



Factor Nine News

The Coalition for Hemophilia B

SUMMER 2020



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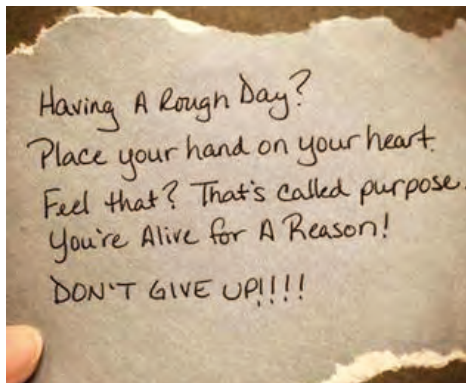
Infuse With Hope - Page 2



Infuse With Hope

BY RENAE BAKER

Hope Woodcock-Ross, RN BSN smiles at me through her phone's camera from the driver's seat of her parked car. It's 8:00 am. She's wearing cheerful, bright blue hospital scrubs and she's ready to squeeze in an interview before a full day of work.



When you meet Hope for the first time you feel as if you are “home.” You feel embraced as her caring, blue eyes look into yours. You feel her warmth as her gentle smile welcomes you. Indeed, all those lucky enough to know Hope are fully embraced. With Hope, there is no judgment. She truly loves what she does and deeply cares for our community. Her reputation for caring, instilling confidence and changing lives precedes her.

Yes, Hope Woodcock-Ross has super powers she modestly calls “IV skills.” She gifts us with her time, patience and commitment to our success. No one who tries to learn to infuse with Hope ever walks away feeling bad. She will point out all of their little successes along the way. Some have success right away, and others may take a little more time, but they walk away feeling determined and confident. No one fails with Hope!

Many members of The Coalition for Hemophilia B are grateful to Hope. Whether they met her at one of many coalition events, at the hospital or at camp, chances are they either learned to self-infuse from her or gained confidence in their abilities to infuse through her nurturing guidance. They have likely also received life-saving advice from her. “If you’re thinking about calling me, you should probably treat,” she tells her infusion trainees. “Even small bumps can cause long-term damage.”

The Coalition’s VP, Kim Phelan, says of Hope, “We are all the better for having a nurse with so much passion about what she does and compassion for all in our community! It was an honor to present Hope with the well-deserved 2019 Eternal Spirit Award for her many years of dedication and service to our community.”





A nurse for 30+ years, Hope explained that it was her IV skills that first led to her working at the UHS Blood Disorder Center in Upstate New York. The Center, which is a blood disorder treatment center, worked in coordination with the UHS Medical Center at which she was employed, to perform outpatient transfusions for oncology patients. Her skills were noticed, and she was offered a job at the Blood Disorder Center where she eventually became the nurse manager. Later, she began employing her IV skills at the HTC/Outpatient Infusion Center. It was there that her nurse manager suggested that she volunteer at Camp High Hopes, a summer camp for boys aged 7-17 who have bleeding disorders. She did, and it would prove to be a turning point in her life.

Seeing the ways the boys at High Hopes embraced their summer camp experiences and leaned on their blood brothers touched Hope. Giving “wings” to these young people became her passion, and she expanded her range and ability to help the hemophilia community by cofounding Camp Little Oak, the only stand-alone, all-girls camp for girls aged 7-17 with bleeding disorders. Camps Little Oak and High Hopes are not-for-profit 501(3)(c) organizations for which Hope volunteers. She doesn’t get paid.

“When I worked at UHS Wilson, I had to save 80 hours of vacation time to attend, plus promise my coworkers that they could have any other vacation time they wanted,” Hope asserts with a determination that reveals her intense devotion to the bleeding disorders community.

Perhaps it’s stories like that of Ben that keep her spiritually tethered to this community and The Coalition for Hemophilia B. At seven years old, Ben was attending the symposium, and waiting to spend time with the nurse

“ Giving “wings” to these young people became her passion... ”

who would teach him to infuse. He had heard about how nice she was, and that she had a fake arm to practice on. When it was his turn, he took a jab at the practice arm and then Hope had him try infusing a saline solution into his mom and dad. Then it was time to take that big leap to infusing himself. He tried... Nope. He tried again. It wasn’t happening for him yet. Young Ben was getting frustrated, but Woodcock-Ross’s skills go beyond IV infusion.



Perhaps her greatest skills lie in the infusion of confidence into her trainees. Hope gently praised Ben. "It's OK," she said. "What you accomplished today was a good start! Don't give up. Just keep on trying." Later that day, during Hope's infusion event at the symposium, Ben saw a woman with bad veins poke herself six times, and he said, "If she can poke herself six times, I can poke myself once." He tried again, and this time he was successful!

Seasoned self-infusing bleeders like the woman Ben witnessed will generously demonstrate their process at Hope's infusion table at The Coalition for Hemophilia B events. Hope is a big advocate of watching others infuse because, "They may do things differently than you do, and you can ask them why and learn something that might work for you too." "There is nothing more amazing, to me, than to see a child or parent infuse for the first time and realize that, as afraid as they are, they can do it," Hope says, nodding her head with a satisfied smile.

Elizabeth VanSant's story continues to touch Hope as it unfolds. At sixteen years old, Elizabeth met Hope at the Eternal Spirit Award Dinner. She was getting anxious about the fact that college was right around the corner, and that she still had a port. She felt an urgent pressure to learn how to self-infuse. Hope encouraged Elizabeth to attend Camp Little Oak. The idea made Elizabeth nervous, but the idea of Elizabeth not knowing how to self-infuse while living so far from away from a bleeding disorder center made Hope even MORE nervous. Hope persisted in her encouragement, and Elizabeth decided to go for it.



a needle in your arm, or look to me that way, or I'm gonna have to worry!" It's a camp favorite. It's funny even to the kids who don't fully understand the reference, but more importantly, it helps the kids understand that their fear is normal. There is nothing to be embarrassed about. It helps them to relax and become more confident as they step outside of their safety zone.

Elizabeth continues, "She was such an instiller of confidence. These lessons have stayed with me, and I am forever grateful for her." As it did with Hope, camp became a passion for Elizabeth. Following in her mentor's footsteps, Elizabeth takes time off from her year-round work as a music therapist to volunteer at camp and Coalition events whenever she can. Here and there, members of the Coalition will see Elizabeth and Hope teaming up to teach infusion skills and inspire others. What do they teach the girls at Little Oak? "To not let yourself be held back just because you're a girl." Hope

“ ...it's about helping them get over the nervousness of sticking a needle in their arm. ”

"Hope is the reason that I fell in love with camp and was able to self-infuse," she said. "It was all so much fun, but Hope really put the experience over the top for me. That's because of how she was able to talk to me about self-infusing. She gave me mantras like, 'Hemophilia sucks, but I'm gonna kick its butt!'" Elizabeth found her confidence through these mantras and was soon able to overcome her fears.

"Infusing isn't really that hard." Hope says. "When you're teaching someone, it's about helping them get over the nervousness of sticking a needle in their arm. At camp, they're all scared. Anyone doing it for the first time kind of freaks out a little bit, and I'll look right at them, and I'll say, 'The minute you like sticking a needle in your arm is the minute I check you into rehab.'" She delivers this with a wry smile. "So you better never tell me that you enjoy sticking

emphasizes to the girls that, "You can be smart and sassy, do well at STEM and still do your arts and crafts and paint your nails! We teach them to be strong; to voice their opinion and go for what they want. We teach them to stand up for themselves. We teach them that they matter. We teach them to surround themselves with people who care."

I asked Hope if there was a need that she would like to see filled in the bleeding disorder community. Without hesitation, she said, "Hope emphasized the importance of female bleeders, getting a proper diagnosis and treatment. It's important to look beyond the lab values to the actual ways in which female patients bleed, because this has a profound impact on their lives. If not picked up on and diagnosed and treated properly, bleeds can have long-term, devastating results.

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

Rebiny® elevates factor levels above your normal levels^a

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

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

With a single dose of Rebiny® 40 IU/kg in adults with $\leq 2\%$ FIX levels^a

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

Achieve higher factor levels for longer
Compared with Alprolix^{®c}, Rebiny® provides

4x greater factor coverage

6x

higher factor levels at 7 days

Image of hemophilia patient shown is for illustrative purposes only.

^aIn a phase 3 study of adults, single dose pharmacokinetics were tested during the first Rebiny® 40 IU/kg dose in 6 adults.

^bBased upon a 2.34% increase in factor levels per IU/kg infused in adults.

^cBased upon a phase 1 study comparing a single 50 IU/kg dose of Rebiny® 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 Rebiny® Coagulation Factor IX (Recombinant), GlycoPEGylated?

Rebiny® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebiny® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebiny® when you have surgery. Rebiny® 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 Rebiny®?

- 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 Rebiny®.

Who should not use Rebiny®?

Do not use Rebiny® if you:

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

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

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 Rebiny®?

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

What are the possible side effects of Rebiny®?

- 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 Rebiny® 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.

Rebiny® 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 rebiny.com and connect with your local HCL



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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 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>

Manufactured by:

Novo Nordisk A/S

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COMMUNITY – A KEY INGREDIENT FOR THRIVING WITH HEMOPHILIA B MANNY’S STORY

“My parents are the reason that I’m here today. If they hadn’t been willing to fight so hard for my life, I don’t know what would have happened to me.”

Speaking those words clearly energizes Manny who was raised in Puerto Rico by a hard-working, relatively poor family. It’s Manny’s gratitude and love for his parents that gave him the fortitude and desire to persevere through some excruciating, seemingly unendurable times.

Manny was diagnosed with hemophilia B as an infant. He is the only one in his family who has it. The nearest hospital ER was a two-and-a-half-hour drive away. Back then, the roads were underdeveloped on the island, and when Manny had a bleed, they’d have to make that long drive on bumpy, winding, narrow mountain roads; sometimes late at night.

“We had a fairly big extended family,” His mother’s side was small. “Mom’s parents were extremely involved in my care.” Manny says, with gleaming eyes.

Manny’s father was one of a whopping seventeen children. His siblings and their families were more well-off financially, but Manny and his parents felt like the ugly ducklings by most of them. We needed their support with my hemophilia care and most of them acted like they didn’t care.” It was hurtful. There were two aunts who did care. They lived near the hospital. One of them opened her home and kitchen to them whenever Manny was hospitalized. Sometimes Manny’s mother needed to stay for weeks while Manny had extended hospital stays.

“My mother didn’t drive and my father had to work, so when I had a bleed, he would drive us to the hospital and turn back and drive the two and a half hours back home



to work. My aunt’s husband would drive my mom back and forth from the hospital to my aunt’s house to sleep, shower, shop or whatever she needed and then drive her back to be with me at the hospital. His wife would send food with him for us.”

When Manny was about 5 years-old, his parents began to hear about home infusions. “They weren’t a thing in Puerto Rico yet, and resources were scarce, so it took a lot of advocacy on my parents’ part. They had to work hard to convince the doctor to let them do home infusions.” However, they persisted and were able to

start infusing at home.

“Not having to go to the ER for an infusion was a life-changing experience, I remember poking multiple times trying to find a good vein took a long time! Those were really rough and exhausting days!” After years of watching my parents do my infusions, when I was in eighth grade, I decided to try it myself. I was successful and continued doing my own infusions from then on.”

Manny and his parents moved to the mainland USA from 1999 through 2007. They found that the mainland had better products and care than they were able to get in Puerto Rico. Manny attended middle and high school in Erie, Pennsylvania, and became very involved with the hemophilia community in the states.

“I went to a lot of educational events and did a lot of other things with the community,” he remembers. While attending high school, he had the opportunity to apply to a 3-year culinary arts program.



In Puerto Rico, cooking was a big part of the culture, and his mother taught him how to cook. In Puerto Rico, Manny recalls, there was no stereotype against boys and men cooking and helping around the house. “In our household,

we did everything. Dad would say, ‘The only thing you can’t do is get pregnant!’” Manny laughs. “Other than that, you can do everything.” We did everything from working on cars to sweeping and mopping the house.”

“I was accepted into the vocational culinary program and really enjoyed it. I became a really big fan of Emeril Legasse. I loved watching him make all those wonderful dishes.” Manny developed a passion for cooking and decided that it was his dream to become a chef like Emeril. He was accepted but two things crushed his dream. “I just couldn’t afford it and my main concern was my hemophilia being on my feet for 15 to 16-hour days, and I wondered how I would be able to control bleeds.”

Manny gave up his dream. Realizing that he wouldn’t be able to pursue a career in the culinary arts triggered, in him, an inner rebellion against hemophilia. To

Manny, it felt like the rug was pulled out from under his feet. “I entered what I call my ‘hemophilia dark ages’, when I felt angry at my life and angry at my hemophilia. I was rebellious about the idea that hemophilia was here to stay and not going anywhere. I was lamenting ‘Why me? What did I do to deserve this chronic disease that frequently pulls the rug out from under my feet and makes me trip and makes me hurt?’”

Manny and his parents moved back to Puerto Rico, and he entered college to study business, but he shares, “I was still angry and stopped taking proper care of myself. There was a hemophilia chapter on the island, who tried to connect and educate community members, but unfortunately, I chose to step away from that. I didn’t want to be involved. So, I became stagnant as an individual. I just chose not to connect. I had moments of frustration when I just didn’t want to infuse. At one point, it was almost an entire month that I didn’t infuse. It wasn’t until I had a major ankle bleed that I gave in and treated.”

“I was still angry and stopped taking proper care of myself.”

In spite of his depression, Manny moved forward with his college education and received his degree in business, but things in Puerto Rico were financially difficult. Manny found himself on the unemployment line. Then – a glimmer of light – he found a federal aid program that would help him put his business mind and his culinary skills to work. Through this program, Manny received an 8x6 foot trailer intended to be used as a food cart. He started “Manny’s Quick Stop,” and he cooked burgers, hot dogs, breakfast and more for locals working in the downtown area.

“I did well my first two years, but then the economy tanked.” Manny found himself struggling again. “I was getting up really early and going to work with bleeds.” Faced with multiple obstacles, it all became too much for Manny. “Those were the hardest days of my life. I’d put so much work into it, but I couldn’t save the Quick Stop.” Once again, he felt the rug being pulled out from underneath him.

Then, three things happened that would work together to turn Manny’s trajectory around and point him back to the hemophilia community. “With perfect timing, a friend of mine contacted me to tell me he was opening a specialty pharmacy and had a part time position for me. The pharmacy believed in me when I didn’t believe in myself. Then I received a letter from the HTC about The Coalition for Hemophilia B’s Generation IX program. I was the first person to fly from Puerto Rico to the program, which was being held in Oregon. It was a LONG trip!” recalls Manny. “It was my first time visiting the west coast. I was like,

‘Wow! What is this? Who are these strangers picking me up from the airport and driving me who knows where?’”

Those strangers were Kim and Chris from

The Coalition for Hemophilia B. Manny remembers, with grateful incredulity, how kind, welcoming and helpful they were to him. “They didn’t simply worry about getting me to the program in time; they made my time there special. They picked me up, took me to the hotel room they’d arranged for me, and provided me with food the next morning before I met the others at the program.” Manny looks back on that experience and credits the GEN IX program and The Coalition for Hemophilia B for being one of the catalysts for his deep involvement with the bleeding disorders community. He greatly appreciates the warm welcome and generosity that he received from the Coalition and does all he can to pay it forward to other community members and society members alike.

“While attending Gen IX, Pat Torrey asked us, ‘If someone asks for your help, would you immediately help them?’ Everyone in the room raised their hand, ‘Oh yeah, I’d totally help.’ ‘If you, yourself, needed help, would you actually ask for help?’ An eighth of the room raised their hand.”

Manny is still incredulous at the truth of this he knows from first-hand experience. He also credits Torrey with the image of the patient at the center of a wheel, and all of the resources, helpers and people the patient can draw upon surrounding him; social workers, infusion nurses, doctors, partners, physical therapists and friends from the community. Manny is able to imagine himself as a chef in the center of the wheel, and the helpers all around him are the spices he can use to create a more flavorful and enjoyable life.

Manny now acknowledges, “If you don’t have support people to depend on, you could fall into that dark space for a long time and have depression and anxiety, which is already a part of what we live on a daily basis, so having people to help me pull myself out was crucial. The individual with the bleeding disorder really needs to depend on multiple people and multiple sources. If they don’t lean on them, they will struggle. Maybe they just don’t realize it, but this community will help in a heartbeat!”

“It is the reason the Coalition for Hemophilia B and Generation IX will always have a special place in my heart, and why I’m so committed to giving back to the Coalition as a mentor,” he said. “At Generation IX, I started developing connections with strangers, who are now my friends.”

The third event brought home the idea of the power of community even more. A friend he’d met at a conference in the states helped him to get out of his “hemophilia dark ages.” He flew to Puerto Rico to talk to him about how he had gotten through his own hemophilia dark ages, “Hearing his story was so powerful and gave me hope. That’s how I saw that I needed the community.” Manny was so touched by this act of kindness by a man who understood his pain, that he strives to be that person for others today.

Today, Manny is an advocate for a specialty pharmacy in the states. His role there is to help coordinate patients with their professional resources. He is also an active member of and volunteer for The Coalition for Hemophilia B and he is never more gratified than when he can be on the spice rack of resources to help a fellow bleeder.

“One thing I really appreciate about The Coalition is that my being in the industry hasn’t made them push me away. They see me. They value my experience and ideas, and I appreciate that.” They understand that many of us have passion for helping others and we have to wear many hats. The Coalition for Hemophilia B puts their trust in us to remember which hat you’re wearing at all times.”

Manny, who is always conscientious of being ethical considering that he is both a patient and a professional within the hemophilia community, states that he has important personal and intimate relationships through this community, “I can help teach them by just sharing my story.” He illustrates with this memory: “A dad once said



to me, ‘My son is having an issue with infusion. Can you help?’ I talked to the kid and of course I told him exactly what his father had told him, but sometimes kids just need to hear it from someone else; someone who is speaking from experience.”

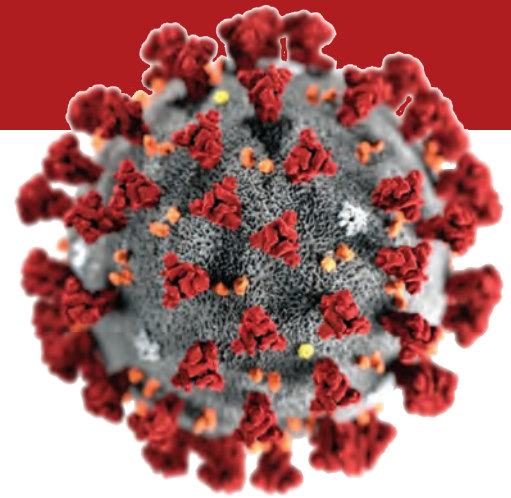
“It’s important that everyone is on the same page. Stay connected with your professional helpers. Unfortunately, the healthcare system we have forces the patient to pull their different doctors and resources together, when there should be constant communication and cooperation between your primary care physician, your hematologist, your social worker and pain management clinic. I’m relatively low maintenance, but I’ll send out a lot of messages and let people know how I am and what my plans are, and they actually appreciate that I do that. A lot of patients don’t do that, so when they have a need, it’s a much bigger request of an HTC when they’re totally unaware of what’s going on.”

Manny leaves us with one more story: “Last year, I went skiing and partially tore my ACL. Hemophilia had caused atrophy in my leg muscles, so again, the rug! When I enter these spaces of lamenting and mourning, I might hold myself in my room and maybe even regret being born, but then I think of my parents and how they didn’t give up on me. They could’ve given me up for adoption because I was too expensive, time-consuming and took an emotional toll on them. But they didn’t give up on me, so who am I to? I believe there’s purpose in the things we experience. Because of what I’ve gone through, I believe I am here to help young people get out of those moments of darkness.”

Sounds like Emeril Lagasse has nothing on Manny!

SURVIVING THE 2020 COVID-19 QUARANTINE AND LOCKDOWN

BY PAM WILLIAMS



“Think back to December 31, 2019 - New Year’s Eve. Can you believe we actually cheered and yelled “HAPPY NEW YEAR” for 2020? What a year this has already been, and we still have three more months to go!

2020 was supposed to be my year. I turned 60 in February and my best friend would be turning 60 in August. We had made big plans to reunite with our college roommate and spend a few days in Memphis, visiting Graceland and taking in the sights. In April, unsure of what the future would hold, we cancelled those plans. I’d also planned to take a weekend solo trip, to somewhere I’d never been. I had a cute little Country Inn picked out in Georgia and I was totally excited. Some people thought I was crazy wanting to go to a strange place alone, but I felt it was something I had to do for myself. The Inn too closed due to the crisis.

My gym closed. Theme parks in Orlando closed, making my usual monthly trips to Universal and Sea World a thing of the past. Life came to a screeching halt. Seeing friends became a thing of the past. Wearing masks at work and when out grocery shopping became the new norm. Time was escaping before my eyes and there wasn’t a thing I could do about it...or was there?

Another bummer, our county’s annual “Mayors’ Fitness Challenge” Event, scheduled for April was cancelled. I was our city’s team leader this year, and my group went from 11th place (dead last) for the past two years, to placing 5th out of the 11 teams. I was so excited and proud of my group and I wanted the other cities to see that Rockledge was definitely the most “improved” city in this county challenge, but there was no awards ceremony; no team to give congratulatory hugs. I sent congratulatory and thank you sentiments via email. Truly not the same. I knew I had to do something to keep busy. As elective surgeries were put on hold, my work hours decreased.

I was beginning to wonder how I was going to keep my wits about me during this time. Enter Maddie, a friend who teaches yoga. I had been taking her yoga class in person on Thursday evenings. Then the world shut down and we could no longer meet. Maddie didn’t let that stop her. She set up Zoom Yoga, and each Thursday at 6:30 pm, this small group of three couples and myself would log on and yoga our hearts out. Whenever I was able to Zoom in for these sessions, I felt and slept so much better.

Carl, a friend from the hemophilia community, set up regular Saturday night Zoom sessions where you could join for as little or as long as you were able and chat with mutual friends. It was great to see and talk to other hemophilia friends and see how they were handling the crisis. Then came GAME NIGHTS. These nights literally got me through the quarantine. Beginning in early May, team members from The Coalition for Hemophilia B chose to spend their Saturday nights with whomever wanted to join them for Zoom or Kahoot Trivia games. We had so much fun! The knowledge and useless trivia that I learned (I surprised myself with what I already knew!) was the highlight of my week. I looked forward to checking in with the gang. We were always aware if someone was missing and we’d wait to get started so they could still join us. There were prizes to be won, and I actually did win several over the course of the next month and a half. Trivia ended on June 27. I attended some other community hemophilia Zoom events and luncheons too.

As a member of the Hemophilia B Advisory Board, our spring meeting went virtual this year, and we met on a Saturday morning to discuss the topics at hand. These



health reasons, so we'd bring them to her too. It always brought smiles to their faces when we pulled up and left the box on their doorstep.

Our local CBS-affiliated television station created "Make Ends Meet," an update on the frustrations that many Floridians were having with the unemployment website, or just the mere loss in wages for their families. It warmed my heart to see and hear how many strangers reached out to help other strangers, simply because they heard their stories on Channel 6. It showed me that the world still cared about others, even amidst the riots and protests. It gave me hope. I checked in with my high school friends on FaceBook to make sure they were handling things okay. Many of us had known each other since we were in kindergarten, and we can "read" when one of us is falling down that dark, depressive rabbit hole. One simple reach out to say "Hey, are you okay? What's going on? Can I call you?" was often all any one of us needed to pick ourselves up, wipe the tears and stand tall to tackle another day. Again, never underestimate the power of a hug, even if it's a virtual one. To say that life is different, is an understatement.

Our annual hemophilia conferences that we look forward to each year have either been totally cancelled or gone virtual. Our hemophilia family is unique. We may not have known all the members all of our lives as we do with our high school friends, but we all share a unique and forever bond. I know that I can pick up the phone and reach out to many of them, and they will be there to listen, without judgment.

I call my boys on a weekly basis to make sure they are both okay, their wives are okay, and they aren't sick. I wish I didn't live so far from them.

meetings have always been filled with laughter, talking, catching up and, of course, LOTS of "Hemophilia HUGS," so the switch to the remote meeting was hard. For those of us who are huggers, the struggle not to hug has been real. The Coalition for Hemophilia B also set up focus groups with varying topics and I was asked to participate in two separate groups. Zoom-based again, but it gave me the opportunity to see my friends and we could hang out on the connection after the meeting and just talk.

Everyone handles the stress of quarantine differently. COVID-19 has made me retreat back to my writing; something I'd let go for way too long. Every few weeks, I would send a hand-written note to various friends around the country, just letting them know I was here, I was thinking about them, and that I hoped they were doing okay in all of the craziness the year was bringing. My aunt and I would venture out to the local Krispy Kreme donut shop when it was "buy-a-dozen, get-a-free-dozen," and deliver them to various friends. My mom always loved that donut shop the best, but she couldn't get out because of

I can't wait until we can plan a family get together again. I've begun to venture out a little more, always wearing my mask and carrying several bottles of hand sanitizer (who knew all that stuff from the many hemophilia conferences I've attended over the years would come in so handy?). I even took a trip to Universal after they'd been reopened for about a month. I didn't stay long; maybe an hour. Florida summer heat and masks on your face make for an even hotter experience than normal. I can't wait to have our "girl's days out" Saturdays again, when we can explore the farmers' markets, parks and nearby villages. Most of all...I can't wait to HUG. Be safe. Find ways in your own setting to get through these trying times. Exercise, call a friend, or expand your cooking and experiment with some new recipes. If you have children at home, enjoy the time with them. As we've learned, they grow up quickly, and in the blink of an eye, they're off on their own life's journeys. Finally, my biggest takeaway and newfound knowledge for the 2020 Quarantine: Bigfoot's name is Darryl.

DON'T STAND ON THE SIDELINES



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

What is RIXUBIS?

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

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

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

Who should not use RIXUBIS?

You should not use RIXUBIS if you

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

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

What should I tell my healthcare provider before using RIXUBIS?

You should tell your healthcare provider if you

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

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

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

What are the possible side effects of RIXUBIS?

Allergic reactions may occur with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.

Some common side effects of RIXUBIS were unusual taste in the mouth and limb pain.

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

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

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

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

RIXUBIS
[COAGULATION FACTOR IX
(RECOMBINANT)]

MOVING FORWARD

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Important facts about RIXUBIS®:

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.

RIXUBIS
[COAGULATION FACTOR IX
(RECOMBINANT)]

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

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- 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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BECOMING LEADER OF THE PACK



Fel Echandi with his pets

FINDING “HOME” WITH A PET

BY GLENN MONES AND RENAE BAKER

It seems like the whole world has been turned upside-down. Our front-burner vocabularies likely include terms like pandemic, PPE, sheltering-in-place, social distancing, and the word “novel” as not referring to a book. The novel coronavirus and Covid-19 have caused the world’s population to make adjustments to how we are living. We hear endless stories about the people who have been impacted by the virus and the changes to which they’ve adapted, but we don’t hear as much about the animals; in particular – pets.

Having a pet can enhance our lives, improve our health, and increase our happiness. According to the Centers for Disease Control and Prevention (CDC), the benefits of being a pet owner include increased opportunities to exercise, a decrease in blood pressure, cholesterol and triglyceride levels, decreased feelings of loneliness and depression, and better stress management. For people dealing with chronic conditions, these benefits can lead to improved health outcomes overall.

Fel Echandi, a member of our hemophilia B community, told Glenn about how their first dog, a chihuahua named Bowser, helped their son, who has hemophilia, get exercise and feel better about not being able to play contact sports with his friends.

Stephanie Aholt, another community member, shared her family’s experiences rescuing several pets. One, in particular, a dog named Ruby, had been surrendered by a previous owner who didn’t want to deal with Ruby’s medical issues. “Having Ruby helped us all understand that no matter what is medically wrong, you deserve love,” said Stephanie. “All three of our rescue dogs are such wonderful pieces of joy in our lives, plus they help teach us and our children about the struggles that everyone - animal or human - go through.”

Milinda DiGiovanni holds her two canine family members, Cloudy and Flo, up to the Zoom screen. She rescued

them, as puppies when a family member was suddenly unable to care for them properly. Her children, Andrew and Gabriella, were aged five and four, respectively, at the time. Andrew has hemophilia B. Before Milinda found The Coalition for Hemophilia B, they didn’t know anyone else who understood what Andrew’s life was like. Andrew often felt lonely and misunderstood. Cloudy helped Andrew feel like he had a buddy. Even Flo, who is not as friendly as Cloudy, will still come to sit quietly next to Andrew when he infuses. As is the experience of many bleeders, the gentle canine presence helps calm Andrew and make the infusing process easier.

People with hemophilia have long known the blessings of having pets around. With today’s new set of circumstances, brought on by the pandemic, legions more people are awakening to the goodness of pets. Renae Baker (co-author of this article,) spent six weeks suffering from a “mild” case of Covid-19, and her two cats brought her loads of comfort. “The cats, Bowie and Shadow, seemed delighted to have me there 24/7 for so many consecutive weeks!”

But what happens when a pet owner is hospitalized? What happens when a pet owner has a “mild case” of Covid-19 for which they don’t need to be admitted into a hospital, but they are extremely fatigued and in pain? What happens when pet owners lose their income and can no longer afford to take care of their pets and the local animal shelters have had to shut down, because of the crisis?

This crisis, which has shuttered many businesses, has forced some animal shelters to close and others to find creative ways, like a live-streamed video of their adoptable residents, to raise awareness of these potential pets and thereby attract more adoptive and foster families. You may see happy social media posts about empty animal shelters during this pandemic. Scores of people are indeed taking advantage of this time to foster or adopt a pet, and that is good news! The numbers of animals in the shelters are

dramatically down, but pet owners who are ill and/or dealing with a loss of income are finding themselves unable to care for their pets during this difficult time. Animal rescues and shelters are working expeditiously to arrange foster and adoption placements for these animals. As happy as the staff and volunteers at remaining shelters like Dumb Friends, the largest animal shelter in the Rocky Mountain region are, they want us to know that they still have over 1000 cats, dogs, and other small animals in their care.

Many people who had previously felt that they couldn't take proper care of a dog have taken advantage of this time to take the plunge and foster or adopt one. The timing is undeniably advantageous. Sheltering in place means being "home" not only for people, but for pets, and none more than canines. Steve Lanker, founder of Speak Dog! and author of the international best-selling book, *How I Learned to Speak Dog!* sat down with Renae to discuss the meaning of "home" to a canine.

"Dogs are pack animals," Steve begins. "A lot of other animals are too: dolphins are mammals who swim in pods, elephants travel in tribes, horses form herds, but dogs are different in that they have an innate and biological need for both social structure and leadership. Not having that is a "homeless" situation for a dog."

Steve explains that creating a "home" for a dog requires understanding that you and your dog are in the same pack, and you are the leader of that pack. "Dogs don't understand physical houses. They're not interested in the roof over their heads or the pile depth of your carpet. That's not what home means to a dog."

Steve gently cautions that we might have a single dog in a mansion with every creature comfort a human could imagine, but if we don't provide leadership, social structure, and companionship for our dog, that canine will feel homeless. "Some families are at work and school all day, and it's no wonder our dogs are jumping at us when we get home! For

them, it's like their oxygen has been withheld from them all day, and when we return, they're clamoring for it."

In bleeder terms, it can feel like treating when you're overdue. "This is like factor for a dog. They can't function well without social structure and leadership, so people with time and understanding are the best dog owners on the planet. This explains why we so often see homeless people with such happy, loyal dogs, sitting at their sides on the sidewalk." Lanker says.

He suggests that this set of canine needs makes for a unique and rewarding opportunity for people with hemophilia, because, "You don't have to be rich or be an athlete. That's not what a dog needs. Dogs need what you may be best at providing; a home in the context of relationship."

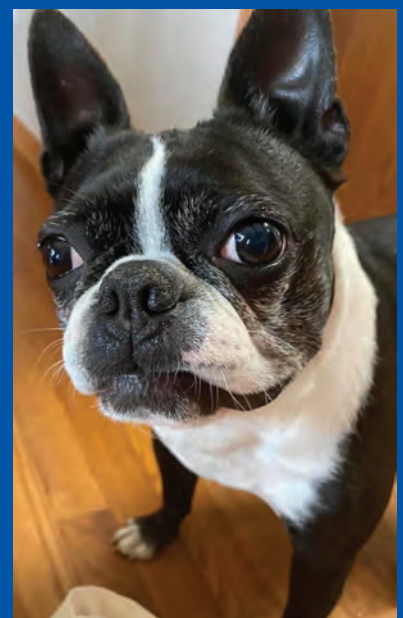
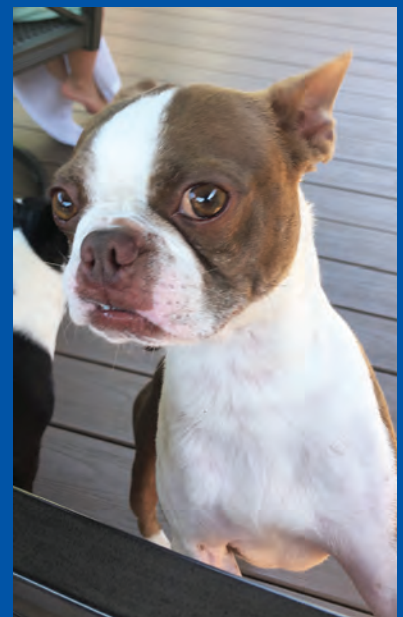
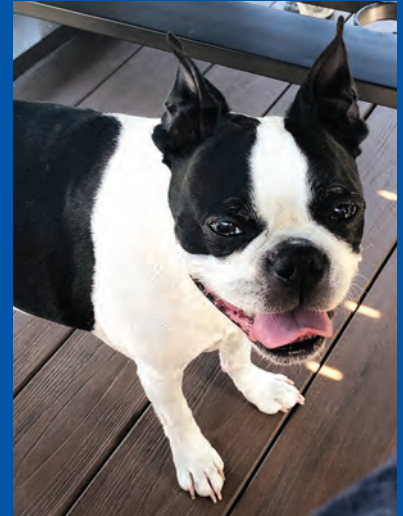
If you're considering fostering or adopting a pet during this vital time, there is more good news: many pet rescue and adoption organizations have streamlined their application process making things easier for people who want to foster. Interviews and home visits can often be done virtually before the adoption. One group that is doing a great job at matching prospective fosters with animals in need of a home is The Shelter Pet Project, a collaborative effort of the Humane Society of the United States, Maddie's Fund, and the Ad Council. The project works to "break down misconceptions surrounding shelter pets" and celebrates "the unique bond between every shelter pet and parent." You can learn more about their efforts and even search for a pet to foster by visiting their website at:

<https://theshelterproject.org>.

The bottom line is that fostering a pet is an amazing way to help save an animal's life while enriching your own in immeasurable ways. Talk to almost anyone who has done it and they will tell you it is one of the best decisions they ever made. To learn more about how to speak dog and become the leader of the pack, go to:

www.LearnHowToSpeakDog.com.

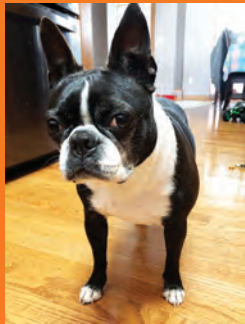
Stephanie Aholt's "family"
Pearl Maria, Jasper Stone and
Ruby Jean



Our Pets

We have a few furry friends that our community members would like to introduce you to. Please meet some wonderful pets that show us love, affection, and give us comfort and unconditional love.

Stephanie: We have three joyful fur kids: Pearl Marie, Ruby Jean, and Jasper Stone. We got Pearl when she was just 7 weeks old. She's now 12 1/2 and basically the love of our entire house! We rescued Ruby from a shelter, where her owner had surrendered her because they didn't want to help her with her medical issues. And our newest addition, Jasper, came straight from an Amish puppy mill. He was used only as a stud and had never had love from humans. He has been here 2 months now and is doing great adjusting to being snuggled and loved!



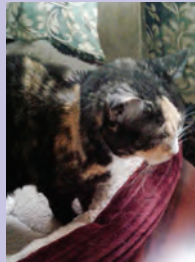
Dave: Peyton, our pug, is president and CEO of the household. She is very social and knows everyone in the neighborhood, even people we don't know. She doesn't do well at holding her licker.



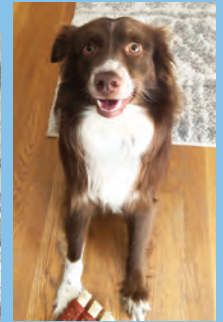
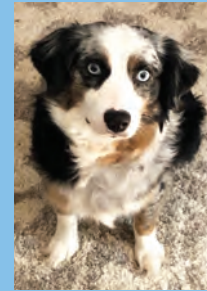
Karen: KiKi is here to distract at a moment's notice! She's thinking TGIF because that means tomorrow is #Saturday!



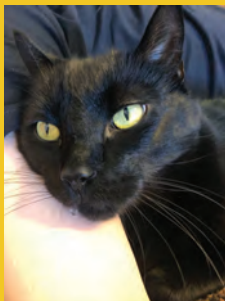
Ron: My cat, Cookie, is the funniest cat ever, and she always waits at my door. Cats are good for therapy and they provide good company.



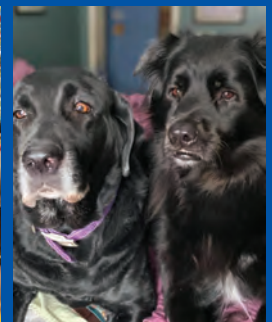
Kendall: We have two wonderful mini Australian Shepherds: Ellie (blue eyes) and Buddy (brown eyes). Ellie is shy and prefers her family to strangers, while Buddy likes to talk and make friends. They produced one litter of puppies together so far! Besides providing our family companionship, our dogs are a stress relief for my oldest son, who has autism. All our boys seek them out to play and pet them, but it's our oldest who I visibly see relax when focused on the pups.



Shannon: These are our two awesome fur babies. Charlie is our all black cat and Bobby is our yellow tabby cat. We call Charlie "our little drool boy" because he loves to drool when he is comfortable telling you that he likes you. Bobby is our sleepy boy, and we call him our "old man". He loves his treats and loves to be pet. We just love our boys.



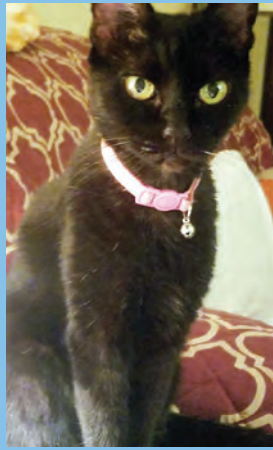
Wayne: These are our two beautiful girls Stella and Zoey. Stella likes to jump in the pool even though she is not allowed, and she likes to sleep on my side of the bed. Have you ever tried to move a 125 lb. sound asleep dog? It doesn't happen! Zoey has her own chair that nobody sits in except her. At dinner, they both hover around the table like a couple of hawks waiting for their prey. When the kids are at the table, it is like yippee! Between what they drop and what they feed them, they know that they are going to get food from the table. It's a picnic! They both bark at everything even if there is nothing outside. I call them my lounge lizards because all they do for the most part is sleep all day.



Milinda: Please meet Claudio and Florinda aka Cloudy Boy and Flo. They are the sweetest! Cloudy is my security guard. He enjoys his chicken, sleeping, and taking walks with his wife Flo. She loves her beauty sleep and wants to eat everything in sight! They are a big part of our world.



We love them, and they help us cope with everyday life. They comfort us, and we live a better quality of life because of them. We are so thankful for our puppies!



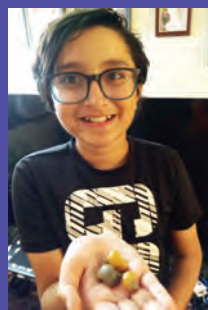
Pam: This is my cat Onyx. She was found on a friend's doorstep and came home to live with us. She's only affectionate under her rules and wants attention when you have food. She hates being held, and she loves hanging out on the pool deck.

Carrie: This is Paws, aka Pawpaw-roni and Izzybelle. They are my son Nathan's brother and sister. We rescued them when Nathan was one so that they could grow up together. Pawpaw is a lovebug that eats a second breakfast every day. Izzybelle gives really hard head bumps to show her love for us. They both absolutely love their treats and Nathan, who has become quite the expert on how to care for and treat animals.



Quinn and Debbie: We have cat sisters: Rae and Stampy Cat. They make us laugh and keep us entertained during times of bleeding and infusions. They have their own pet fish, and they prefer to drink water from glasses. In this picture, Rae is on top of Stampy, who likes to lay with her leg straight out. They provide us with a soft acceptance.

Aamina: We have three water snails: Mrs. Basil E Frankwiler, Bowser, and Minnie. According to Ismaeel and Ahmad, they have no feet and they cannot hear. Snails are one of the best hidiers in the animal kingdom. They can hide inside their shells for hours and sometimes days. Ahmad says his pets always make him happy, and he is grateful that they do not have to worry about getting hurt or not playing. He is happy that they can swim and jump around in the water. According to Ibraheem, often our snails are moving... very, very slowly...but when they aren't, they're eating and sleeping. They may seem boring, but their energy radiates through the room.



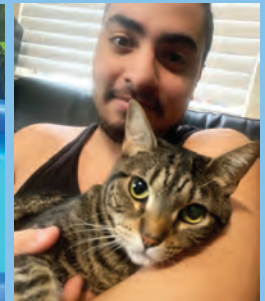
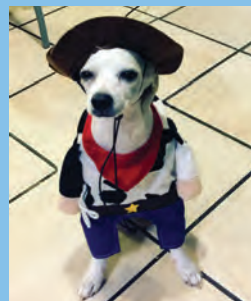
Heidi: This is my husband David and Cow #8. While taking a break from irrigating, his favorite old cow always finds him to say hello and get her ears scratched.



Rocky: Lady rules the roost at our house. She purrs as loud as a chainsaw and is teaching 18-month-old November what "gentle touch" means.



Fel: We have three rescue pets. Our first was Bowser (chihuahua), who we got to help our son Fiach exercise when he was disappointed he couldn't do the same impact sports his friends played. (Bowser also looks great as a cowboy!) When we moved to our new house, we got Fritz (schnauzer), who loves to play in the pool. Most recently we got our cat Phoenix. All three help our family be less stressed!



Chris: This is (Super) Rockie and Purl! Ready to venture into Chris' yard, they are prepared for epic battles with wind, bugs, and grass!



Heidi: First up is Maggie Bear! Her favorite things are her daddy and any ball! She's a professional ice cube catcher and will do ANYTHING for some belly rubs! If you visit her, make sure to bring one of the above and she'll be your best friend!



Next is Theodore! He's six months old and SO sassy! He is so smart and is obsessed with his big sister. If he could talk, he'd probably say "This is my world, and y'all are just living in it!"



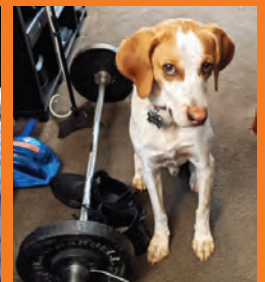
Kim: When Jojo is not working with mommy Kim, he is on his dates with kitty cat Lulu!



Anna: Sully is a favorite on Capitol Hill! Named after Captain "Sully" Sullenberger, he is proud to work on important pawcicy!



Kirstin: Our hearts are in rescuing, as we haven't had any of our dogs since they were puppies. The closest would be Zelda, who we got at 7 months. Zoey was 3, Daisy was 4 and Luigi was 3 when we adopted them. Luigi is like a giant cartoon character of a hound and makes us laugh daily. Zoey and Daisy dance constantly in hopes of a treat and live for cuddles. Zelda is unable to walk due to a health condition but she is as happy as can be, and enjoys joining us on walks in her wagon!



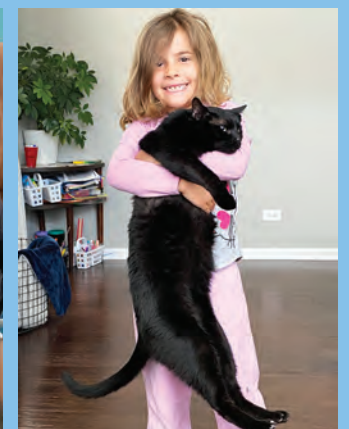
Rick and Leslie: Our dog Daisy was a stray that hung around our town for a few weeks. She was fed all over the village and a friend to all the children. One day, I was walking back home, and she fell in beside me, following along. I arrived home and she followed me in the door like she picked us to live with.



Saugway was a tiny kitten who was abandoned by her mother at 2 weeks old. Our daughter Cassandra was living at home and took Saugway in. Cassandra bottle-fed her, but then moved when Saugway was a couple of months old, so Saugway quickly became my cat. Saugway is typically aloof, but she often seeks attention on her terms.



Mike: We have two cats: Ra's al Ghul (Razzy for short) and Batman. Razzy is gray and loves to talk a lot even if it is not food time. When he's not eating, he is usually sleeping or chasing random bugs. Batman is black and will jump in your lap when you sit down and acts like a dog. He doesn't believe in closed doors so he will cry until you open it so he can join you on your lap. Razzy and Batman are the best of friends but will occasionally get into a friendly wrestling match for fun. These cats definitely help relax our entire family environment. They naturally act as therapy cats, and they love to cuddle and give affection.





Dear Members,

If you have a working laptop or tablet that's less than five years old, please consider donating! Together we can help a deserving family access programs, information, and support and keep connected, which is so important during the current COVID-19 pandemic.

To donate, email us at contact@hemob.org (please put in subject line "Donation"). We will arrange shipping and a donation letter for tax purposes. You can also write a note to the family you are donating to! We will include it when we ship to them.

You can make a real difference in the lives of other families and individuals in our amazing community! Thank you.

THE COALITION FOR
HEMOPHILIA





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TROUGH
LEVELS
WITH 7-DAY PROPHYLACTIC USE‡

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steady-state FIX levels

*Zero median annualized spontaneous bleeding rate when dosed at 7 or 14 days in clinical trials.

†Once well controlled (1 month without spontaneous bleeding or requiring dose adjustments on a weekly dose of ≤ 40 IU/kg), people 12 years and older can be transitioned to 14-day dosing.

‡The average dose for people receiving prophylaxis every 7 days was 37 IU/kg and every 14 days was 73 IU/kg.

§Hemophilia FIX Market Assessment. Third-Party Market Research.

Is it time for a switch? Learn more at IDELVION.com



Important Safety Information

IDELVION 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 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.

Please see additional Important Safety Information and 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**.

IDELVION is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC. IDELVION® is a registered trademark of CSL Behring Lengnau AG. Biotherapies for Life® is a registered trademark of CSL Behring LLC.

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www.CSLBehring.com www.IDELVION.com IDL-0307-MAY19

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Important Safety Information (cont'd)

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.

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 May 2018 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.

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LET'S TALK™

MENTAL HEALTH

You won't want to miss the new film *Let's Talk*, streaming Saturday, October 3rd at 7:00 pm EST during The Coalition for Hemophilia B Symposium! It's sure to be a highlight of the weekend! Join Pat Lynch to view the powerful new film *Let's Talk*, an immersive journey through the lives of five members of the US bleeding disorders community, as they open their hearts and lives to show how we can gain strength through struggle, and that perhaps we aren't so different after all.

Made by Believe Limited and produced in partnership with Mental Health Matters Too, the film is intended to spark conversation, increase awareness, and decrease stigma. We're honored to present the film and excited to share it with you!

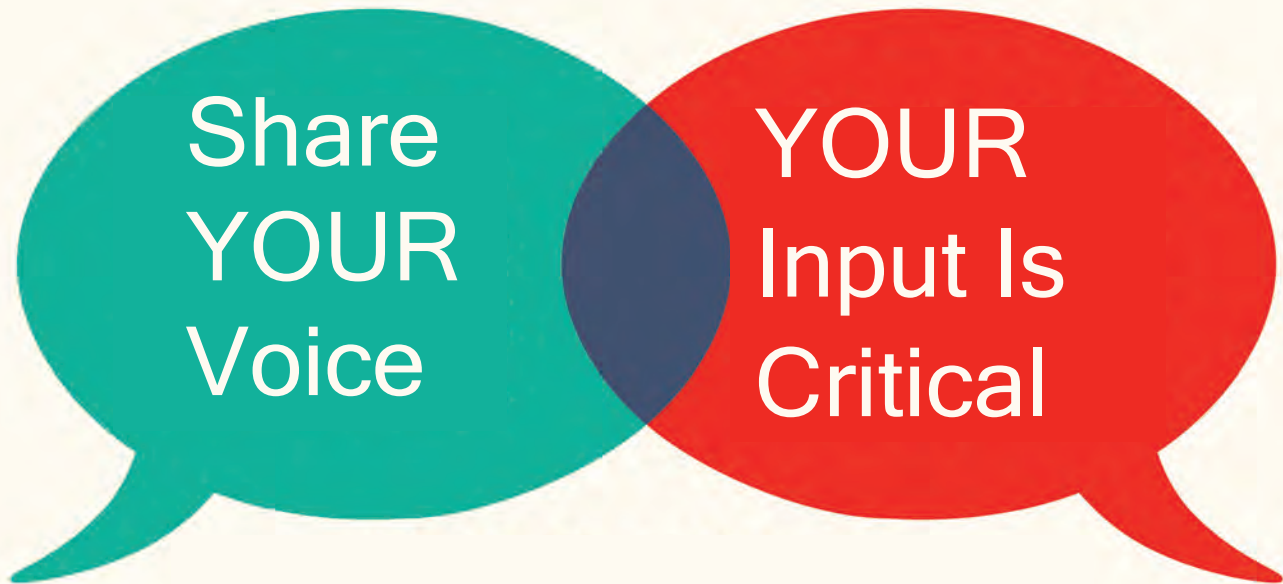
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www.LetsTalkMH.com



Deadline October 24th

Coalition Membership Survey

Why a Survey?

- New developments demand that we take stock of the experiences, needs, and concerns of the members we serve. Your responses allow us to improve the programs we offer you and will assist us in future planning.
- We received many mail-in and electronic survey submissions since February and have started to compile the results. Thank you!
- For anyone who has not yet participated, we encourage you to fill out the improved (shorter) electronic survey now; it will take approximately 20 minutes. Watch your email.

Bonus!

Everyone returning a survey will be entered into a drawing to attend, in person, our 2021 Symposium in Orlando (June 4-7, 2021), inclusive of airfare, hotel, and tickets to a theme park, or receive something of equal value (e.g., gift cards).

There will be 50 winners.

We are asking that all surveys be completed by October 24th.

Drawing will be October 29th.

All members have receive a survey in the mail.

If you have not received yours, please contact farrahm@hemob.org. Survey is anonymous.

PLEASE TAKE THE SURVEY!

“One of the most important things you can do on this earth is to let people know they are not alone.”

— Shannon L. Alder



THE COALITION FOR HEMOPHILIA B PATIENT ASSISTANCE PROGRAM

The high cost of medical care is often a challenge for people with hemophilia B. Fortunately, insurance coverage, government programs and other forms of patient assistance cover much of that cost. Unfortunately, these programs do not cover the cost of non-medical emergencies, which may interfere with a family or individual's ability to deal with day-to-day life with a bleeding disorder. These emergencies may involve struggling to having enough resources for housing, food, transportation, or a range of other necessary and critical needs.

When these needs are not met, the health and well-being of the patient as well as the entire family can be negatively affected. Often, assisting a person in an immediate circumstance is all that's needed to keep the situation from spiraling out of control.

The Coalition for Hemophilia B deeply cares about families and individuals, and the urgent needs they may face. Several years ago, because of this and in order to live true to our mission statement, we established a patient assistance program for hemophilia B patients and families. We reintroduce our program as **BCares**.

BCares operates with funding generously donated by pharmaceutical manufacturers, homecare companies, business partners, and other interested supporters.

Those donating share our belief - in the case of an urgent situation, we can all do more to help. It is our obligation as a community to lend a hand and assist those in short-term, dire straits.

The Coalition for Hemophilia B is able to offer a limited amount of financial aid to our factor 9 community members who face a financial emergency. Those requesting assistance can submit a simple, confidential application. Each application will be reviewed thoroughly by a committee, who will determine and prioritize grants based on the request and level of urgency.

How you can help: We are exceedingly grateful to the donors whose charity and compassion have made this critical program possible. Please consider becoming involved by offering additional funds so we may help more hemophilia B patients through challenging times.

For more information, please contact:

Farrah Muratovic
farrahm@hemob.org
The Coalition for Hemophilia B

Tel: 212•520•8272
hemob.org



TREATMENT NEWS

BY DR. DAVID CLARK

Cost of Treatment for Hemophilia B

7/12/20 A study of the costs of hemophilia B treatment in the U.S. was presented at the International Society for Thrombosis and Haemostasis (ISTH) Virtual Congress. The average annual medical cost for patients with hemophilia B was \$205,783. The average costs ranged from \$83,291 for patients with mild disease to \$643,979 for those with severe disease. [ISTH 2020 abstract PB0861]



Catalyst Presents Final Results of Phase IIb Study of DalcA

6/15/20 Catalyst Biosciences is developing dalcinonacog alfa (DalcA), an extended half-life, subcutaneous (SubQ) high-activity factor IX for hemophilia B treatment. At the World Federation of Hemophilia (WFH) Virtual Summit, they presented final results from their Phase IIb clinical study. With daily SubQ dosing all six patients achieved an average steady-state factor IX level of 19.4% (range 14 - 28%) after 28 days.



There were no serious or thrombotic adverse events, and no inhibitor development. Some patients exhibited injection site reactions for the first few infusions. There were no breakthrough bleeds in any of the patients. [Catalyst press release and poster, 6/15/20]

Catalyst Presents Data on MarzAA for Inhibitor Treatment

7/13/20 Catalyst is also developing marzeptacog alfa (activated) (MarzAA), an extended half-life subcutaneous activated factor VII product for treatment of hemophilia A and B patients with inhibitors. At the ISTH Congress, they presented pharmacokinetic, pharmacodynamic and safety results from their Phase I clinical study. The data confirm that they have selected the optimum dosing for their Phase III study set to begin in late 2020. (A separate Phase II study has also been completed.) [Catalyst press release and posters, 7/13/20]



Sanofi Presents Update on Fitusiran

6/19/20 Sanofi presented an update on their Phase II extension study for fitusiran at the WFH Summit. Fitusiran is a novel RNA interference (RNAi) drug that inhibits production of the anticoagulant antithrombin. By reducing the anticoagulant activity in



the coagulation system, Sanofi has shown that they can restore the balance in the system to permit the blood of patients with hemophilia to clot more easily. Fitusiran is a monthly subcutaneous injection for treatment of hemophilia A and B patients with or without inhibitors.

In patients who have been treated for up to 4.7 years (median 2.6 years), the interim results show that monthly fitusiran dosing can reduce the production of antithrombin by about 75%. Hemophilia A and B patients without inhibitors achieved a median annualized bleeding rate (ABR) of 1.01, compared with a pre-study ABR of 2.0. An impressive result was seen in patients with inhibitors who went from a pre-study ABR of 42.0 down to 0.44 after treatment. No new inhibitor development was seen. [WFH 2020 abstract MED-FP-002(598)]

Novo Resumes Clinical Studies of Concizumab

8/13/20 Novo Nordisk announced that they are resuming their Phase III studies on concizumab, an anti-tissue factor pathway inhibitor (anti-TFPI) treatment. The studies had been halted after three patients developed non-fatal thrombotic events (dangerous internal clotting). Novo and FDA have agreed on new safety measures and guidelines, and the clinical hold has been lifted.



Concizumab is a monoclonal antibody that binds to the anticoagulant protein TFPI and prevents it from slowing the clotting process. Concizumab and several other treatments are being developed to increase the ability of hemophilia patients' blood to clot by inhibiting various anticoagulants (inhibiting the inhibitors). The product is expected to work in patients with either hemophilia A or B, with or without inhibitors. [Novo Nordisk press release 8/13/20]

GENE THERAPY

CSL Acquires uniQure's Hemophilia B Gene Therapy

6/24/20 CSL Behring has entered into an exclusive licensing agreement to obtain worldwide rights to uniQure's gene therapy treatment for hemophilia B, etranacogene dezaparvovec, also known as AMT-061. AMT-061 is currently in Phase III clinical studies, which uniQure will be responsible for completing. [CSL and uniQure press releases, 6/24/20]



Freeline Reports on Phase I/II Results



7/13/20 Freeline presented new results on their FLT180a gene therapy treatment, which is currently in Phase I/II clinical studies. FLT180a uses a proprietary AAV vector called AAVS3 that has a higher efficiency in transducing liver cells (introducing the new gene into liver cells). It also uses the higher-activity Padua variant of the factor IX gene.

They looked at four doses ranging from 4.5×10^{11} to 1.5×10^{12} vg/kg (vector genomes per kilogram of body weight; one vector genome is essentially one virus particle). In ten patients they found sustained factor IX levels ranging from 38% at the low dose to 160% at the highest dose. One high-dose patient achieved a level of 253%, approximately 2.5 times the normal level. Freeline believes that they can thus bring hemophilia B patients up to normal factor IX levels. [Freeline press release, 7/13/20 and ISTH 2020 abstract LB/CO01.1]

Intellia and Regeneron to Collaborate on Hemophilia Gene Therapies



6/1/20 Intellia Therapeutics and Regeneron Pharmaceuticals have agreed to collaborate to develop gene therapies for hemophilia A and B. They will use a CRISPR/Cas9 gene editing approach to insert a factor IX gene in patients using their proprietary insertion technique. Regeneron will be the lead organization. Further details have not been announced. [Intellia and Regeneron press releases, 6/1/20]

Pfizer Reports Successful Surgeries in Two Gene Therapy Patients



7/12/20 Pfizer is developing a gene therapy for hemophilia B called fidanacogene elaparvovec, which was originally developed by Spark Therapeutics. The product is currently in Phase III clinical studies. At ISTH, they reported on two study patients who had unrelated surgeries, an appendix removal and a procedure to remove a spinal disc. The patients had factor IX levels of 26.3% and 11.8% (mild hemophilia range) after their previous gene therapy treatments. The surgeries were successful without excessive bleeding and without additional factor treatments. [ISTH 2020 abstract PB1096]

1,800,000,000,000,000



6/30/20 That's the number of AAV virus vector particles that an average 90 kg (198 lb) male would receive in uniQure's Phase III gene therapy study. Written in scientific notation, which is used to express large numbers, this is 1.8×10^{15} virus particles. The actual dose per kilogram of body weight is 2×10^{13} vg/kg. Pfizer uses a somewhat smaller dose of 5×10^{11} vg/kg for their hemophilia B gene therapy, but it's still a huge number.

There has been concern that assaulting the body with this many virus particles could be harmful. In a recent gene therapy clinical study for a rare disease called myotubular myopathy (MTM), three patients receiving AAV doses of 3×10^{14} vg/kg developed severe liver toxicity, and two of the patients died. Six previous patients who had received a one-third lower dose of 1×10^{14} vg/kg had shown encouraging results. Note that these patients were all children, since MTM patients usually die in childhood.

Several patients in gene therapy studies for Duchenne muscular dystrophy and spinal muscular atrophy, treated with AAV doses in the range of 10^{14} vg/kg have also exhibited signs of liver and kidney damage. Fortunately, all of the patients recovered. Some previous animal studies had also shown severe liver damage and other toxicities after high doses of AAV.

We don't know yet what causes these toxicities. One idea is that the immune system, after being overwhelmed by the huge number of viruses, responds with an uncontrolled inflammatory response. This may be similar to what we've seen in COVID-19 where patients with severe infections are actually being harmed by an overactive inflammatory response that can damage major organs. Much research remains to be done in both cases.

What does this mean for the hemophilia patient considering gene therapy? It means caution. So far, in the hemophilia gene therapy studies, we haven't seen much of this although some patients have developed temporary liver inflammation. Also, the hemophilia gene therapy treatments generally use somewhat lower AAV doses.

One concern is that clinical studies usually use "perfect patients," that is, patients who are in generally good health who don't have other diseases or disorders. Until these treatments are licensed and available to the average patient, we may not know what will actually happen. [Wilson JM and Flotte TR, Hum Gene Ther, epub ahead of print, 6/30/20]



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HEMOPHILIA UPDATE

BY DR. DAVID CLARK

How Many Hemophilia Patients Are There?

4/24/20 Following a study last year [lorio et al., Ann Int Med, Epub 9/10/19] that suggested that there could be up to three times more hemophilia patients than originally estimated, a group of researchers studied the prevalence of hemophilia in the U.S. Using data on the number of patients seen at Hemophilia Treatment Centers (HTCs), adjusted to account for the percentage of hemophilia patients who use HTCs (67 - 80%), they estimate that there are approximately 29,761 to 32,985 males with hemophilia in the U.S. 76.5% had hemophilia A, and 23.5% were Bs. This gives an estimated prevalence of 6994 to 7751 males with hemophilia B in the U.S. They estimate that the incidence of hemophilia B is 1 in 19,283 live male births.

Incidence and prevalence are two different measures. When we ask how many people currently living have hemophilia, we're talking about prevalence. Prevalence always refers to a time period. We could ask how many people have hemophilia now, or sometime in the past. For hemophilia, prevalence refers to the number of people with hemophilia compared to the total number of people in the population being studied.

Incidence is how often something happens. Hemophilia only happens to a person once, so for hemophilia the incidence is equal to the number of births of people with hemophilia compared to the total number of births in the population being studied. If everyone lived exactly the same lifespan, the incidence and prevalence of hemophilia would be equal. Since lifespans vary, they are different.

One thing the researchers did was to calculate the prevalence for different racial and ethnic groups. They found a higher prevalence of hemophilia among whites (15.1 per 100,000 males) than among Blacks and Hispanics (both were 12.4 per 100,000 males). At first, Blacks and Hispanics appear to have an advantage, but that's not actually true. As far as we know, the incidence of hemophilia is the same regardless of race or ethnicity. That is, everyone has the same chance of being born with hemophilia. The difference comes from the risk of death for the group. Blacks and Hispanics tend to live shorter lives than whites in the U.S. Therefore, they don't contribute as much to the overall prevalence as whites.

Note that the study also did not compile data on women with hemophilia. That is probably much more difficult since many female hemophilia patients have trouble receiving treatment and therefore are unknown to the system.

Including females could significantly increase the numbers. It has been estimated that for every male with hemophilia there are 4 - 5 associated female carriers, sisters, mothers, aunts, etc. We don't know how many of those will actually have hemophilia, but it could be a substantial number that could more than double the overall estimate.

[Soucie, JM et al., Haemophilia, 26(3) 487-493, 2020]

Intracranial Hemorrhage

7/12/20 A study presented at the International Society for Thrombosis and Haemostasis (ISTH) Virtual Summit looked at intracranial hemorrhage (ICH; "brain bleed") in patients at 13 Italian hemophilia treatment centers over a ten-year period from 2009 to 2018. ICH is the most serious complication of hemophilia and can lead to permanent disability and death. Over the ten years, the centers treated 44 cases of ICH in 4990 patients with hemophilia (A or B), or about 0.9% of patients. Historically, the greatest risk for ICH has been in children up to 2 years of age and in adults 50 years and older, and the study found a similar result. 31.8% of the ICH patients died before or during treatment and 43.3% became permanently disabled. ICH was spontaneous in 69.8% of the patients and due to injury in the others. Only 16% of the ICH patients were on prophylaxis, which the authors suspect may be an important preventative measure. Of the 44 patients, 61.4% had severe hemophilia, but all of the children with ICH were severe. About half of the adult patients had hypertension (high blood pressure). Inhibitors were present in only 13.6% of patients.

[ISTH 2020 abstract PB1040]

Bleeding in Mild and Moderate Hemophilia

7/12/20 Two studies presented at ISTH looked at bleeding in patients with mild or moderate hemophilia; both are less well-researched groups. In the PROBE study of 144 patients with moderate hemophilia and 143 with mild hemophilia (both A and B including women) they found, as expected, that the milds bled less often than the moderates but both groups had significant issues. Acute pain was reported by 67% of the mild males and by 77% of the moderate males. For women the numbers for acute pain were 52% and 67%, respectively. Overall, 35% of milds and 61% of moderates (both male and female) reported impacts on activities of daily living.

[ISTH 2020 abstract PB1005]

In the DYNAMO study of 101 milds and moderates (72 As and 29 Bs), 79% of patients experienced at least one



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To join B contact administrators,
Rick Starks and Shad Tullidge at:
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- » DR. DAVID CLARK: NEW PRODUCTS IN DEVELOPMENT & GENE THERAPY
- » DEBBIE DE LA RIVA, LPC: MENTAL HEALTH & BLEEDING DISORDERS

Why B Connected?

New therapies are flooding the market. It's more important than ever that everyone in the Hemophilia B community has a way to:

- » Get critical information in a timely way.
- » Dispel false rumors immediately and get correct information from expert sources.
- » Stay engaged with the community virtually even if your hemophilia limits your mobility.
- » Ask questions and share experiences with other patients and caretakers.
- » Customize and control the content you want to receive notifications for.

contact: bconnected@hemob.com

PEER SUPPORT & ASK THE EXPERT GUESTS

Through B Connected you can also digitally join online **Ask the Expert** sessions – hour-long discussions on topics such as advocacy, depression, pain management, unaffected siblings, physical therapy and how to cut down on joint bleeds, nutrition and exercise, inhibitors, new family support, aging with hemophilia, and much more!

JOIN TODAY!

Hemophilia B Connected online discussion board is hosted on Slack and is 100% HIPAA compliant.



HEMOPHILIA UPDATE

bleed that required factor treatment from 2009 to the present. In the last ten years, 34 patients experienced a total of 176 factor-treated joint bleeds, of which 14% were spontaneous. The majority, but not all, of the joint bleeds were seen in the moderate patients.

[ISTH 2020 abstract PB1022]

Both groups of authors show that milds and moderates may still have serious bleeding episodes and other hemophilia-related issues. They encourage future research to identify the optimal management of patients with mild or moderate hemophilia.

Severe Hemophilia Patients Show Increased Plasmin Generation

7/12/20 While a clot is forming, it already incorporates molecules that will lead to its destruction. Breakdown of a clot is a process called fibrinolysis. Fibrin is the protein that forms the clot, and lysis means to cut. Breakdown of a clot is an important process in the eventual healing of an injury. Plasmin is the major enzyme that breaks down a fibrin clot. An enzyme is a protein that causes a chemical reaction. In this case plasmin reacts with fibrin to break apart the fibrin molecules

Plasmin circulates in the bloodstream as an inactive form called plasminogen. When a clot forms, it entraps blood cells and platelets as well as proteins like plasminogen. An injury to a blood vessel breaks open endothelial cells, which are the cells that line the inside of the vessels. The broken endothelial cells release tissue factor and collagen that start the clotting process. Broken endothelial cells also release tissue-plasminogen activator (t-PA), but much more slowly. (Recombinant t-PA is used in emergency medicine to treat stroke patients by breaking up the clot(s) that have formed in their brains.)

The slow release of t-PA starts to convert the plasminogen entrained in the clot into plasmin, which starts the process of breaking down the clot. This is usually a process that takes place over several days, leaving the clot strong to stop the bleeding at first but then gradually eliminating the clot as new tissue is formed in the healing process. Some hemophilia patients use antifibrinolytic medications, like aminocaproic acid (Amicar) and tranexamic acid (Cyclokapron and Lysteda) to treat minor bleeding such as nosebleeds and from dental procedures. These drugs interfere with the conversion of plasminogen to plasmin and thus keep the clot from starting to break down.

A group of Irish researchers wondered whether differences in the amounts of plasmin generation from patient to patient could help explain the differences in bleeding behavior (phenotype) among those with severe

hemophilia. Most severe patients bleed severely, but about 15% bleed more like milds and moderates. We don't know why. Using plasma from 78 severe male hemophilia A and B patients and comparing that to plasma from 100 males without a bleeding disorder, they looked to see how much plasmin was generated when the plasma was clotted. The result was a surprise.

They found that all of the hemophilia plasma showed significantly increased plasmin generation compared to the non-hemophilia control group. Interestingly, the amount of plasmin did not depend on whether the subjects had hemophilia A or B, or on their residual factor levels. The researchers had taken the initial plasma samples from the hemophilia patients when they were at their trough levels, but when they took additional samples after the patients had received their factor infusions, the results were similar. All of the severe hemophilia patients showed increased plasmin generation no matter what their factor level was.

This is now a mystery upon a mystery, but potentially an extremely important finding. They didn't find out why phenotypes differ, but they discovered a phenomenon in severe hemophilia patients that we didn't know existed. Often when experiments don't give you the result you expected, you actually end up learning more. A wise scientist said that significant breakthroughs are not as often announced with "Eureka!" but more often by "That's funny". More research will determine whether this is indeed an important discovery or just a laboratory curiosity. [ISTH 2020 abstract PB0830]

von Willebrand Factor and COVID-19

7/17/20 Von Willebrand Factor (vWF), a protein that plays several important roles in clotting, has recently become a subject of interest in COVID-19. Dr. Leonard Valentino, CEO of the National Hemophilia Foundation (NHF), published an update of the situation on the NHF website. VWF has at least two important roles in clotting. First, it protects factor VIII in the bloodstream. Factor VIII, the protein deficient in people with hemophilia A, is a fairly fragile molecule that tends to degrade when it is by itself in the bloodstream. VWF binds to factor VIII and keeps it in good shape.

VWF also helps to bind a growing clot to the walls of blood vessels at the site of an injury. This keeps the clot where it is needed, but too much vWF can be dangerous and lead to too much clotting. Another protein called ADAMTS-13 keeps the amount of vWF under control. Researchers have discovered that excess vWF may play a role in the organ-damaging clotting that is seen in many COVID patients. It has been suggested that people with naturally lower levels of ADAMTS-13 may be at higher

HEMOPHILIA UPDATE

risk of developing severe COVID-19. Their lower levels of ADAMST-13 may allow the levels of vWF to get out of control. An Italian study found that 5 of 6 severe COVID patients who had low levels of ADAMST-13 died. The COVID-19 story is still unfolding, and this is just one discovery along the path. It still remains to be seen what the outcome will be. Research continues. [NHF website: <https://www.hemophilia.org/Newsroom/COVID-19-Information/COVID-19-and-VWF>]

Health Status of Older Hemophilia Patients

7/12/20 Two groups presented studies on older hemophilia patients at ISTH. A multinational study looked at health status and quality of life in 1157 people with hemophilia from 33 countries who had participated in the PROBE project. Using patient-reported outcomes from several questionnaires, the researchers found that in spite of the advances in life expectancy for people with hemophilia, they tended to have a steeper decrease in health status and quality of life as they aged than did people without a bleeding disorder. [ISTH 2020 abstract PB1012]

Another study looked at all the severe hemophilia patients in The Netherlands. In 116 severe patients older than 50 years of age, they found that 70.4% had severe joint impairment at present. 73.5% had undergone orthopedic surgery with a median of 2.5 (range 1 - 4) operations per patient. The most common co-morbidities (other diseases or disorders besides hemophilia) were hypertension (high blood pressure) in 46.4% of patients, high cholesterol in 17.3%, cancer in 13.0% and diabetes (Type 2) in 10.9%. 11.9% of patients were HIV-positive and 94.6% had previously been infected with hepatitis C, but only 2.3% (2 patients) were still HCV-positive. Overall, their health status was worse than that of the general population. [ISTH 2020 abstract PB1046]

Despite improved factor products and prophylactic treatment, both studies showed that hemophilia patients still have a poorer health status and quality of life than the general population. Therefore, more work still needs to be done to improve treatment of hemophilia.

Handheld Ultrasound for Home Use

7/12/20 Recent reports have shown that ultrasound is as accurate as MRI and more accurate than X-rays for assessing bleeding in joints. With the relative simplicity and lower cost of ultrasound equipment, researchers explored whether ultrasound could be used by patients at home. Ten men with severe hemophilia A and an average age of 38 years were trained on a portable ultrasound apparatus by the Seattle HTC. The images were sent

electronically to the HTC for diagnosis of their joint conditions. This allowed more accurate determination of whether they were actually having a bleed and whether any change in their treatment was needed. [ISTH 2020 abstract PB0969]

Vitamin D and Osteoporosis

7/12/20 Vitamin D is important for bone health, but its levels and impact on osteoporosis (low bone mineral density, which results in fragile bones) in hemophilia patients has been little studied, especially in younger patients. A group from Egypt presented a study at ISTH that showed that a group of young hemophilia patients (average age 12.2 years) did indeed have significantly lower levels of vitamin D, as well as low bone mineral density. They found a significant association between hemophilia severity and both vitamin D deficiency and bone health markers that could negatively impact future bone health status. [ISTH 2020 abstract PB1054]

Previous studies have shown that the American population overall tends to have low vitamin D levels. This study suggests that the problem could be even worse in people with hemophilia, including younger patients. Take your vitamins!

Activated Protein C and Bone Health

7/12/20 Activated protein C (APC) is an anticoagulant that helps to control clotting. Like many other proteins in the body, it also has other jobs, one of which appears to be maintaining bone health. It is known that osteoporosis is an aspect of hemophilia, but the actual cause is unknown. Some researchers have suspected that the decreased amounts of thrombin generated when hemophilic blood clots could be the cause of the reduced bone density. Thrombin is the final enzyme generated in the clotting cascade. It converts fibrinogen to fibrin. Fibrin is a sticky protein that gloms together to form a clot.

Working with hemophilia A mice, the researchers found that thrombin actually tends to decrease bone density, so the fact that hemophilia patients produce less thrombin is actually good. What they also found was that APC worked to increase bone density. Therefore, higher amounts of APC are beneficial. Unfortunately, the clotting defect in hemophilia that results in less thrombin formation also results in less APC formation. It's a tricky situation since increasing APC generation reduces clotting. Research continues. [ISTH 2020 abstract PB0853]

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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 25, 2020**
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 25, 2020. 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: _____

Please give an exact description of your child's wish item.
Gifts will be purchased and sent to your home.

Child's Name and Age:

Child's Name and Age:

Child's Name and Age:

Wish List:

Wish List:

Wish List:



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



Emergencies happen. What go-to items do you pack in case of an emergency?

Give us a peek inside your emergency bleed kit and tell us what your basic and special supplies are, and why. For example, are there certain types and sizes of bandages that you prefer?

We are asking all of our members because this information is something we can offer as a useful resource for everyone in the future—so your ideas are very important. Please send your ideas to Rocky Williams at rockyw@hemob.org.



THE COALITION FOR
HEMOPHILIA



SAVE THE DATES

Things are different now, but together we are going to keep things as normal as possible! Our mission is the same, only the format has moved online for bringing education, advocacy, resources, and support to families everywhere living with hemophilia B!

August 19

Generation IX Virtual Hangout

September 8, 10, 15, 17, 22 & 24

Generation IX - Virtual
Advocacy

September 17

Let's Play IX Golf In-Person
Event (venue TBA)

October 2, 3, 4, 9, 10 & 11

Virtual Symposium

October 26, 29 &

November 2, 5, 9 & 12

Generation IX - Virtual
Mentorship Training - Young
Adult Mentors

October 29 &

November 5, 12

Generation IX - Virtual
Mentorship - Mentors & Teens

November 6 - 8

Women's Virtual Retreat

November 20 - 22

Men's Virtual Retreat

December 4 - 6

Women's Virtual Retreat

December 11 - 13

Men's Virtual Retreat

**SNEAK PEAK AT 2021
30TH ANNIVERSARY YEAR!**

Virtual Meetings on the Road
Saturdays in January, February
and March! Each meeting will
have designated states.

**Annual Symposium In-Person
June 4-7, 2021**



"ON THE ROAD" VIRTUAL MEETINGS

January 9, 2021

January 30, 2021

February 27, 2021

January 16, 2021

February 6, 2021

March 13, 2021

January 23, 2021

February 20, 2021

March 20, 2021



Each Virtual on the Road Meeting will have designated states.
Further information to follow.



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

VISIT OUR SOCIAL MEDIA SITES:

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Twitter: <https://twitter.com/coalitionhemob>

Instagram: www.instagram.com/coalitionforhemophiliab

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



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



inspired!

Stories and artwork from teens in the Hemophilia B Community

SUMMER 2020

IN THIS ISSUE:

- Andrew D. - PSONE: Positivity Shall Overthrow Negativity Energy
- Parker F. on Becoming a Music Mogul
- Join the Teen Task Force!
- Gen IX Virtual Mentorship Program
- Let's Talk Mental Health
- The Beats



PSONE Positivity Shall Overthrow Negative Energy

Andrew DiGiovanni, aka YungMischief, discusses his music and how having hemophilia B influences him.



Parker Feagins on Becoming a Music Mogul

Andrew D.
PSONE
Positivity
Shall Overthrow
Negative Energy

BY ROCKY WILLIAMS



When he was just five years old, New Jersey native Andrew D. discovered his passion for music. “I fell in love with words and phrases in songs,” he said. “I was influenced by old school boom bap music at a very young age before any other type of genre of music.”

When he was just five years old, New Jersey native Andrew D. discovered his passion for music. “I fell in love with words and phrases in songs,” he said. “I was influenced by old school boom bap music at a very young age before any other type of genre of music.”

Now 17, Andrew has started making his own mark on the music scene. In September 2019, he started releasing his own music on SoundCloud, an online music platform, under the stage name YungMischief. He uses a program called FL Studio to create the sounds of instruments and weave them together into songs. His friend Lansingburgh helps him mix the songs, but YungMischief is also learning to mix himself.

As a result of his hard work, YungMischief has achieved more than 20,000 streams/plays of his songs and got more than 400 followers in less than a year. He has even started helping fans write and create their own music.

“Music genuinely means the absolute world to me,” he said. “I remember hitting 1,000 streams/plays in total and it meant so much to me because I was just getting started—but as I was going through this path of becoming a music artist I realized it’s just numbers. What I get out of this is many other accomplishments as well. As soon as I release a song, I try to make it sound better than my last. The feeling that I get is very determined and also humble because I still have a long way to go and I still have many things to learn.”

Living with severe hemophilia B has had a big impact on his music. “I write my past/present emotions in songs that have dealt with my hemophilia,” he said. “I try to make these emotions relatable to my audience, which really helps me with fan engagement.”

In one song, called “I miss you” featuring Shiloh Dynasty (produced by TENX and mixed by Lansingburgh), YungMischief confronted some of his struggles with hemophilia directly in his lyrics and resolved to surround himself with positivity. “You gave me these scars now I’m bleeding,” he wrote in the lyrics, recalling his experiences with internal bleeding and getting hurt all the time.

“Ima turn all my pain into happiness”

“Forget about torture and loneliness“

“Cause Ima be better than who I am”

“Said Ima be better than what I am”

“These lyrics I created were inspired by the feeling of wanting change,” he said “This was myself going through the stage of understanding that I cannot run from what I have. I’ve always felt lonely because of having to deal with the obstacles and challenges with hemophilia. I came to the realization that I couldn’t just sit around and face depression because of my blood disorder. I had to become stronger.

Parker F. on Becoming a Music Mogul

Parker F. is a teenager who doesn't let his hemophilia B get in the way of pursuing his dreams. A lot of people want to be on stage—but Parker wants to be the guy behind the music. The 15-year-old from Knoxville, Tennessee, has been producing music since seventh grade and runs his own business called YP Entertainment.

"I manage artists, which means I control business decisions related to their brand such as when music is released, what music is released, and how it is marketed," Parker said. "My involvement with their music starts as soon as they have created it. I have to license samples, get cover art, plan marketing, and merchandising efforts, and send the music to distributors to be published."

Today, he's currently managing two artists: one makes a subgenre of rap called drain and the other makes indie-pop music. The self-described lover of all kinds of music said that getting involved in music management and production has changed the way he listens to music. "Being involved in the music business has made me a lot more perceptive to what goes into a song," he said. "When I listen to a song I consider what makes somebody want to listen to it and how it was marketed."

With the support of his family, Parker has even started to tackle some of the more difficult aspects of music management: understanding the legalities of copyrights and distribution. "The legal system surrounding music is set up in a really ambiguous way that makes it hard to navigate what you can and can't do without a lawyer," he said. "There are contradictory copyright laws, and restrictive rules about sampling."

This past April, for example, an artist Parker manages released an EP titled "Tiger King" that included a cover of a song by Joe Exotic, an eccentric zookeeper who was recently the subject of a Netflix documentary also called "Tiger King." Parker explained, "After it was released we were sent a takedown notice from our distribution company for the entire EP. We found out that Joe Exotic actually didn't make any of his music and the rights were owned by the original creators, so we had to remove the cover from the EP and rerelease it after clearing it with



their legal team."

Challenges aside, Parker has been enjoying getting to know the business, his artists, and the accomplishments they achieve together. His biggest accomplishment was acquiring the rights to an artist's catalog, which he'd helped the artist develop over the course of eight months, and selling it for \$4,000. "Seeing a tangible outcome from my work made me feel more confident about turning music into my career," he said. "I want to get my MBA, and my dream is to work for myself. In five years I would like to own my own management and promotion business."

He's even worked with a fellow member of the hemophilia B community—Andrew D. "I helped Andrew set up a distributor account and we discuss marketing music sometimes," Parker said. "I love interacting with people and helping their ideas become a reality. I have made many friends and hopefully will be able to turn music management into a career."

Parker's interest is an example of how powerful music is in uniting people. The Coalition for Hemophilia B agrees and offers the Beats Music Program to the community with the same goal in mind. It is designed to connect and to build strong relationships through music.



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



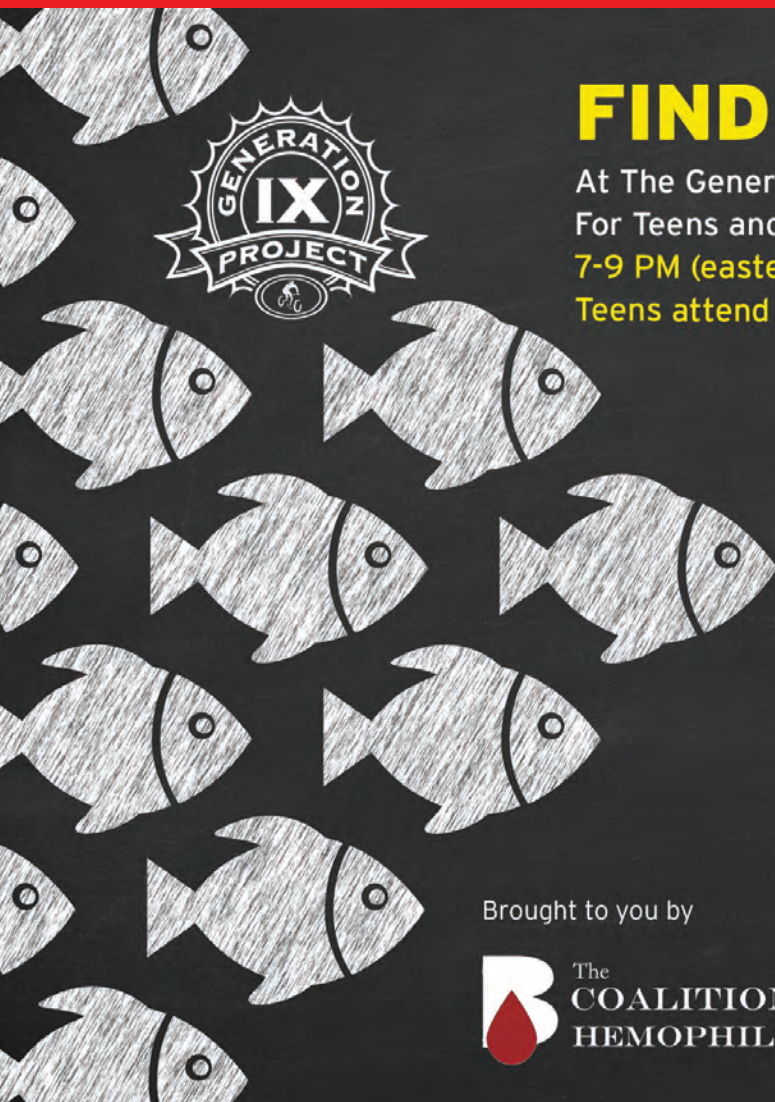
Join the Teen Task Force!

The brand new Coalition for Hemophilia B Teen Task Force will lead a very exciting project: reimagining the teen section of our newsletter.

Our newsletter goes out four times a year to the entire hemophilia B community, and we are looking for teens, parents, and anyone else who's interested to help us explore new topics, highlight incredible personal stories, and ensure the opinions and ideas of teens are well represented.

However you want to be involved—pitching ideas, writing, reporting, taking photos—we'd love to have you! This is a great opportunity for budding writers, editors, and journalists to gain experience in a volunteer communications role.

If you like writing, have some cool ideas, or just want to be involved, please join us! We will meet once monthly. Contact Rocky Williams at rockyw@hemob.org.



FIND YOUR DIRECTION

At The Generation IX Project's **VIRTUAL MENTORSHIP PROGRAM** For Teens and Young adults in the Hemophilia B community.
7-9 PM (eastern time) virtual sessions from Oct 26 - Nov 12
Teens attend Thurs and Mentors attend Tues and Thurs

APPLY BY OCTOBER 12TH!
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LET'S TALK™

MENTAL HEALTH

You won't want to miss the new film *Let's Talk*, streaming Saturday, October 3rd at 7:00 pm EST during The Coalition for Hemophilia B Symposium! It's sure to be a highlight of the weekend! Join Pat Lynch to view the powerful new film *Let's Talk*, an immersive journey through the lives of five members of the US bleeding disorders community, as they open their hearts and lives to show how we can gain strength through struggle, and that perhaps we aren't so different after all.

Made by Believe Limited and produced in partnership with Mental Health Matters Too, the film is intended to spark conversation, increase awareness, and decrease stigma. We're honored to present the film and excited to share it with you!

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www.LetsTalkMH.com



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