nordisk and the Alliance Pharmacy (Gold), Rarity Health (Bronze), Grifols (Benefactor), and Accredo (Friends). Thank you all!

The evening ended with our popular silent auction, with many attendees taking home a variety of wonderful "treasures." (We are very thankful for all donations of raffle prizes received for this event1) Proceeds from the evening also support the BCares Emergency Assistance Fund and the BVoice Advocacy Program. BCares provides urgent help to individuals or families affected by hemophilia B facing a variety of crisis situations. This fund has been especially crucial as needs have skyrocketed during the current COVID-19 pandemic.

BVoice organizes community members and provides information and tools to allow them to advocate with elected officials and others. This program has recently focused on ensuring uninterrupted access to healthcare during the crisis.

"Awesome - we had a great night! You guys did a wonderful job as usual," said attendee and community member Meaghan. Maria, another participant, said "had a great time as always it was a perfect night."

Our heartfelt thanks to everyone who helped make the evening a great success, including our sponsors, honorees, speakers, entertainers, volunteers, Coalition staff and of course, the community members in attendance. We look forward to seeing you all again at Symposium and at many other events in the near future.

Thank You, Sponsors!

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Bronze

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GRIFOLS

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2021 ETERNAL SPIRIT AWARD RECIPIENT

Congratulations to Debbie De La Riva, LPC

Beacon of Light – Compassionate Healer & Teacher – Beloved Community Advocate

For your many years of dedicated service to the bleeding disorders community

When **DEBBIE DE LA RIVA**'s son was born with severe hemophilia, she quickly became involved in the community on a local and national level and has served in numerous positions throughout the years.

With a strong background in stress management and mental health, Debbie founded *Mental Health Matters Too* in 2018. She is a certified Mental Health First Aid Instructor providing training to community members, bleeding disorders organizations and Hemophilia Treatment Centers across the nation.

Debbie's passion and dedication shine brightly in our community. What a wonderful world with you in it, Debbie! We are thankful for you!

2021 ETERNAL SPIRIT AWARD RECIPIENT

Congratulations to Heidi Ramsey–Lynch

Gifted Volunteer – Social Outreach Extraordinaire – Women Bleeder Advocate

For your many years of dedicated service to the hemophilia B community

HEIDI RAMSEY-LYNCH has served as a devoted volunteer with The Coalition for Hemophilia B for several years. She has dedicated her weekends to assist with the with *Meetings on the Road*, the *Annual Symposium*, and leading personal outreach to community families.

Heidi is also a woman with hemophilia B and a strong advocate for women with bleeding disorders. She has also volunteered at many bleeding disorders camps across the US.

She is currently enrolled in North Mississippi College of Nursing and will graduate in December 2022. Keep shining brightly, Heidi! Thank you for all you do!
















30
YEAR













HEMOPHI





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.

Takeda

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

The Gift of a Broken Scone: Cassandra's Family

BY RENAE BAKER

"Every little, minute detail has a huge effect on what happens." Cassandra is describing – wait for it – pole vaulting! "It's kind of a perfectionist's sport. What I love about it is the technicality. You improve by changing little things; like the way you're running on the runway before you're even vaulting!"

Cassandra, her husband Paul and their two-year-old toddler, Clyde, seem to be very grounded people with a passion for life. Cassandra's father, Coalition member Rick, participated in The Beats music program where he gave a soulful performance in the inaugural concert in 2019 and again in the virtual Mini Beats program last year.

Growing up with Rick as her father, hemophilia B has always been a part of Cassandra's life. "We knew that I was a carrier, but I wasn't tested until my junior year of high school." Her recollection is that her initial diagnosis was that of "symptomatic carrier," but that her HTC changed it to "mild hemophilia B" pretty quickly, for which she is grateful. She understands the health insurance barriers that can come with the nuances of diagnosis. It was the joy of pole vaulting that led to Cassandra learning that she did, indeed, have the bleeding disorder.

"I had started pole vaulting, so I was wearing my spikes which had no cushion on the foot. So, I had really bad shin splints, and they weren't getting better. My parents had warned me, but I didn't really understand that I could be affected by hemophilia. I also didn't understand that Ibuprofen could cause more bleeding, and I was taking it every day just so I could practice. One day, Dad realized what was going on and said, 'Wait a second!' That's when we called the HTC, infused and I got tested." She wasn't surprised to learn that she had hemophilia. "On some level, I guess I'd always known because I'd always bruised easily, had joint pain and other injuries."



Cassandra didn't let the diagnosis change much in her life. She simply adopted a new awareness of her bleeding disorder, made sure she had a factor supply and was mindful of the risks which could affect her long-term mobility. She continued pole vaulting through college. "Another reason I love pole vaulting is that I realized that it's a mental game," Cassandra continues. "You have to really master your mind in what you tell yourself. If I had any hesitancy or thoughts of 'I can't do it,' then that's what happens. You have to constantly be telling yourself 'I'm going to make this! I'm going to DO this!'

What Cassandra has been doing with her pole-vaulting practice is manifesting positive outcomes, which – one could argue – is a great practice for life in general. She has applied the wisdom she has gleaned from the sport to other areas of her life and has had other outlets, for pole vaulting, since leaving academia.

"For one outlet, I started training for American Ninja Warrior, because it's very similar in the mental challenge aspect. I loved it, but there was something missing. I could be doing very well and succeeding at some of these things, but the satisfaction was always short-lived. I realized that – although it's great to work on and improve my skills – I needed to find that missing element."

That search took her from Nebraska to Illinois to Montana to Colorado and – as they say – to her own backyard, where her father invited her to participate in a Tai Chi class he was leading. She found and enjoyed communities of people that raised her awareness of her spiritual self. She began to realize that what was missing could be realized through meditation, Tai Chi and developing her spirituality. And then she met Paul. Cassandra was working in a coffee shop in Mesa, Colorado when he walked in.

As Paul says, "I went in for a coffee and a burrito and saw her. Sparks flew!" They talked for about 20 minutes. Cassandra was stocking the baked goods when she came across a broken scone. One of the perks of her job was that the employees got to keep the broken scones. She thought, "I like him. I think I'll just give him this broken scone." He liked the scone but didn't pick up on the significance of the gesture, he says, shaking his head and laughing. "But I did find out that she was new to the area." So he invited her to call him if she was ever in Grand Junction, about 40 minutes away.

Spoiler alert: She called him.

"Very early on I told Paul about my hemophilia B," she says. "It was our second date, and I had a shoulder bleed, so I said, 'Hey, wanna watch me infuse?'"

"I can tell you exactly what was going through my head," Paul blurts out, with his eyes getting big. "I'm not a big fan of needles!" Cassandra is laughing at the memory.

"Wait," Paul reenacts, "You're…you're getting out a needle? You're gonna poke veins?! I'm holding my breath and thinking, 'Oh gosh - that's gross!'" Cassandra is almost falling off the chair with laughter at this point.

"But I was impressed." Paul comes around. "I was like, 'Wow, this is quite the process! Pretty crazy to know how to do that!'" Cassandra gave him what Paul calls "the elevator speech," and he quickly understood that she'd lived with hemophilia B her whole life, and it was no big deal; just something she had to do.

Indeed, Cassandra grew up watching her father infuse at least three times a week. It was just a normal part of her family's everyday life. "I never thought anything about it, until I started having problems myself, and then I thought, 'Oh wow – this is what he's been going through!' With her eyes opened to the challenges and struggles her dad had been facing, her respect for him grew. "It totally changed my perspective. It made me have more compassion and admiration for him."

Paul is a supervisor for the Bureau of Land Management. "In other words, I sit at a desk and tell send other forest

rangers out to do fun stuff," he says, clearly missing his days as a forest ranger working outdoors in Colorado. Clyde was born in Colorado. Paul's promotion to supervisor brought the family to Montana.

Paul and Cassandra enjoying exposing Clyde to the great outdoors they have enjoyed all of their lives. Before Clyde was born, the couple talked about their mutual desire to have children, and the possibility of their children having hemophilia B.

"When I was pregnant with Clyde, I wanted to have an all-natural birth with midwives at a birthing center. The midwives were saner than I was, and insisted on us having a hospital birth, but they were the ones delivering the baby." Cassandra relates, "The birth was great!" She had learned that meditation can be a powerful tool during birth.

They had Clyde tested for hemophilia immediately after the birth, but wouldn't know the results for a couple of days. Meanwhile, Clyde developed a hematoma on the back of his head in the next few hours. They suspected that the test would return as positive. The hematoma worsened as the day progressed, so a decision was made to infuse that evening and the next day. "That was challenging," Paul admits.

Cassandra piggy-backs, "It is very hard to find the veins in a newborn infant. Watching him get poke after poke was hard." Cassandra's parents soon visited which was a great comfort to the couple. "It was very cool to have my dad there and connect in that way."

The test results came back with a diagnosis of "severe." After that initial first week, they didn't have any problems for about several months. "For the first eight or nine months, I wouldn't have known he had hemophilia; no bruises or anything," says Cassandra, incredulously. "But he also wasn't very mobile…"

"Yeah," Paul interjects, "Once he started crawling around –"
"He got a knee bleed pretty quickly," Cassandra finishes.

It became obvious that weekly infusions were necessary. The hospital staff did their best with Clyde's tiny, little veins, but - as Paul tells it – "It was really challenging watching them blow through vein after vein."

I recall that it must have been doubly challenging for Paul considering his feelings about needles, and Cassandra is quick to give him praise, "Actually, it was really cool the way Paul challenged himself, all through the pregnancy, making himself watch blood draws." They made the decision to have a port implanted. After several months of help from a home health nurse, Paul and Cassandra now infuse Clyde through his port on their own weekly. They have learned so much in two years, and it all started with a broken scone.

"What's really cool is that having Clyde has sort of linked me with my grandmother," Cassandra says. "I had a conversation with her. We talked about my dad when he was Clyde's age. He spent a lot of time in the hospital!" She'd like to hear more stories from her grandmother, who had two sons with hemophilia. "I'd like to tell her just how much I admire her for her strength, courage and ability to still be present for her other children while dealing with the challenges of hemophilia."

The transition from self-sufficient adult being in control of her own life to not being able to control everything in her child's life has been quite the experience for Cassandra.

"Looking back, I always tried to have so much control over my life. As I've developed my spiritual life, I've become more trusting in the universe and accepting that I can't control everything. There is a reason that Clyde has hemophilia. It's not just a random thing that he has to suffer through. It's all part of a

learning phase that is part of a grand plan."

And Paul has had to transition from not having direct experiences with hemophilia in his life, at all, to having a father-in-law, a wife and a son with hemophilia.

"There's definitely a lot to learn. It's mostly about logistics. We like to travel and spend time outdoors, so it's more about 'Okay - how are we going to do that with the hemophilia? Where and when to infuse?' It's a new way of life."

Cassandra, ever-ready to give Paul accolades, chimes in, "One of the things that I've noticed about you is that you're just really accepting of the whole situation. You don't fight it at all. You're like, 'Okay, this is what's happening. Let's move with it.' It's been really helpful."

Paul attributes this to his "go-with-the-flow" personality. "Definitely, what has changed my perspective with it is understanding the history of hemophilia. I'm very grateful that we do have medication. He's had some bleeds, and he's been in some pain, and we have to do this thing every week, but thank the Lord, because just a generation ago the hardships that Cassandra's father went through - Wow! Just understanding that makes me realize that this isn't that bad!"

Paul has learned a lot about hemophilia through Cassandra. They also watch documentaries, and he has found a heightened interest in history because of hemophilia. "Rasputin! He was around the royal family because the little boy had hemophilia!"

Cassandra makes a pitch for the power of community: "I wasn't really plugged into a hemophilia community until after college. Then I started being asked to do some speaking programs, and then I was turned on to the Gen IX and mentorship programs through The Coalition for Hemophilia B. That really opened the doorway for me, and I began to realize how much I'd been missing out on by not being in community with other people with hemophilia B, because we share so much in common. There is so much strength and hope we can get from listening to each other's stories and learning from what they've gone through. I started participating in more events, and it's like a family to me each time I go to an event. Dad and I went to the advocacy training event in the fall together. That was a great bonding experience!"

Some core tenets Cassandra espoused during her pole-vaulting days are still serving her well and helping her family to thrive: being fully present in every moment, training her mind on positive messaging and being mindful that little changes make huge differences. "I'm continually improving myself just to be a better person, a better wife, mother and contributor to society. I've found that it is the little things that make all the difference, and those little moments exist in the present. Did I meditate today? Say my prayers? What was my attitude? What am I thinking right now? What is the tone of voice I'm using with my family? Is it kind and gentle or tense and stressed? Am I being present with my son? Am I fully listening to Paul while he's talking? While these things may seem small, each one can have a big impact on how the day unfolds. Every little action or thought or word we say is what makes up our reality and it's by being intentional and aware of what's going on right now that we create our future."

Carrying this practice in her hemophilia experience, she says, "The little things are the thoughts and attitudes I have around the bleeding disorder as well as taking the extra precautions when I'm traveling or doing activities that could potentially cause a bleed. When I do have a bleed, what am I telling myself about the bleed; that I deserve it? That I'm being punished for something? Or can I open my heart and give myself extra love, both in thought and action, with the awareness that this is a challenge and obstacle that I can overcome, learn from and become a better person from."

Maybe most important is the golden rule: Don't hesitate. Go confidently in the direction of your dreams. Hey, you never know what could come from the gift of a broken scone!

ADVOCACY UPDATE

BY GLENN MONES

As of the writing of this update, the Senate is still considering major funding for infrastructure, which may or may not have passed by the time this goes to print. The proposed funding does include some money for healthcare including a possible expansion of eligibility for Medicare. We will continue to follow the budget bill's progress and provide updates when they are available.

In late July, the Centers for Medicare & Medicaid Services (CMS), which is part of the US Department of Health and Human Services (HHS), sent a notice to the administrators of state Medicaid and Children's Health Insurance Program (CHIP) programs agencies saying that eligible immigrants should be encouraged to apply for these crucial programs. Having Medicaid (except Medicaid for long-term institutionalization) is no longer a factor in determining someone's immigration status. We encourage all community members who need health insurance to apply for these programs regardless of immigration status.

The Coalition has been working with a group called United for Charitable Assistance (UCA) and other community-based organizations to reintroduce a piece of legislation called the "Access to Marketplace Insurance Act." The bill is designed to remove any obstacles to nonprofits who provide patients with insurance premium assistance. In the past, insurance companies and some government payers have used accumulator adjustor programs and other measures to impede this kind of assistance. Without this legislation, some patients could be forced to pay much more of their drug costs out of their own pocket. In the case of conditions like hemophilia, these costs are just not affordable. Although the bill has some potential support in Congress, other priorities have delayed action on this and many other measures. It is likely that the measure will eventually get folded into broader healthcare legislation. Once there is further action on the bill, we will ask community members to contact their own members of Congress to solicit their support.

We have also been working with the American Plasma Users Coalition (APLUS), of which we are a member, to address an issue that has the potential to affect the supply of source plasma in the United States. Source plasma is collected from donors across the county and is used to manufacture factor for people with hemophilia as well as other therapies for a variety of conditions. In the past, plasma collection centers near the U.S.-Mexico received some of their donations from Mexican nationals who were able to cross the border legally on visitor visas. They must go through the same rigorous screening process as American citizens prior to donating. More recently, U.S. Customs and Immigration have reclassified their donations as "work" because they receive compensation. As a result, they would need work visas which are much harder to get. This could have a serious negative impact on the plasma supply in the U.S. as well as in other countries that rely on U.S. plasma. APLUS is working to get the appropriate government agencies to revert to the earlier policy.

Advocacy will continue to be an important Coalition focus through the remainder of the year and beyond. Stay tuned for more updates!

ADVOCACY – HHS TO STATES: TELL IMMIGRANTS MEDICAID AND CHIP ARE FOR THEM TOO

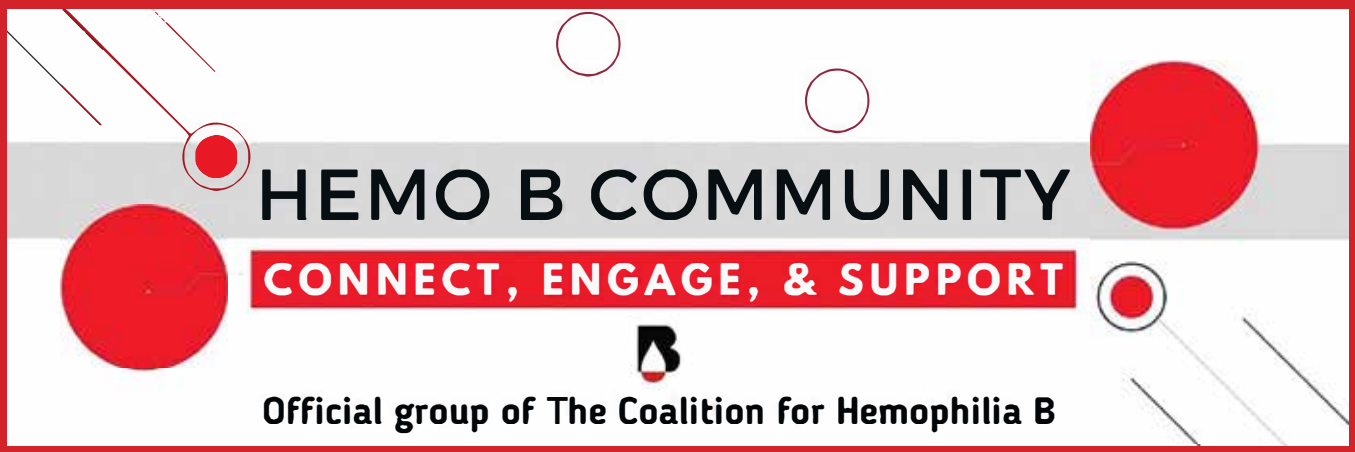
The Centers for Medicare & Medicaid Services (CMS), which is part of the US Department of Health and Human Services (HHS), recently sent a notice to the administrators of state Medicaid and Children's Health Insurance Program (CHIP) programs agencies saying that eligible immigrants should be encouraged to apply for these crucial programs. Having Medicaid (except Medicaid for long-term institutionalization) is no longer a factor in determining someone's immigration status.

"We invite states and our community partners to spread this message far and wide: we are here to help…All our communities deserve the peace of mind that comes with having access to quality care," said HHS Secretary, Xavier Becerra.

States have a duty to protect patient data and are not permitted to share a Medicaid applicant's or beneficiary's information for any purpose other than to administer the state's Medicaid plan.

For more information about this important guidance, please read the CMS press release at https://www.cms.gov/newsroom/press-releases/hhs-encourages-states-educate-eligible-immigrants-about-medicaid-coverage. Centessa Reports on Results for SerpinPC

NEW FACEBOOK GROUP!



Join Our NEW Facebook Group! You may already know about The Coalition For Hemophilia B Facebook PAGE, but we have now created 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.

TAKE CONTROL TO A HIGH LEVEL WITH REBINYN® IN HEMOPHILIA B

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

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

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rebinyn®
Coagulation Factor IX (Recombinant), GlycoPEGylated

rebinyn®

Coagulation Factor IX (Recombinant), GlycoPEGylated

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 86°F (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

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USA17BIO03951 12/2017

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Emerging Therapies

BY DR. DAVID CLARK

Several of the reports below are from papers presented at the annual meeting of the International Society on Thrombosis and Haemostasis (ISTH), July 17–21, 2021. This is one of the big international scientific meetings every year that includes studies on hemophilia. You can read the abstracts (summaries of the presentations) for free at https://abstracts.isth.org/.

Centessa Reports on Results for SerpinPC

9/9/21 Centessa Pharmaceuticals and their subsidiary ApcinteX are developing SerpinPC, which is a rebalancing agent that inhibits activated protein C, an anticoagulant. It is a subcutaneous monthly injection expected to be useful for controlling bleeding in both hemophilia A and B patients, with or without inhibitors. In results from their Phase IIa study in 23 patients, they saw only one adverse event, an injection site reaction in a patient with a pre-existing skin condition. Two patients developed anti-drug antibodies (antibodies against SerpinPC), but those did not appear to interfere with the drug's action in enhancing clotting. They saw no evidence of thrombosis. Although preliminary, the median annualized bleed rate for the patients was reduced by 88%, and they saw a significant reduction in target joints. Centessa expects to have results from a 48-week extension study in the second half of 2022. [Centessa press release 9.9.21]

HEMA Biologics Explores Action of Sevenfact for Inhibitor Treatment

7/17/21 HEMA Biologics' Sevenfact (eptacog beta, activated; EB) was recently licensed by FDA for treatment of hemophilia A and B patients with inhibitors. It is very similar to its competitor NovoSeven (eptacog alfa, activated; EA), but the clinical studies showed that 17% less EB than EA was required to give similar bleeding protection. At ISTH, HEMA researchers presented some data on why there might be a difference.

First, EA is produced using baby hamster kidney (BHK) cells, while EB is produced in the milk of transgenic rabbits (rabbit mammary cells). These two types of cells produce molecules with the same protein structures but with different glycosylation patterns. Glycosylation refers to carbohydrate chains (strings of sugar molecules) that are attached to specific places on the protein molecules. The effects of different glycosylation patterns on the biology of the proteins hasn't been studied comprehensively, but we do know that they can cause differences. Whether that causes a difference in performance between EA and EB is currently unknown. Note that neither type of cell produces a glycosylation pattern identical to that produced by human cells.

HEMA also found that 40% more EB than EA binds to activated platelets during clotting. However, they have not been able to determine whether that enhanced binding makes a difference in overall clotting performance. Even with this difference, there is no way to tell whether EA or EB would be a better product for a given patient – remember that every patient is different. With our current state of knowledge, the best guidance is probably to just try them and see what works best for you.

HEMA presented three other papers that discuss the results of their clinical studies of Sevenfact. They showed that it is safe and effective for treatment of bleeding episodes in adult and pediatric inhibitor patients and for treatment of patients undergoing surgery. [ISTH abstracts OC24.1, PB0536, PB0544 and PB0547]

Medexus Completes Enrollment in Phase IV Pediatric Prophylaxis Study for IXINITY

8/12/21 Medexus markets IXINITY, a recombinant factor IX product for hemophilia B. They have just completed enrollment of subjects in a Phase IV study (a study after a product has already been licensed) of prophylaxis in patients under 12 years of age. They expect to complete the study and submit the results to FDA by the end of 2022. If FDA approves, that will result in a label indication for prophylaxis in children. Note that a physician can prescribe any approved drug for any indication, and some pediatric patients may already be on IXINITY prophylaxis. However, a company cannot advertise or market a drug for an indication that has not been approved by FDA. Also,

insurance companies can decline to pay for use in an unapproved indication. [Medexus press release 8/12/21]

Novo Provides Updates on Concizumab Development

7/17/21 Novo Nordisk is developing concizumab, a monoclonal antibody that inhibits tissue factor pathway inhibitor (TFPI), an anticoagulant. This would be a once-daily subcutaneous injection to restore the clotting balance in hemophilia A and B patients, with or without inhibitors. By inhibiting TFPI (inhibiting the inhibitor), Novo hopes to rebalance the clotting system to allow the blood to clot more easily, even in the absence of factors VIII or IX. In their Phase II study, they found that some patients developed antibodies against concizumab. These anti-drug antibodies (ADAs) were temporary and did not appear to affect the product's performance. One patient with a low ADA level developed a much higher ADA level after trauma, but the effect on bleeding was inconclusive.

A second related paper reported that in a study of eight inhibitor patients (six As and two Bs), they saw average annualized bleeding rates (ABRs) of 19.2 for on-demand treatment and 4.9 for prophylaxis, both with concizumab. One patient saw no improvement in bleeding, even at the highest dose, and was withdrawn. Three patients experienced zero bleeds after their last dose. There were no safety concerns.

A third paper reported on 61 patients (including 10 Bs with inhibitors) in an extension study of up to 102 weeks for the main and extension parts combined. The results were similarly good leading to Novo's current Phase III study. [ISTH abstracts OC32.3, PB0503 and PB0514

Pfizer Reports on Long-Term Study of Anti-TFPI Marstacimab

7/17/21 Pfizer is developing marstacimab for treatment of hemophilia A and B, including patients with inhibitors. Marstacimab is a subcutaneous, monoclonal antibody that inhibits tissue factor pathway inhibitor (TFPI), like concizumab, above.

At ISTH, they reported on the long-term (up to one year) safety and efficacy of marstacimab in their Phase II clinical study. The 20 patients, including seven with inhibitors (all had hemophilia A, except one B without inhibitors) were equally divided into a 150 mg/week group and a 300 mg/week group. The 150 mg/week group saw their average annualized bleeding rate (ABR) decrease from 17.4 before treatment to 2.7 over an average of 318 days after treatment. The 300 mg/week group saw their average ABR decrease from 20.2 to 1.5 over an average of 335 days. There were only three treatment-related adverse events, two injection-site reactions and one hematoma. There were no reports of thrombosis. Pfizer is currently recruiting severe hemophilia A and B subjects for a Phase III study. [ISTH abstract OC32.4]

Protein Z As a New Target for Rebalancing the Coagulation Cascade

7/17/21 Protein Z is another anticoagulant in the clotting system, and a group from INSERM in France (the French analog of NIH) has shown that it can potentially be targeted to help restore the balance in the system in patients with hemophilia. The target is actually Protein Z-dependent protease inhibitor (ZPI), which is a cofactor for Protein Z. A cofactor is a molecule that significantly increases the activity of an enzyme like Protein Z. An example is factor VIII, which is a cofactor for the enzyme factor IX. Without factor VIII (hemophilia A), factor IX has very low clotting activity.

The researchers produced antibodies against ZPI in llamas, and used the antibodies to inhibit ZPI in plasma from hemophilia A and B patients. They showed that the clotting characteristics of the hemophilia plasma samples could be improved from the severe to the moderate hemophilia range. This is an early laboratory study that could present another possible target for hemophilia treatment. [ISTH abstract OC14.2]

GENE THERAPY

Belief Biomed Developing Gene Therapy for Hemophilia B

8/10/21 Belief Biomed, a Chinese company, has received approval from the Chinese government to begin a Phase I/II clinical study of a gene therapy for hemophilia B. Their treatment, BBM-H90, uses a proprietary AAV vector to deliver a codon-optimized human factor IX gene. In an earlier Phase I study started in 2019, they found good safety and efficacy in three patients. Their annualized bleeding rates (ABR) declined significantly, with stable factor IX expression and no serious adverse events.

The company's founder, Dr. Xiao Xiao, has extensive U.S. experience in gene therapy having worked at the early gene therapy company Bamboo Therapeutics (since purchased by Pfizer). He was also a co-founder of Asklepios BioPharmaceutical (AskBio), which was recently purchased by Bayer. [Belief Biomed press release 8/10/21]

Freeline Looks at Assay Variations for Factor IX Gene Therapies

7/17/21 Freeline Therapeutics is developing verbrinacogene setparvovec (FLT-180) as a gene therapy for hemophilia B. Their treatment uses the higher-activity Padua factor IX variant as the new gene, as do many of the other products under development, including those from uniQure/CSL and Pfizer. Factor IX-Padua is about eight times more active than normal (wild-type) factor IX. The higher activity helps these treatments to achieve factor IX levels in the mild to normal range with lower AAV doses.

At ISTH, they presented papers on two studies of assay variability for the measurement of factor IX-Padua.

Results from 15 different commonly used clotting assays showed a greater than three-fold variation in factor IX activity depending on the assay used. Thus, the various Padua-based gene therapies being developed cannot be directly compared because of the different assays used by the different manufacturers. A gene therapy that appears to put the recipient in the mild range by one assay could instead put him in the normal range when the patient's levels are tested by a different assay. Freeline also developed computational models that can be used for comparison of results from different assays.

They also found that the patient's factor X levels, but not his factor VIII levels, affect the patient's assay results. This could be one of the reasons that all of the gene therapies under development seem to give widely varying results from patient to patient. This kind of work will be important in helping patients choose among the various gene therapies once they are approved. [ISTH abstracts LPB0021 and PB0655]

Pfizer Reports on Five-Year Liver Health Study for their Gene Therapy Treatment

7/17/21 Pfizer is developing fidanacogene elaparvovec, a gene therapy treatment for hemophilia B, which is currently in Phase III clinical studies. At ISTH, they presented results of liver health in a five-year follow-up of their Phase I/IIa study. The hemophilia population has a history of infection with hepatitis B and C, both infectious liver diseases, which makes the role of gene therapy in long-term liver health important. Ten of the 14 patients who entered the long-term follow up study had prior hepatitis C infections that had been successfully treated, and seven had prior histories of hepatitis B. The patients undergo annual ultrasound liver examinations. In follow-ups ranging from 32 to 60 months, one patient was discovered to have a fatty liver condition. Fatty liver is a collection of conditions in which too much fat builds up in the liver, which can sometimes go on to produce liver damage.

They found no evidence of alpha-fetoprotein elevation, which is a marker (indicator) of liver cancer. They did see mild elevations of alanine aminotransferase (ALT) in some patients, which have been a common occurrence in gene therapy. Such elevations are usually temporary and are treated with steroids. Pfizer will continue to follow these and other patients receiving their gene therapy treatment. [ISTH abstract PB0532]

FDA Requires More Data from uniQure/CSL for Licensure of Their Gene Therapy Treatment

6/22/21 uniQure and CSL Behring are developing etranacogene dezaparvovec (AMT-061), a gene therapy treatment for hemophilia B, which is currently in Phase III clinical studies. They reported on a pre-BLA meeting with FDA, which is a meeting held prior to submitting a Biologics License Application (BLA) to confirm FDA's expectations for the data to be submitted. The companies had planned to submit their BLA with data from patients 52 weeks after administration of the treatment. However, FDA informed them that they wanted 52-week data starting from the point that the patient's factor IX levels attained steady-state levels. Since steady-state levels are reached about six months after infusion of the treatment, that will delay the submission by about six months while they collect the required data. Although it has not been specifically reported, this will most likely be a requirement for all hemophilia gene therapies. [uniQure press release 6/22/21]

uniQure Presents Six Papers at ISTH on Etranacogene Dezaparvovec Clinical Studies

7/5/21 uniQure presented six papers at ISTH on the development of their AMT-061 gene therapy treatment. At the 52-week point of their Phase III study, they saw an average factor IX level of 41.5% of normal (range 5.9 – 113%) in 54 subjects with severe or moderately-severe hemophilia B. The study did not exclude patients with pre-existing antibodies against the AAV5 vector used to deliver the new factor IX gene. Except for one patient with an extremely high anti-AAV5 level, they did not see any effect of anti-AAV5 antibodies on the treatment results. They did see mild or moderate infusion-site reactions in seven of the 54 patients (13%), which they learned could be managed by slowing the rate of infusion and/or treating the patients with steroids and antihistamines.

At the 52-week timepoint they discovered one patient with hepatocellular carcinoma (HCC or liver cancer), which caused a temporary halt to the study. This was in a 69-year-old moderately-severe patient with a history of hepatitis B and C infection, smoking and a family history of cancer. The patient had no evidence of HCC at the beginning of the study. Extensive study showed no evidence that the subject's HCC was a result of the gene therapy treatment, and the study was re-started. Note, however, that we know so little about these things that we cannot say definitively that the gene therapy was not the cause. Therefore, all study participants will now be monitored for HCC twice a year.

Two additional papers reported on 2.5-year results from the Phase IIb study of AMT-061 and five-year results from the Phase I/II study of AMT-060. AMT-060 was an earlier version of the treatment that used a wild-type (normal) factor IX gene instead of the higher-potency Padua factor

IX gene used in AMT-061. Both studies showed sustained factor IX levels and no safety concerns. [ISTH abstracts LPB0020, OC26.3, OC67.3, OC67.4, PB0653 and PB0659]

Safety of Gene Therapy

9/7/21 Three significant things happened in the last week in the field of gene therapy safety. 1) Astellas Pharma, which is developing an AAV gene therapy for a rare neuromuscular disease, had their study put on hold last year after three children receiving the treatment tragically died from liver problems. With FDA approval, they re-started their study last December using a lower dose of the AAV vector, but now have voluntarily halted it again after another instance of unusual liver function in a patient. 2) BioMarin, who are also developing a gene therapy for hemophilia A, had a study for a gene therapy treatment for phenylketonuria (PKU) placed on hold by FDA. In animal studies for the PKU treatment, they found evidence that the new genes had inserted themselves into the genome of six mice that later developed liver cancer. 3) FDA held a meeting of their Cellular, Tissue and Gene Therapies Advisory Committee on the safety of gene therapies that use AAV vectors.

There have also been warning signs from other gene therapies. Novartis' Zolgensma, one of only two currently licensed gene therapies, has been associated with thrombotic microangiopathy (TMA) in nine of about 1400 patients so far. Zolgensma is used to treat spinal muscular atrophy. TMA is a rare condition characterized by blood clots and injury to the linings of small blood vessels, which can lead to kidney damage. TMA has also been seen in other gene therapy clinical studies, mostly ones that use higher AAV doses than have been used in the hemophilia gene therapy products under development.

Other gene therapy clinical studies have seen liver, brain and blood abnormalities, either in patients or in associated animal studies. One problem in the field is that animal studies don't always accurately reflect what happens in human patients. FDA has also been concerned about the lack of consistency in results among patients. One patient will have a superb outcome, while another will see little or no effect. We've seen this repeatedly in hemophilia with widely varying factor levels from the same treatment. FDA wants to see industry pay more attention to this rather than rushing into clinical studies.

FDA is treading very carefully in deciding how to analyze the safety of the various gene therapy treatments being developed, not just for hemophilia, but also for many other disorders. There are now reported to be more than 300 gene therapy treatments under development for various conditions. A year ago, they surprised the whole community by delaying approval for BioMarin's hemophilia A gene therapy. As with the report on uniQure above, they wanted longer-term data to have more confidence that the products are safe and effective.

AAV (adeno-associated virus) is used to deliver the new genes by most gene therapies currently under development. It is considered a "safe" virus because although it can infect humans, it doesn't cause disease. Also, the genes that it carries usually do not integrate (insert) into the genome and so, do not disrupt other genes. However, the sheer numbers of virus particles used in gene therapy have raised concerns from a number of scientists. As described on page 26 of the Summer 2020 issue of Factor Nine News, this can typically be 1,800,000,000,000,000 (1.8 quadrillion) virus particles.

Gene insertion is usually considered to be a random process (it might not be). The new gene can insert itself anywhere, which sometimes causes no problems but sometimes can disrupt an important gene. We all carry a number of cancer genes in our genomes (the complete collection of all the genes in a body). They are normally turned off, but a disruptive insertion can turn them on. This happened in some early gene therapy studies, causing leukemia in a few patients. That may be what happened to the mice in BioMarin's study described above.

One of the industry researchers at the FDA meeting pointed out that: "More than 3000 patients have been treated with gene therapy, and there are no reports of cancers emerging as a consequence." There are at least two problems with a statement like that. First, human cancers can take years or even decades to develop, and we haven't been doing gene therapy that long. The other is that it's likely that cancer is a rare development, and we might just have been lucky so far. Just as an example, if a cancer rate is one in ten thousand, treating 3000 patients doesn't give you much information.

There was no definitive outcome to the FDA meeting – mainly that we just need to be more careful. This also alerts industry that FDA is going to be very cautious. They're developing complex products in an area that is still poorly understood. This is nicely summed up by the title of an article that was published last year by people from WFH, NHF and several other European hemophilia organizations: "Gene therapy to cure haemophilia: Is robust scientific inquiry the missing factor?" [Pierce GF et al., Haemophilia, 26(6):931-933, 2020]

This is a community that has been "burned" before. Gene therapy holds the promise of a future cure for hemophilia, but we may be getting ahead of our knowledge. Dr. Wilson Bryan of FDA opened the meeting with the following statement: Our enthusiasm for this field must be balanced by caution. The patients who enroll into these clinical trials are heroes, and we owe them a great debt. We must honor their sacrifice by minimizing the risks for future study subjects and patients." [Sources: multiple news articles]

RICK HAS RELIED ON IDELVION FOR 4 YEARS TO PROVIDE HIGH FACTOR IX LEVELS

Rick has always been drawn to martial arts. While he loved competing as a young man, he knew taekwondo was too hard on his body and led to joint damage. Rick knows it's important to maintain his joint health by keeping his Factor IX levels high. That's why he trusts IDELVION.

Rick has not experienced a single breakthrough bleed* while on IDELVION in the last 4 years.

*Breakthrough bleed refers to a spontaneous bleeding episode.
†Hemophilia FIX Market Assessment, Third-Party Market Research.

Learn more about Rick's experience at **IDELVION.com**

"With the high factor levels of IDELVION, I'm confident in my ability to take care of myself. That way, I can do things that really matter to me."
— Rick

Important Safety Information

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP), is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce the number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

In clinical trials for IDELVION, headache was the only side effect occurring in more than 1% of patients (1.8%), but is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away, or if bleeding is not controlled with IDELVION.

Please see brief summary of prescribing information on adjacent page and full prescribing information including patient product information at IDELVION.com.

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**.

You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

IDELVION®
Coagulation Factor IX (Recombinant), Albumin Fusion Protein

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein
Initial U.S. Approval: 2016

BRIEF SUMMARY OF PRESCRIBING INFORMATION
These highlights do not include all the information needed to use IDELVION safely and effectively. Please see full prescribing information for IDELVION, which has a section with information directed specifically to patients.

What is IDELVION?
IDELVION is an injectable medicine used to replace clotting Factor IX that is absent or insufficient in people with hemophilia B. Hemophilia B, also called congenital Factor IX deficiency or Christmas disease, is an inherited bleeding disorder that prevents blood from clotting normally.

IDELVION is used to control and prevent bleeding episodes. Your healthcare provider may give you IDELVION when you have surgery. IDELVION can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use IDELVION?
You should not use IDELVION if you have had life-threatening hypersensitivity reactions to IDELVION, or are allergic to:
- hamster proteins
- any ingredient of IDELVION

Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using IDELVION.

What should I tell my healthcare provider before using IDELVION?
Discuss the following with your healthcare provider:
- Your general health, including any medical condition you have or have had, including pregnancy, and any medical problems you may be having
- Any medicines you are taking, both prescription and non-prescription, and including any vitamins, supplements, or herbal remedies
- Allergies you might have, including allergies to hamster proteins
- Known inhibitors to Factor IX that you've experienced or been told you have (because IDELVION might not work for you)

What must I know about administering IDELVION?
- IDELVION is administered intravenously, directly into the bloodstream.
- IDELVION can be self-administered or administered by a caregiver with training and approval from your healthcare provider or hemophilia treatment center. **(For directions on reconstituting and administering IDELVION, see the Instructions for Use in the FDA-Approved Patient Labeling section of the full prescribing information.)**
- Your healthcare provider will tell you how much IDELVION to use based on your weight, the severity of your hemophilia B, your age, and other factors. Call your healthcare provider right away if your bleeding does not stop after taking IDELVION.
- Blood tests may be needed after you start IDELVION to ensure that your blood level of Factor IX is high enough to properly clot your blood.

What are the possible side effects of IDELVION?
Allergic reactions can occur with IDELVION. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

IDELVION might increase the risk of abnormal blood clots forming in your body, especially if you have risk factors for such clots. Call your healthcare provider if you experience chest pain, difficulty breathing, or leg tenderness or swelling while being treated with IDELVION.

A common side effect of IDELVION is headache. This is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

Based on July 2020 revision

Please see full prescribing information, including FDA-approved patient labeling.

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.

Mental Health in a Pandemic Age

BY FERNANDO REYES, M.ED.PSY.

The bleeding disorders community has always met challenges with grace and resilience. It is part of who we are. The warrior spirit within all of us has kept our community overcoming adversity and innovating new ways to surmount obstacles (through a cooperative union, supporting each other, and maintaining our health).

Hemophiliacs are no strangers to pain (whether physical or emotional); it comes with the territory when you have a coagulation disorder. As a member of the hemophilia community myself, growing up as a teenager in the 1980s, bleeds felt intrusive and not welcomed occurrences in my life (I always had a breakout bleed the day before Thanksgiving or Christmas).

I endured excruciating pain from bleeds in my knee or ankle. I infused sensitive skin, spent numerous months in the hospital, and went through knee surgery. When I was thirteen years old, I used crutches for nearly three years (at a time in school when status and a network of friends starts to matter). Bleeds undoubtedly took a toll on my ability to view life with a constant happiness filter.

That was a long time ago (sigh of relief). Our past must not serve as a life sentence. The past instead is lessons learned and wisdom accrued.

However, I decided to avoid victimizing myself for having a bleeding disorder. As an adult, I realized I was indebted and [grateful] for all the kindness, compassion, and loving care I received from medical professionals (H.T.C., nurses, social workers, etc.). I had to find a way to pay back all the healing energy I received.

I realized that I could shift my focus to emotions that were pleasant and healing in my life. When I recall the countless acts of kindness I have received, I wonder if we can proactively rewrite our narrative. A story of obstacles and regret, to an account of gratitude and triumph.

The advent of COVID-19 has encapsulated our lives with uncertainty and has invoked fear of the unknown. Nevertheless, in these challenging times, I would like to kindly and modestly share some strategies that helped me keep an [accurate] perspective throughout the last twelve months and allowed me to protect my mental health. Remember, you are a vital, essential human being. You merit compassion, healing, kindness, and empathy. If you do not care for yourself, then who will care for you? Let us get started.

THREE STEPS TO IMPROVING MENTAL HEALTH:

1.) The first thing I did was recently get a thorough health screening with my physician (blood pressure levels, glucose levels, thyroid screening, cholesterol, and triglyceride levels, etc.).

Also, I asked my doctor to check my vitamin D levels. Lab work (blood samples, M.R.I.'s, etc.) provides accurate, factual data. To prevent low levels of vitamin d, some medical professionals recommend getting 15-20 minutes of sunlight per day.

It is okay if you wish to apply sunblock before sun exposure. According to Harvard Health Publishing (2020), most people do not apply enough sunblock to block all UVB light completely.

> **"Today, something great is going to happen."**

I want to reveal that I am not a fan of positive thinking (I am a fan of accurate thinking). Positive thinking allows us to possibly justify poor decision-making, such as, "I will have a third bowl of ice cream, and it will not affect me. I will be okay as long as I work out all next week."

Taking responsibility for your health and utilizing accurate

health data gathered by your physician will help you know where you stand health-wise. Thus you will be able to establish healthy goals to reach optimal health.

Worthwhile objectives are increasing muscle and joint strength, establishing a healthy weight, and assuring we have healthy blood pressure levels. Always consult with your doctor and physical therapist.

Remember, body and mind are connected. The healthier your body is, the more you will notice your thoughts and mood improving. A healthy body will correlate to a healthier mind. According to McGrane (2021), a proper diet (as recommended by your doctor) is a factor that could play a role in improving mental health.

2.) Treat your body with kindness and respect (nutrition). Therefore, limit foods that will cause inflammation. Remember, the food and mind connection is gaining more traction in the medical world (nutritional psychiatry). The foods you eat may promote anxiety and depression and lead to poor mental health.

Over 90% of serotonin (5-hydroxytryptamine) production may come from the gut system. Serotonin is the feel-good, happy hormone. If we consume foods that cause a gut imbalance and inflammation, we risk limiting the number of vitamins, serotonin, and nutrients our body and brain need.

Our gut has a direct connection to the brain via the vagus nerve. When we consume highly processed foods or foods that contain lots of refined sugars, it may put our gut in dysbiosis (an imbalance in favor of the harmful bacteria).

Recent studies show that a gut in dysbiosis is associated with mental illnesses such as Major Depressive Disorder (M.D.D.). Research by Yong (2020) has identified some specific strains of bacteria present or absent in those suffering from mental health ailments.

If your gut is inflamed, it will function poorly and not send the proper messages your brain needs (e.g., hormones that stabilize your mood).

Medical professionals recommend limiting our sugar intake (such as maltodextrin and high corn fructose syrup). Also, avoid highly refined carbohydrates, alcohol, foods high in sodium, and foods with hydrogenated fats such as microwave popcorn, baked goods, frozen foods, and fried foods. Research shows these foods are not beneficial for your mental health.

Skip the sugary drinks such as soda, and the store sold fruit juices and sugary energy drinks. Also, limit coffee house prepared cappuccino drinks with whipped cream, caramel sauce, and chocolate sauce.

If you need your coffee fix, drink black coffee with almond or coconut milk as your creamer and avoid artificial sweeteners.

A healthy way to hydrate yourself is to drink water infused with lemon or cucumber or have a soothing cup of chamomile tea in the evening.

A study by Breit et al. (2018) reveals that sugar and highly refined carbs are well known to cause gut inflammation. If your gastrointestinal system (gut) is inflamed, it hinders the interaction between the gut, neural, endocrine, immune, and humoral links.

An excellent recommendation is a diet high in greens (cruciferous foods such as kale, broccoli, brussels sprouts, and cabbage). According to the nutritional psychiatrist from Harvard Medical School, Dr. Uma Naidoo (2021), these foods, as mentioned above, are rich in folate or B9 and are essential for mental health.

Avoid foods containing G.M.O.'s (genetically modified organisms are foods resistant to pesticides such as glyphosate). Instead, opt for grass-fed beef, green salads, turkey, avocados, walnuts, wild-caught salmon, free-range organic eggs, and berries (blackberries, blueberries, and raspberries).

According to Collins (2017), exercise is an excellent way to boost your "feel-good" neurotransmitters such as norepinephrine, serotonin, and dopamine. These neurotransmitters increase the sense of "well-being" and play an essential part in regulating mood and feeling a sense of accomplishment.

As always, consult with your doctor or licensed nutritionist to obtain the best possible meal plan. You and your doctor can devise a healthy meal plan suited for your needs.

Modifying your diet can help you impact your physical

and mental health by eating food full of nutrients, free of harmful carcinogenic chemicals, and food that will dynamically influence your mood.

3.) It is always the right time to ask for help. Resist the urge to "tough it out" and do not perceive that asking for help is somehow a sign of weakness. As Dr. Daniel Amen says, challenge the A.N.T.S. (automatic negative thoughts).

It is okay not to feel okay. Reaching out for help does not make you any less of a person. On the contrary, it takes courage and the belief in hope to move forward. I prefer to progress over perfection. As the former president Abraham Lincoln once said, "I walk slowly, but I never walk backward."

It is helpful to celebrate even small accomplishments. I have made it a routine to wake up in the morning and be grateful for a new day, which is another opportunity to experience life.

I will repeat optimistic affirmations such as, "Today, something great is going to happen." And I am always right (I am grateful I have clotting medication and thankful I have friends and family that offer a shoulder to lean on). Plus, I still get super excited about eating salad every day.

If you, a friend, or family member ever feel you have lost hope and are contemplating hurting yourself, please know there are professionals twenty-four hours a day, seven days a week, that you can call.

The National Suicide Prevention Hotline is free; confidential support is available in English and Spanish. They also offer help to the LGBTQ+ community and to the deaf and hard of hearing community. The number is 1-800-273-8255, https://suicidepreventionlifeline.org/.

In summary, it is essential to obtain factual evidence of how our health is doing. It is ideal to get a comprehensive check-up from your doctor and know where you stand (based on accurate laboratory test results).

Second, feed your body healing and nourishing food that will balance your gastrointestinal health and mental health. The food you eat and your mental health are connected.

Third, it is vital to reach out to your physician, nurse, social worker, family, or friends and let them know that you may be feeling depressed, angry, or anxious.

Talk to your doctor or schedule an appointment to meet with a mental health therapist (which is confidential).

I wish you all much happiness, peace, success, and blessings. Thank you.

OTHER SUPPORT SERVICES:

- Veterans Crisis Line: Suicide Prevention. 1-800-273-8255, confidential, available 24/7, all veterans, all service members, family members, and friends. https://www.veteranscrisisline.net/
- SAMHSA (Substance Abuse and Mental Health Services Administration). SAMHSA's National Helpline: 1-800-662-HELP (4357). SAMHSA's National Helpline is a free, confidential, 24/7, 365-days a year treatment referral and information service (in English and Spanish) for individuals and families tackling mental and substance use disorders. http://samhsa.gov

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ABOUT THE AUTHOR:

Fernando Reyes, M.Ed.Psy. obtained his bachelor's degree in psychology and his master's degree in mental health counseling from the University of Texas at El Paso. He currently work as a college advisor for a community college with over twenty-five thousand registered students. He works with students from all walks of life (military students, students with learning challenges, and international students).

Fernando Reyes, M.Ed.Psy. writes this article as a member of the hemophilia community. This article, opinions, and statements are his own.

4 REASONS TO BECOME A MENTAL HEALTH FIRST AIDER

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Jan 29, 2022
Feb 26, 2022
Mar 12. 2022
Mar 26, 2022

What hemophilia tracking app should I be using?

BY ROCKY WILLIAMS

In the span of a generation, cell phones went from being a luxury to a necessity—and they're not just for calling and texting anymore. We do everything on our phones: email, shop, listen to music, post on social media, play games, and track everything from our finances to our fitness. In fact, today there is a large selection of health and well-being apps available to help users keep tabs on their diet, exercise, mental health, and health conditions such as diabetes.

It's no surprise, then, that several apps have been developed for those living with hemophilia to keep a record of their bleeds and infusions. These records help families, caregivers, and doctors to better understand trends in treating and help in customizing care plans. Some apps also offer other bells and whistles, such as reminders to infuse, the ability to take pictures of medication to capture information like expiration dates and lot numbers, and integration with other health apps.

So what apps are currently available and how do they compare?

HemMobile and MicroHealth Hemophilia

Two of the most popular hemophilia apps are HemMobile (developed by Pfizer) and MicroHealth Hemophilia (developed by MicroHealth). Both apps are currently available from the Google and Apple app stores and allow users to record infusions, log bleeds, track physical activity, and create reports. They both also allow users to keep track of doctor appointments, set reminders, and set up multiple profiles. With permission, both can share information directly with your care team. HemMobile uses your device's camera to capture medication lot number, product expiration date, and IU amount of your infused factor product. MicroHealth can also scan lot numbers and more, as well as help you monitor your factor inventory levels and ask for timely refills.

MicroHealth has higher ratings in both the Google and Apple app stores, although many of the reviews for both are at least a few years old. HemMobile is for only Pfizer products. The HemMobile app also offers the ability to find nearby hemophilia treatment centers (HTCs) and National Hemophilia Foundation chapters.

Both also have a fitness app integration: MicroHealth integrates with Health app on your iPhone to get your minutes of exercise per day. HemMobile integrates with Google Fit or a Striiv wearable device, which can track your heart rate, steps, and other activities.

Get the app: HemMobile: App Store (Google and Apple)
MicroHealth Hemophilia: App Store (Google and Apple)

myWAPPS

A third app, myWAPPS (developed by Design 2 Code Inc. with a grant from Bayer), offers many of the same features such as recording infusions, logging bleed activity, creating reports, and setting up reminders. Where it stands out is its ability to gauge your factor levels, including showing trough and peak levels before and after infusion. This app is also available in the Google and Apple app stores, but myWAPPS registration requires a pharmacokinetic (PK) report completed by your treating physician. To use this app, you will have to undergo a PK study and not every HTC uses myWAPPS. Ask your HTC if you're interested.

Get the app: MyWAPPS: App Store (Google and Apple)

ATHNadvoy

Another app that community members mention using is ATHNadvoy (developed by the American Thrombosis and Hemostasis Network, or ATHN). Like the others, it enables users to record infusions, log bleed activity, create reports, set up reminders, and transmit your treatment information to your HTC.

Get the app: Register at www.ATHNADVOY.COM

Look into the app best for you

All four apps can be helpful tools for those living with hemophilia B. Which app is best for you is a personal choice, and community members differ on what they prefer. "I have used HemMobile," said April "I like the idea of syncing it with my Fitbit." Meanwhile, Stormy said she likes MicroHealth: "I love that it connects to my specialty pharmacy and lets the nurse know if I log a bleed."

Since the usefulness of the app may depend heavily on what your doctor or HTC can accommodate, we recommend discussing it with your care providers to determine what would fit best into your lifestyle and treatment plan.

women bleeders

A NEW FEATURE SECTION

ARTICLES TO SUPPORT WOMEN WITH HEMOPHILIA B

Don't Give Up on Living Your Best Life! Heidi's Story

BY RENAE BAKER

"When my little brother was born, it was anticipated that he might have hemophilia B because my grandfather had it," Heidi explains. "When I was born, girls weren't diagnosed with hemophilia because – you know…it's *a boy thing*."

It was necessary for her brother to be seen by a hematologist from the time of his birth. He was taken to St. Jude's where he was diagnosed with hemophilia B. During that time, the research hospital conducted a study on her family, tracking their genealogy so far back "the chart took up an entire wall!" Heidi exclaims. "It showed everyone in my family who had hemophilia B and von Willebrand disease. It was crazy!"

The research also included testing Heidi and her older sister for carrier status. Her sister was 18 and had been experiencing bleeding issues her whole life. Heidi was eight at the time and, although plagued with lengthy nosebleeds, she was not aware of the internal bleeds she was also having. "I broke my arm seven times when I was a kid. Two of those breaks happened before my diagnosis. My arm would swell so badly that three days the cast would slip right off because the swelling would have gone down." She remembers walking up to her mother with her cast in her hand and asking, "Mom, is this normal?"

Her mother knew it wasn't. Back to the hospital they would go, but additional x-rays would only reveal the break, not the hemophilia.

Nevertheless, Heidi considers herself extremely lucky to have gotten the diagnosis of moderate hemophilia B at an early age. "The title," as she calls it, seems to be a passport of sorts. She frequently encounters people who doubt her claim that she is a bleeder, and she finds it a relief to be able to tout the credential of the diagnosis from the esteemed research hospital.

Once diagnosed, Heidi was instructed to infuse one day before her menstrual cycle and three days into her period. She would also infuse whenever she experienced a bleed confirmed by her doctor. In retrospect, she realized this probably wasn't the optimal course of action. Heidi was frequently on crutches due to knee bleeds. "Or I'd hit my toe and it would swell up to an abnormal size. We asked to be put on a prophy regimen but the following course of action was to increase my on-demand prescription. However, it was just not adding up as to why I was having so many bleeds. I was finally put on prophy at age 17." From then on, Heidi was able to infuse once a week to prevent many of the bleeds she was experiencing.

With her brother's diagnosis, Heidi's parents became connected with the bleeding disorders community and began attending local events and attended The Coalition for Hemophilia B symposiums in New York City. Heidi also began to attend local chapter events and got to go to a bleeding disorders camp in her area.

At age 17, Heidi became very active with her local chapter and The Coalition for Hemophilia B, and was soon connecting with other women with hemophilia B. When she was 20, Heidi attended her first Gen IX meeting. She has since been to multiple mentorship and advocacy Gen IX events.

"I'm so close with the hemophilia B community now because of the Coalition's programs, symposium, women's retreats, Gen IX events, and more. These events have helped me meet so many people who have had similar experiences with bleeding issues like I have!"

Heidi is actively involved with the Coalition. The Coalition's acknowledgment and support of female bleeders have been a tremendous help to her because as Heidi shares, "One of the most frustrating things has been having people tell me to my face that I can't have hemophilia, that it's *impossible*." Indeed, she has even heard this from her own father.

"My dad, to this day, isn't convinced I have hemophilia because of the old-fashioned beliefs that it only affects boys." Heidi laughs through her ascending inflection as if the statement was a question. "He's coming around to it more now because of all the education we have received through the Coalition. There is so much education within The Coalition for Hemophilia B and my parents and I have learned so much! Genuinely, this group is *family!*"

"Some days, I might have an elbow bleed and be in so much pain I feel the weight of the world on my shoulders and then blow a vein while trying to infuse. That's the worst," she continues. "Thankfully, I have such an amazing husband. Jacob encourages me and says I've got to get the infusion done. If I just can't, he will do it for me in spite of the fact that he hates needles. He's such a blessing!"

Just past newlywed status, Heidi and Jacob have been together for six years and have known each other since they were babies attending the same church. He accompanies Heidi to as many Coalition and community events as possible.

"Hemophilia is often very challenging, painful, and stress-inducing; however, the family feel, the connection and hope this close-knit community continually offers me is extremely comforting and rewarding.

If I didn't have hemophilia, I would not be the person I am today," Heidi says with gratitude, "and I like the person I am today!"

The person she is today has just started nursing school, "I love learning new things and am especially interested in learning about illnesses and medicine." Heidi says with a light in her eyes. "At the airport during a long layover on our way to our honeymoon, I came across a book called, "Girl, Wash Your Face" by Rachel Hollis. I felt very motivated, and while on our flight, I turned to Jacob and anounced, 'I think I want to go to nursing school!'"

Although Heidi's knees bother her a lot, she has decided if there is something she wants to do that she is passionate about, she isn't going to let her hemophilia stop her. Heidi hears women speak up at bleeding disorder meetings and talk about how they haven't been able to obtain a proper diagnosis yet, how they can't get in to see the right doctor, or how they feel they are being dismissed and are not being listened to, and it's really upsetting to her.

"Once I received my diagnosis, I didn't have to worry about all of that anymore. I feel a little like I have something like survivor guilt because I was able to be diagnosed. There are so many women who have been struggling, who have had such rough childbirths, and who feel like their bodies breaking down because they've been bleeding their whole lives without the help of a true diagnosis and benefit of treatment. I feel deeply for them. It hurts my heart."

Heidi tells all the women she meets who are struggling that she will help in any way possible – whether it's advocacy, sharing resources and information, or assisting in finding a doctor who understands bleeding issues in women. She offers this advice to women in the community who know something is wrong and that they need help obtaining a proper diagnosis, "Just keep pushing. Keep advocating for yourself. Reach out to other women who can help you advocate – including me. Don't give up. Until you have the answers you are looking for you won't be living your best life."

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.

FACT SHEET

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FREQUENTLY ASKED QUESTIONS ON WOMEN AND GIRLS WITH BLEEDING DISORDERS

Q. What is an inherited bleeding disorder?

Injury and bleeding result from damage to blood vessels, from which blood leaks out. Your body's natural response is to try to limit this blood loss by stopping the flow out of the vessel and then later repairing the damage. The first response to blood loss is that your body will try to seal the gap at the bleeding point by making a blood clot at that point. This clotting process uses a combination of blood clotting proteins called clotting factors, and blood cells called platelets that are naturally present in the body. The first factor to arrive to sites of injury is von Willebrand Factor (VWF); it binds to the lining of the damaged blood vessel and attracts platelets to the area to help the blood clot to form. More platelets and other clotting factors are then attracted to the site, making the clot stronger and halting the bleeding. A clot therefore occurs when blood is converted from a liquid form to a solid state (and can no longer flow) and further blood loss is prevented.

An inherited bleeding disorder is a condition where either the platelets are abnormal and non-sticky, or clotting factors are decreased, abnormal or absent. This makes it difficult for a person to stop bleeding and they continue to lose blood.

Q. Who is affected by an inherited bleeding disorder? What are the types of inherited bleeding disorders?

An inherited bleeding disorder is passed down from parent to child and can manifest at any age in men, women, boys, and girls. It can also be a spontaneous mutation, meaning there is no family history. Because of monthly periods or pregnancy, women and girls are more likely to experience heavy menstrual bleeding (HMB), bleeding during pregnancy and childbirth, and bleeding following childbirth (also called post-partum hemorrhage).

Approximately 1 in 10 women with heavy periods have an underlying bleeding disorder. However, heavy periods can also occur due to other gynecological conditions such as uterine fibroids, polyps, endometriosis, or female hormonal imbalance. Non-gynecological causes of heavy periods include thyroid problems, systemic diseases such as severe liver or kidney diseases, or non-inherited (also called acquired) abnormalities of blood coagulation or reduced platelet count.

The types of inherited bleeding disorders include 1) platelet function disorders where the platelets are non-sticky and do not clump (called platelet function defects), and 2) clotting factor deficiencies. The most common inherited bleeding disorders are von Willebrand Disease (VWD), and deficiencies of factor 8 and factor 9 (called hemophilia A and hemophilia B, respectively). Rare bleeding disorders include deficiencies of other factors (factors 1, 2, 5, 5+8, 7, 10, 11, 13, congenital deficiency of vitamin K-dependent factors, plasminogen etc.)

Q. What are the symptoms and signs of bleeding disorders in women and girls?

- Heavy bleeding during menstruation (menstrual period) that can include:
  - Bleeding that lasts longer than 7 days from the time bleeding starts until the time it ends.
  - Flooding or gushing of blood that limits daily activities, such as work, school, exercise, or social activities.
  - Passing clots that are bigger than a grape.
  - Soaking a tampon or pad every hour or more often on the heaviest day(s).
- A diagnosis of "low in iron" or having received treatment for anemia. Anemia can make you look pale and feel tired or weak.
- Symptoms of easy or frequent bleeding may include:
  - Nosebleeds that occur for no apparent reason and last longer than 10 minutes, or that need medical attention.
  - Easy bruising that occurs with no physical injury.
  - Excessive bleeding after a medical procedure or dental procedure.
  - A history of muscle or joint bleeding with no physical injury.

If you have one or more of the bleeding symptoms listed above and a family member with a bleeding disorder (such as von Willebrand disease, hemophilia, or clotting factor deficiencies), you should arrange for laboratory testing to determine whether you have a bleeding disorder. If you have heavy periods as well as other bleeding symptoms or needed iron, admission to hospital, or a blood transfusion in the past, you should also arrange for testing.

Q. What are bleeding symptoms that are distinctive to women and adolescent girls with bleeding disorders?

- Heavy menstrual bleeding as described above.
- After menarche (your first period) or as you reach menopause (your last period), all women may experience heavier or irregular periods; this may be more marked in women and girls with bleeding disorders.
- Pain in the middle of your menstrual cycle (also called mittelschmerz, a German word that means "middle pain"). This pain occurs secondary to bleeding from the ovary at the time of egg release into the peritoneal cavity (the space within the abdomen that contains the abdominal and pelvic organs) which irritates the peritoneum (the membrane that connects and supports the internal organs in the pelvis and abdomen). Please note that this bleeding is not external or visible. In women with severe bleeding disorders, the bleeding may be severe and cause a state of shock or sudden severe pain (called acute abdomen) and require hospitalization. This is rare, but can be life threatening and require urgent medical attention.
- Vaginal bleeding during sex, unscheduled bleeding while taking hormonal therapy, and postmenopausal bleeding.
- Women with bleeding disorders are more likely to suffer symptoms of bleeding and/or pain with common gynecological conditions, such as uterine fibroids and endometriosis.
- Excessive or prolonged bleeding following a gynecological procedure or surgery.

Q. How do bleeding disorders affect pregnancy and childbirth or miscarriage?

- Bleeding can occur during pregnancy or with miscarriages.
- Some types of inherited bleeding disorders can cause an increased risk of miscarriage and loss of baby (fetus) such as severe deficiency of clotting proteins such as fibrinogen or factor 13. It is important to note, however, that for the most common bleeding disorders (carriers of hemophilia, VWD, mild platelet function defects), there is no increased risk of miscarriage.
- Women with bleeding disorders can bleed with procedures, such as spinal anesthesia, Cesarean section, and surgery to remove any remaining products of conception that are still inside the uterus following a miscarriage or termination of pregnancy. Women with bleeding disorders are also at risk of bleeding with any invasive medical intervention such as prenatal diagnostic tests (chorionic villus sampling [CVS] and amniocentesis). For those who are undergoing IVF treatment, the process of ovum collection and embryo transfer can also be associated with bleeding. These bleeding complications can be prevented with prior correction of the disorder.
- Excessive and sometimes dangerous bleeding after childbirth, called post-partum-hemorrhage, can occur. Following birth, the bleeding can be immediate (within 24 hours of birth) or delayed (24 hours to 6 weeks after delivery). Iron deficiency anemia can occur due to blood loss.
- Since bleeding disorders typically run in families, your baby may also be affected and at risk for bleeding. Therefore, you should avoid certain procedures during labor, such as vacuum or forceps delivery, or invasive fetal monitoring (e.g. application of clip to baby's head used to monitor baby's heart rate to prevent head bleeds [brain hemorrhage] in the baby). A doctor specializing in high-risk pregnancies should be consulted.
- Undiagnosed women with inherited bleeding disorders may be at risk for exposure to blood and blood products, and may experience complications such as transfusion reactions and exposure to blood borne infections.
- Excessive bleeding after childbirth (postpartum hemorrhage). Although this may occur at the time of delivery, women with bleeding disorders are also at risk of bleeding days after delivery (secondary postpartum hemorrhage). It is normal after childbirth to have vaginal bleeding similar to a period; this is called a lochia and is usually red in colour for the first 1-2 weeks, gradually changing to dark red and lightening before completely tapering off. For some women, their lochia will decrease by 2-4 weeks after childbirth. However, it is normal for lochia to last up to 6 weeks. Women with inherited bleeding disorders are at risk of bleeding for 2-3 weeks after delivery or experiencing a prolonged period of bleeding (>6 weeks). This is because clotting factors may increase during pregnancy and then return to their low baseline levels by 2-3 weeks after delivery. For women with inherited bleeding disorders, this return to low clotting factor levels may be accompanied by increased vaginal bleeding. If this occurs, medications such as tranexamic acid may be of benefit. If you have bleeding of concern, you should contact your obstetrician and hemophilia centre.

Q. How are bleeding disorders diagnosed?

Your doctor may do the following:

- Obtain a detailed personal history and family history, and perform a physical examination to check for bruises and bleeding sites.
- You may be asked several questions regarding the history and severity of past bleeding symptoms to generate a "bleeding score". This is called ISTH BAT (International Society on Thrombosis & Hemostasis Bleeding Assessment Tool). The score varies with age and sex, and the higher the value/score, the more likely it is that you have a bleeding disorder.
- In menstruating individuals, menstrual blood loss can be quantified or measured using a pictorial blood assessment chart (PBAC). Loss of more than 80 ml of blood per menstrual cycle is indicative of heavy menstrual bleeding. For those using a menstrual cup, the blood loss can be measured directly.
- Another screening tool called the Philipp tool asks a series of questions to identify which women and girls should be tested and further evaluated for bleeding disorders.
- The doctor may order blood tests that measure blood counts and iron levels, screening tests to see if blood is clotting properly, and tests that measure levels of specific clotting factors. Sometimes tests are repeated as the results may change with age or pregnancy. In some countries, specialized laboratories may offer genetic diagnosis for bleeding disorders, such as hemophilia, von Willebrand disease, rare bleeding, and platelet disorders.

Q. How are bleeding disorders treated?

There is no cure for inherited bleeding disorders. However, treatment can control symptoms or prevent bleeding.

- Hormone therapies. Hormone therapies are medications that contain female hormones, such as estrogens and progesterone; they may come in the form of a pill, patch, injection, vaginal ring, and intrauterine device (IUD). In women and girls, hormonal therapies can treat heavy menstrual bleeding or other gynecological bleeding.
- Other medications. These include desmopressin and antifibrinolytics. Desmopressin (DDAVP) is given intravenously, subcutaneously, or intranasally for hemophilia A and VWD. It increases the levels of clotting factors. Currently, some formulations of desmopressin are not available. Antifibrinolytics, such as tranexamic acid or aminocaproic acid, stop bleeding by preventing the breakdown of clots.
- Clotting factor concentrates. Clotting factor concentrates replace missing or deficient clotting factors. They are given intravenously and are used to either prevent or treat bleeding episodes. Different clotting factors treat different kinds of bleeding disorders.
- Iron supplements. Iron supplements are best taken as one tablet every other day rather than daily to boost iron absorption. If your iron levels fail to improve, you may need an intravenous infusion of iron; these are given in a hospital clinic as there is a risk of an allergic reaction with intravenous iron.

Q. What are some of the consequences and issues of untreated bleeding disorders in women and girls?

- Poor quality of life and restrictions in work, school, sports, and social activities, due to heavy menstruations every month.
- Anemia which leads to fatigue, and further negatively impacts quality of life.
- Need for blood transfusion.
- Bleeding in other parts of the body, such as joints, head, ovaries.
- Hysterectomy and other surgery to control heavy periods.

Other issues include:

- Fear of stigma associated with having an inherited disorder is often a barrier to testing.
- Financial burden of heath care and laboratory tests, which may result in diagnostic delays.
- Period poverty due to inadequate access to and cost of sanitary products. It may negatively impact education, causing girls to miss or drop out of school.

Q. What to do if you suspect you or someone you know may have an inherited bleeding disorder?

- The first thing to do is to seek medical care, either from your own doctor or an obstetrician gynecologist, and request referral to a hematologist (a doctor who specializes in blood diseases).
- A variety of treatment options are available, not only for controlling heavy menstrual bleeding, but also as contraception, such as the pill and placement of a hormonal IUD. Note that hormonal therapies while often used for contraception, have a valuable role in controlling excessive menstrual bleeding. These may be recommended by your health care professional, to reduce menstrual blood loss, even if you are not sexually active.
- Your treatment center may have access to a genetic counselor to help with antenatal counselling or prenatal diagnostic testing in the event you are pregnant or planning on becoming pregnant.
- Geographic accessibility, financial accessibility, and availability of care may be a challenge in some countries. The doctor or specialist can either see you in person, or in an outreach clinic or by telemedicine (virtual or video visit) if you live far away. Please see the World Federation of Hemophilia Treatment Center directory at http://www.wfh.org to locate a center close to you.
- If you have a bleeding disorder and need to attend the emergency department, make sure to bring with you a letter or card with details of your bleeding disorder from your Hemophilia Treatment Center (HTC) or specialist. Not all doctors are familiar with the specific needs of people with bleeding disorders, so do not be afraid to advocate for yourself. Inform your HTC that you are attending the hospital so they can communicate with local doctors and provide advice.
- Many doctors and health care providers may not be familiar with bleeding disorders. It is often intimidating to let medical professionals know that you suspect that you have a bleeding disorder. In that case, you may want to seek support from your national/local HTC or health center.

- If you have access to a computer or smart phone, you can download information and share it with the health care team.
- Laboratory tests may not be available in your village or town, and you may have to travel to a city to access a laboratory.
- Treatments such as tranexamic acid, aminocaproic acid, and hormonal therapies may be used to stop bleeding without waiting for a lab test. However, treatment with factor concentrates may require knowing which factor is missing.

Additional Resources

1. Centers for Disease Control and Prevention (CDC), HHS
   www.cdc.gov/ncbddd/blooddisorders/index.html
2. European Haemophilia Consortium
   https://www.ehc.eu/bleeding-disorders/women-with-bleeding-disorders/
3. Foundation for Women and girls with blood disorders.
   www.fwgbd.org
4. Hemophilia Federation of America
   https://www.hemophiliafed.org/home/for-patient-families/resources/toolkits/women-bleed-too-toolkit/
5. National Hemophilia Foundation
   https://www.hemophilia.org/bleeding-disorders-a-z/overview/women-and-bleeding-disorders
6. Office on Women's Health
   https://www.womenshealth.gov/a-z-topics/bleeding-disorders
7. World Federation of Hemophilia
   https://elearning.wfh.org/elearning-centres/carriers-and-women-with-hemophilia/

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GEN IX TEEN MENTORSHIP 2021:

BACK TO THE FUTURE

BY ROCKY WILLIAMS

Since 2014, the Generation IX Project has provided members of the hemophilia B community with immersive learning experiences that are both educational and electrifying. This year's Gen IX Mentorship program, held virtually in May, continued in this tradition. The Coalition brought together teens, and mentors for hands-on activities, interactive play, and for loads of fun! The program was presented in cooperation with GutMonkey, a company that specializes in innovative and engaging experiential learning. The entire event and all "Gen IX" Project programs are made possible through the generous support of Medexus Pharma.

According to Joe, one of the mentors, "Gen IX's Mentorship is about meeting other people with hemophilia and pushing their comfort zone so they grow as people." Another mentor, Marcus, said, "Gen IX means everything to me, ever since the first one in October of 2014. Something that keeps me coming back is the educational element of the programs. Each time there's something new to be learned and the way they teach it to us never gets old. There's always a new twist to it."

The event was a blast! You could even say it was a "Blast from the Past!" Before the program started, participants received exciting boxes of supplies and goodies to use throughout the program. We got the show on the road with a "watch party" inspired by this year's nostalgic program theme, "Back to the Future." Participants had an epic movie night watching the classic film together.

The theme emphasized and supported the ideas that:

- Anything is possible
- You can change
- You are limitless

The program was jam-packed with activities including some "choose your own options," including creating art. In the afternoons, we brought everyone together for lunch breaks and for time to just move about. GutMonkey staff explored and shared stunning views of the trails of Sunriver in Oregon. It was such a cool way to get immersed in the camp setting from the comfort of home.

Evenings were spent exploring the contents of our activity boxes which included decorations to deck out our spaces like a "Back to the Future" dance party. They included a multicolor strobe light. In a way, we were able to create our own Back to The Future Dance. We called it "The Lysol Boogie Down - The Future is Now!"

The boxes also included materials to create a time capsule such as disposable cameras and materials to write a letter to yourself. Mentors wrote down answers to questions such as “what are you snacking on,” “what are you listening to,” and “what’s your favorite thing to wear right now?”

Another favorite activity was a “bead project.” Each participant received a unique bead and shared what they consider to be their “superpower.” We imagined infusing these beads with these incredible powers. When holding that color bead, another participant would think of the person who had that unique bead. In this way, group members could connect to and share about these powers when wearing their friends’ beads.

The late evenings were centered around the campfire. GutMonkey staff set up a beautiful, controlled fire in Sunriver and hosted games, snacks, and hang-out time. Mentors and mentees alike connected around the fire and shared stories and fun.

On Friday, the teens joined the mentors for a variety of activities including morning stretch, virtual rollerblading through Sunriver, and a lesson in create a delectable cheese board.

That night’s full-group program included creating a playlist for the dance party. We divided into three “houses” known as the House of Honey Badgers, the House of Martok, and the House of Flair. Everyone set up and decorated their own rooms and created a brag board about something they are proud of. All participants shared their strengths and accomplishments with each other.

The group got back together for a collaborative game with lots of captivating puzzles and a discussion of what they want their futures to look like. The evening ended back at the campfire, with games, snacks, and a good time!

Saturday morning’s activities included pancake making and more “get-to-know-you” games. These were followed by a day full of guided activities around the themes of “Back to the future” and teen/young adult life in the Hemophilia B community. Participants decorated their “Deloreans,” and talked about how they were feeling and where they are going.

The final activity was a virtual bike ride from Sunriver to Lava Lands, Oregon. If you’ve ever wondered what an old lava field looks like, or how to change a bike tube, this was the chance to learn! It was a very serene way to bring such a dynamic and warm experience to a close.

Mentors and teens alike gave feedback on the program afterward. Mentor Brian said, “I enjoyed feeling engaged with the community and how approachable it was. I think the group was a good size where it doesn’t feel overwhelming to speak up and small enough to get to know people. It helps that there were a good number of familiar faces too that I haven’t seen in a while. The times were convenient and having them in two-hour stints made me feel engaged.”

Ryan, a teen mentee, said, “The thing I like about the Gen IX Mentorship is that all the people in the Gen IX group get what it is like to have hemophilia and how hard it can be sometimes to treat it. What the Gen IX program means to me is that having hemophilia doesn’t stop me from having fun! I learned that I’m not the only one in the world that has a bleeding disorder, and that I can help people in my life understand how hemophilia works and how it affects me.”

Thanks again to GutMonkey, our program partner, Medexus Pharma, our sponsor, to all our mentors and mentees, and of course to our CHB staff. Looking forward to seeing even more of you at our next program!

MEDEXUS PHARMA

Coffee with Friends

BY ROCKY WILLIAMS

There's nothing like a friend and a good cup of coffee. That was the idea behind the Hemo B Coffee Hour, which brought small groups of community members together on weekday mornings for a cup o' joe, some gentle movement and stretching exercises, and an opportunity for creativity, reflection and connections!

The Hemophilia B Connection Club also convened over the summer. This virtual series gave community members and significant others opportunities to gather for fun icebreakers, a relay race, a "handshake game" and many more.

We'd like to thank Medexus for sponsoring both programs, and GutMonkey, our programming partner, for their wonderful session development and facilitation. Stay tuned for more programs throughout the fall.

New Parents

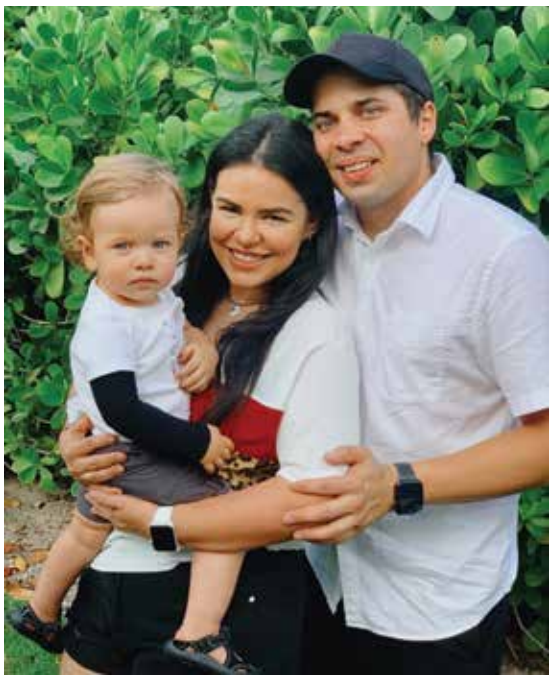
BY CASSANDRA (mom of two-year-old Clyde):

Becoming the parent of a child with hemophilia can be scary, overwhelming, and isolating. Fortunately, there are other parents who have already walked the path and are willing to help new parents. On June 12th, a group of parents of children with hemophilia B gathered to make new friends and offer each other support. The interaction between seasoned parents and new parents created a wonderful and deep bond that will last for years to come.

One mom said, "Now your babies will become friends." The impact the seasoned moms had by sharing what they have gone through and letting new parents know "it's going to be okay" was very empowering. Parents were able to connect by sharing stories that only those who have had such a similar experience would be able to understand and relate to. The seasoned parents also gave everyone a sense of perspective and hope.

When parents connect, this hidden gem becomes obvious, and a great amount of strength and courage, as well as practical knowledge, can be drawn from it, transforming these challenges into a source of confidence, resiliency and connection.

Stay tuned for more gatherings!



Dipping Our Toes In The Water

BY ROCKY WILLIAMS

On Saturday, June 26, The Coalition for Hemophilia B hosted a *Refresh, Revive, Rejoin Virtual Summer Party*. To get everyone in the summertime spirit, participants were sent cool mixer recipes, some of which were provided by their fellow participants! The Coalition also collected favorite summer songs to put together a "rockin' summer playlist."

Attendees were encouraged to wear their favorite summer outfit or hat. Representatives from the Coalition and Medexus, our generous sponsor, demonstrated how to put together quick and easy summer recipes. Fel, one of the participants, demonstrated how to make a mean mojito, and Milinda fried up some Oreos. The evening was capped off with fun and informative Kahoot trivia games and raffle prizes!

REGISTER TODAY!

RETREATS ARE ALL VIRTUAL NOW!

WOMEN'S WINTER EDUCATION & EMPOWERMENT RETREAT

DECEMBER 3-5

DEADLINE TO RECEIVE BOX: NOVEMBER 18

MEN'S WINTER EDUCATION & EMPOWERMENT RETREAT

DECEMBER 10-12

DEADLINE TO RECEIVE BOX: NOVEMBER 26

212-520-8272 30 YEAR ANNIVERSARY THE COALITION FOR HEMOPHILIA B **HEMOB.ORG**

FOR MORE INFO & TO REGISTER: HEMOB.ORG/PROGRAMS-EVENTS

The Coalition for Hemophilia B understands there are families within our bleeding disorder community who feel the effects of the current economic situation. While the Coalition will also contribute to this fund, we ask our more fortunate Factor Nine Families to help us by making a financial donation to the Factor Nine "Holiday Fund" to help buy gifts for children with hemophilia.

To make a donation,
please send a check payable to:

The Coalition for Hemophilia B "Holiday Fund"
757 Third Avenue, 20th Floor
New York, NY 10017

Please respond by **November 24, 2021**
so Factor Nine Santa can load his sleigh with holiday gifts for all good girls and boys!

For families in our community in need of a little holiday cheer, we would like to help put something under the tree for your children! Fill out this form and send it to Santa's special elf, Kim, at the "East" Pole. Factor Nine Santa has a busy schedule, so please send this form no later than **November 24, 2021**. Your name and information will be kept strictly confidential. Send mail this form to:

The Coalition for Hemophilia B Holiday Cheer
757 Third Avenue, 20th Floor; New York, NY, 10017

Name: _____

Street Address: _____

City, State, Zipcode: _____

Phone: _____Email: _____

We wish you all a beautiful holiday season filled with love, happiness and good health!

Please give an exact description of your child's wish item.
Gifts will be purchased and sent to your home.
Please note which child is affected by hemophilia B.

Child's Name and Age:	Child's Name and Age:	Child's Name and Age:
_____	_____	_____
Wish List:	Wish List:	Wish List:
_____	_____	_____
_____	_____	_____
_____	_____	_____

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:

Website: www.hemob.org

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Linkedin: https://www.linkedin.com/company/coalition-for-hemophilia-b/

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

I've Got a Bad Feeling About This… And That's Awesome!

Dylan's Story

AN INTERVIEW BY RENAE BAKER

"Ever since I was little, I've wanted to be an actor or director, but now – with the pandemic – I don't know," Dylan says. It's true that the entertainment industry was hit hard, but where there's a will, there's a way. And Dylan has the spirit to apply the same can-do attitude he practices daily, living with "really severe hemophilia B," to his passions.

"Ever since I was little, I've wanted to be an actor or director, but now – with the pandemic – I don't know," Dylan says. It's true that the entertainment industry was hit hard, but where there's a will, there's a way. And Dylan has the spirit to apply the same can-do attitude he practices daily, living with "really severe hemophilia B," to his passions.

For as long as he can remember, Dylan has been role playing. "Mostly superheroes, Sponge Bob and Star Wars characters," he admits. Though he is a self-professed introvert, many of Dylan's classmates consider him a superhero. During his 16 years, he's had seizures, blood transfusions and life-threatening anaphylactic reactions to medication. He's had four port surgeries due to recurring infections. He's had ankle and knee surgeries, and at times, he was hospitalized for pain management.

Despite the torment and disruptions in his life, Dylan has a reputation for being an exceedingly happy person. Perhaps his superpower is the ability to focus on the positive. That's no small feat when one considers the frequent flyer miles Dylan has racked up as a guest of The Phoenix Children's Hospital. "I basically had two homes

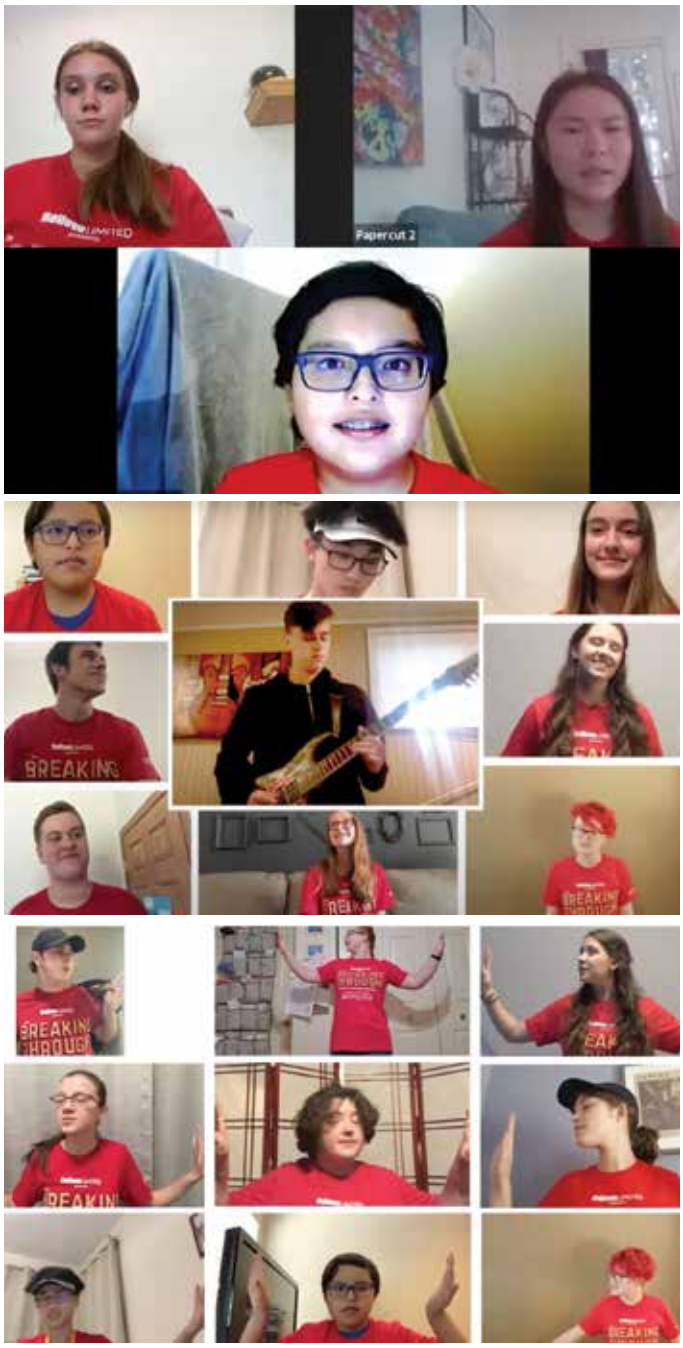
when I was little: here and the hospital," recalls Dylan from his Arizona family dwelling. It seemed to him he spent as much time, or more, in the hospital as he did at home with his family. He spent birthdays and holidays there. He did his homework there. One year, he created a solar system for a school art project, which hung above from the hospital ceiling. His friends sent him light saber and other Star Wars-themed cards, which helped Dylan feel connected to them while he was away.

Another positive focus Dylan has leaned is music, "I used to play violin, but I kept getting shoulder bleeds." Now, he sings in the choir at school and sometimes picks up his Aunt Melissa's guitar. Aunt Melissa has inspired Dylan with her musicality and drive to express herself through music.

2011 was a red-letter year for Dylan and his family, "A year never to be forgotten," as he calls it. Dylan was six-years-old and spent so much time in the hospital that neither he nor his mom, Michelle, can remember how many trips they made. They agree it was upwards of 20 visits, with at least 10 of them being hospital admissions. But 2011 was also the year Dylan's family discovered The Coalition for Hemophilia B and won the lottery to attend the Coalition's Symposium being held in New York City. The Arizona native found that although the city's early March temperatures were "really cold," the experience very exciting. They got to see Carnegie Hall, where Aunt Melissa sang in 2001.

2011 was also the year Dylan was given a Make-A-Wish experience. What did he wish for? "A Jedi experience," Dylan reveals. "It was at Disney World and I got to meet the voice actors for Obi Wan Kenobi, (James Arnold Taylor, from the animated features,) C-3PO (Anthony Daniels, from the films and TV shows) and Ahsoka Tano, (Ashley Eckstein)."

"I was sitting, talking to my dad," Dylan remembers, "And all of a sudden, I heard this voice in my ear, and it was Obi Wan! Obi, quoting his famous line from the movie said, 'I have a bad feeling about this!'" The decade-old memory is still fresh and thrilling to him. The stars of Star Wars sat down and hung out with Dylan. Perhaps it was the experience of hanging out with these heroes that gave him the courage to begin



learning to self-infuse at age seven. Through The Coalition for Hemophilia B, Dylan was able to meet another role model, James Patrick Lynch, who wrote and directed *Hemophilia The Musical* in New York City in 2018. Last year, Dylan auditioned for and was cast in the pandemic adaptation, *Hemophilia The Zoomsical*, also directed by James Patrick Lynch. The experience demanded discipline, early and long hours of rehearsal, and sometimes pushing through the pain of bleeds during rehearsals.

Through the Coalition, Dylan had the opportunity to meet and hang out with Chris Bombardier, the first person with hemophilia B to climb to the summit of Mt. Everest. Bombardier was one of many who has given Dylan the best advice he's ever received – "Never give up on your dreams."

To that end, Dylan aspires to put his talent, life experience and positive attitude to good use by becoming a motivational speaker in hospitals once the pandemic passes and guests are allowed to visit again. He wants to tell his story and emphasize to other young people how important it is to take their medicine as prescribed. He wants to encourage them to persevere through their rough times by sharing the stories of his own rough times through which he endured.

Dylan says The Coalition for Hemophilia B has given him awesome moments. In addition to the trips and meeting inspirational people, he loves meeting all the hemophilia B patients. "I knew a lot of A's, but it was through The Coalition for Hemophilia B that I first met B's. The men were so encouraging. I like how they called me their *Little B Brother* and gave advice on how to take care of myself. It felt like family."

For Dylan's 11th birthday, all he wished for was to get his port removed and to self-infuse into his arm from then on. He met that goal and although he still struggles now and then, he perseveres. He has it on good authority if he sets his sights high and hangs in there, he will reach summits and hang out among the stars. Through laughter, Dylan recalls his many camp experiences where he found himself in the infirmary or the hospital, and how he continued to return to camp, even winning awards for self-infusing and his positive spirit.

His best advice to other teens? "Just keep trying different things and see what you're passionate about. When you discover that *thing* you're passionate about, go for it! Even if you get knocked down, don't give up, just get back up!"

An Unconventional Adventure

BY ELIJAH

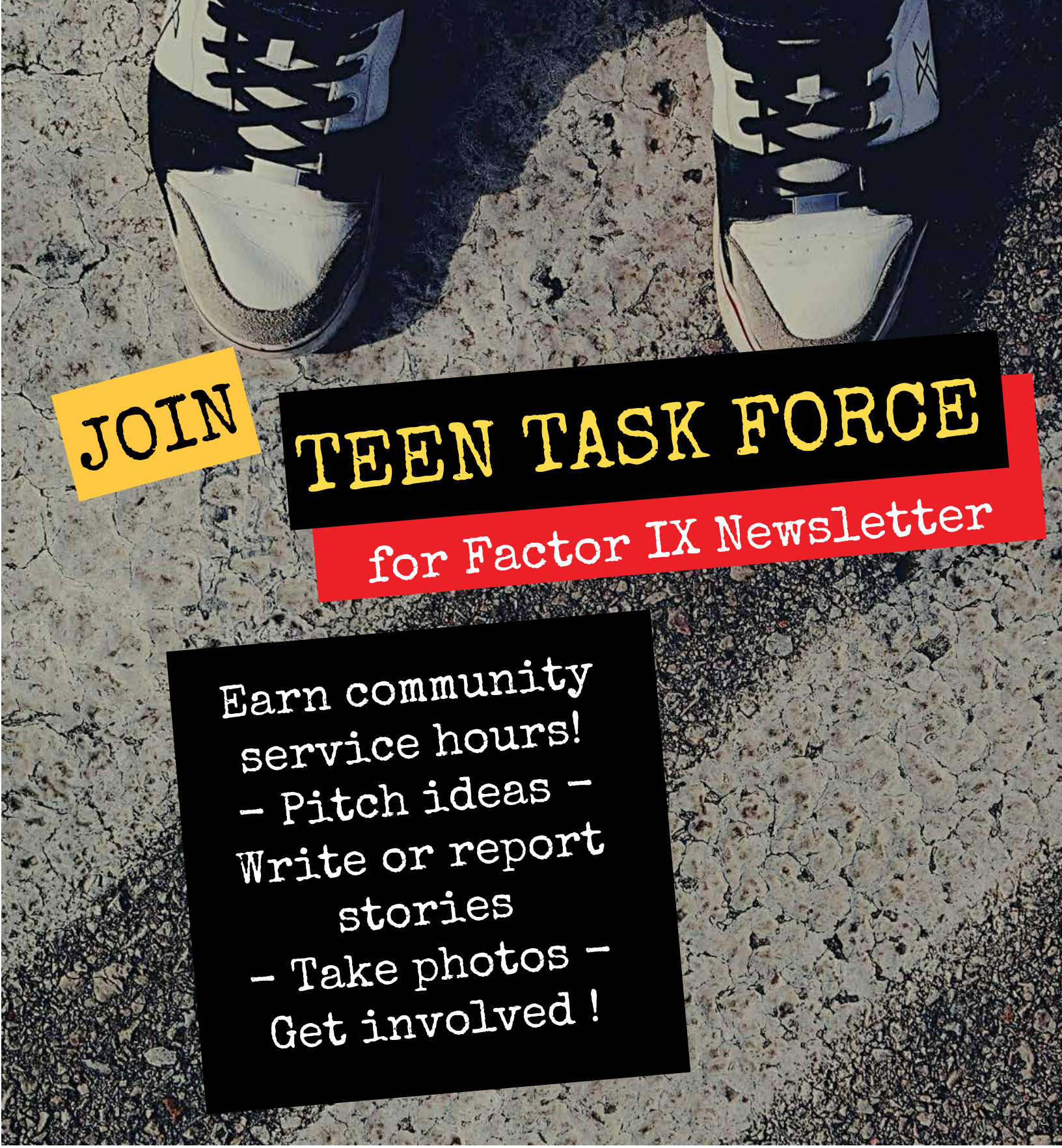
Every year, the New Covenant Academy Senior Class of Springfield, Missouri, goes on a mission trip to a Central American or a Caribbean country and helps with a service project, such as building a house or organizing a Vacation Bible School. However, my senior class had to do things a little differently due to COVID-19 restrictions. It was a rather unconventional trip, but it was unforgettable, nonetheless.

Deciding on a place to go was very limited under the pandemic's circumstances. After overcoming many obstacles, it was decided that we would stay in the United States and work with an organization called Frontline Response in Atlanta, Georgia. In preparation for the trip, our school was able to gather toiletries and other essentials to be put into care packages to donate to Frontline. Those packages would then be given out to homeless people in the Atlanta area. The class (which only consisted of about 32 students, plus seven sponsors) rented four vans and drove down to the camp where we would stay, which is just outside the city. We got there Monday evening, and that night we had an overview of what we would be doing.

Tuesday was filled with homeless outreach. Each van would take a different route through Atlanta and would hand out the care packages, sack lunches, and blankets. While we were there, it was raining. We came across one man who was only asking for an umbrella. One person in my van had brought their own personal umbrella and passed it up to be given to the man. That action turned into a new item being added to the list of what would be given out to homeless people. The next day, our class bought as many umbrellas as we could and gave them out that night.

The latter half of the week was filled with children's outreach, where we would play games with kids and give their parents a break, as most of the schools in Atlanta were virtual and many parents were also working from home. We also helped give out groceries to families who were struggling to make ends meet, as well as picked up trash around the neighborhoods. It was heartbreaking to see how much trash that had been dumped on the sides of the streets and how no one except Frontline was doing anything to help clean it up.

During my time in Atlanta, managing my hemophilia was not too difficult. The last night we were there, I did my infusion on a picnic table, with my friend holding a flashlight to help me see exactly what I was doing. Part of having this disorder is learning to improvise, and that skill came in especially handy during the planning and execution of this mission trip. Whether it was abruptly changing plans in order to stay in the U.S. or spontaneously buying umbrellas to give to people that cannot afford one, being able to adapt was a key part in making that trip one that I will never forget.



JOIN TEEN TASK FORCE

for Factor IX Newsletter

Earn community service hours!
- Pitch ideas -
Write or report stories
- Take photos -
Get involved !

Join The Coalition for Hemophilia B Teen Task Force! Email Rocky Williams for more info: Rockyw@hemob.org

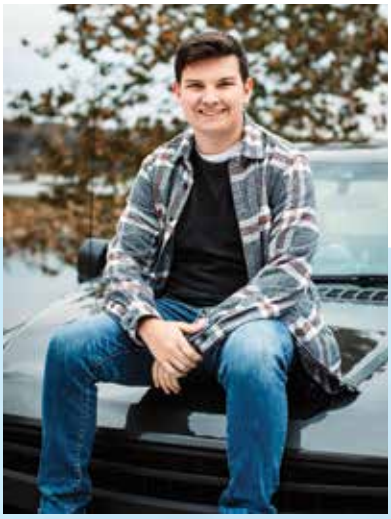
B inspired!

Stories and artwork from teens in the Hemophilia B Community

Summer 2021

IN THIS ISSUE:

I'VE GOT A BAD FEELING ABOUT THIS, AND THAT'S AWESOME! DYLAN



AN UNCONVENTIONAL ADVENTURE: ELIJAH

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!