THE COALITION FOR HEMOPHILIA B

HEMOPHILIA B NEWS

NATIONAL NONPROFIT ORGANIZATION

SUMMER 2022

WOMEN'S EDUCATION & EMPOWERMENT RETREAT

AN EVENING OF CELEBRATION

GEN IX MENTORSHIP

MEN'S EDUCATION & EMPOWERMENT RETREAT

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MISSION

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

An Evening of Celebration

BY GLENN MONES

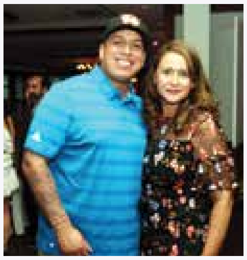
On Thursday, August 11, members and supporters of The Coalition for Hemophilia B gathered in festive celebration for the 2022 Eternal Spirit Award Gala. The event was held at the beautiful Mansion at Oyster Bay in Woodbury, New York, a 1918 estate that once belonged to industrialist Andrew Carnegie. The spacious venue allowed guests to come together safely and comfortably. The special theme was an *Evening in Paris.*

The highlight of the evening was the presentation of the Eternal Spirit Award. It is given annually to two individuals for their strong dedication and commitment to improving the quality of lives of those in the hemophilia community.

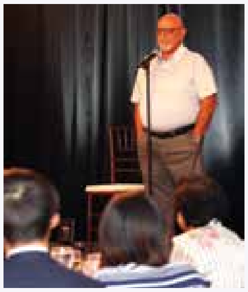
This year's recipients were Roshni Kulkarni, MD, and Ellen Kachalsky, LMSW.

Dr. Roshni Kulkarni is Professor Emerita, Pediatrics and Human Development at Michigan State University, former director of Center for Bleeding and Clotting Disorders and Pediatric Hematology/Oncology (PHO), and former Director, Division of Blood Disorders, Centers for Disease Control and Prevention (CDC) in Atlanta, GA. She is a founding member of the Foundation for Women and Girls with Blood Disorders, a member of the World Federation of Hemophilia Women with Inherited Bleeding Disorders Committee, CDC and National Hemophilia Foundation committees. She has received numerous awards including Hemophilia Foundation of Michigan, Women Leaders in Hematology, NHF's Physician of the Year, MSU Distinguished Faculty, and Federal Drug Administration and CDC 's Distinguish Service awards. Dr. Kulkarni has been a guest speaker at The Coalition for Hemophilia B and other community events. She has demonstrated a deep commitment to serving people affected by bleeding disorders.

Ellen Kachalsky, LMSW, ACSW is a social worker who has worked in the hemophilia arena since 1999. Before that, she worked in hematology and oncology, family practice, and the ICU and step-down units at Harper Hospital, Sinai Hospital, Providence Hospital, and St. Mary Hospital. She also worked for three years at HUD-subsidized senior congregate living helping residents maintain their independence by linking them

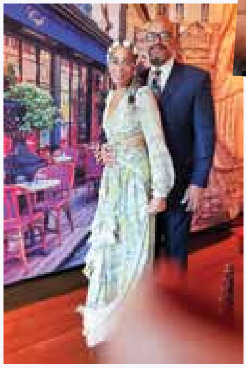













with community resources and providing support, counseling, and programs.

Ellen enjoys teaching clients about the ins and outs of insurance so they can get the maximum benefit from their plans. She helps them realize their full potential in education and employment so they may lead happier and more productive lives while dealing with pain and other issues related to bleeding disorders. She is a frequent and popular speaker at The Coalition for Hemophilia B programs across the country.

Both recipients delivered acceptance speeches that touched all our hearts.

The special night featured the presentation of the William N. Drohan Memorial Scholarship, created to recognize deserving young community members with hemophilia B or their siblings. Nine scholarships were awarded, and three recipients were in attendance this evening.

Dr. William N. Drohan, Ph.D., was a well-known microbiologist and educator who will be remembered for his many contributions to science. He was a pioneer in using molecular biology to produce recombinant proteins and a visionary scientist who dedicated his life to improving the safety of blood and blood products.

Other important contributions include investigating Bovine spongiform encephalopathy (BSE), commonly known as mad cow disease, in the blood supply and his development of novel ways to treat traumatic injuries including bandages to stem hemorrhage.

Dr. Drohan's career included important positions with the National Cancer Institute, the American Red Cross, and private companies dedicated to treating bloodborne disorders, most recently as Chief Scientific Officer at STB, Ltd., as well as Chief Scientific Officer at Inspiration Biopharmaceuticals, Inc. and previously, Chief Scientific Officer at Clearant, Inc. He was a Board Member at The Coalition for Hemophilia B when it first began in the early 1990s. Bill served as Professor in the Graduate Program of the Department of

Genetics of George Washington University and formerly as Adjunct Professor in the Department of Chemical and Biochemical Engineering at the University of Maryland. Dr. Drohan published more than 145 scientific papers and holds 30 U.S. patents.

Three children of William N. Drohan were present to deliver the awards and shared heartfelt remarks on how much honoring the awardees and their late father's memory means to them. While the awardees receive a beautiful Bennett gallery sculpted award, the custom bobble heads were the biggest hit!
The Gala also featured entertainment and our ever popular raffle. Patients shared heartfelt testimonials about how the Coalition for Hemophilia B helped improve their quality of life.

Many thanks to our guests, community members, volunteers, staff and everyone who made this wonderful event possible. Special thanks to the talented Renae Baker who served as MC for the evening. It was a delightful evening, and we are very grateful to all our sponsors for their support in helping CHB continue to provide scholarships and support our patient assistance program.

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MEN'S EDUCATION AND EMPOWERMENT RETREAT

BY CHAD STEVENS

In June of this year, we came together for our first in-person Men's Retreat since the beginning of the pandemic. Held at the Arizona Grand Hotel in Phoenix, AZ, it was a pleasure to see some familiar faces and to meet a few new members of the "B" community. With COVID still a threat, the first order of business for each participant and speaker to take a COVID test.

We opened the event with a breakout session called "Transitions through the Ages" which I facilitated alongside the always entertaining Carl Weixler. This was followed a session geared for fathers called "Let's have a Conversation" led by community member Matt Sclafani.

Each morning of the retreat featured a physical activity with a choice of either a nature walk led by Matt or Aqua Therapy 101 with Erin Dupree. Swimming lessons were also offered by Carl.

Day two began with a great presentation on practical tips to improve communication skills. The takeaways could be applied to our daily lives, whether speaking with a significant other, coworkers, or a medical professional. We then had two breakout sessions. "Aging with Hemophilia" focused on financial planning and retirement, and 'the Road to Independence" was geared toward young adults and fathers. We then had the opportunity to express our "inner artist" with a try at some landscape painting followed by some fun games at the "Bleeder Olympics, a tradition at the men's retreat.

The final day featured "Cooking with Heart" with Chef Mike Hargett. Mike showed us how to make a delicious Asian-inspired salad using ramen noodles, a staple in the diet of many college students. Mike also shared his personal story of having hemophilia and undergoing two organ transplants. He also taught the group safe cooking techniques such as the correct way to hold a knife when chopping food.

This was followed by several information sessions. One focused on stress management with therapist, author and person with hemophilia by Matt Barkdull. Matt taught some techniques to lower stress. A session with Mark Zatyrka discussed medical Cannabis and pain relief. Dr. Robert Friedman presented the "Akers Science of Happiness" and how we can achieve a more fulfilling and happy life. Finally, attorney Donnie Akers discussed "drowning in debt - financial dos and don'ts," featuring ways to avoid making bad financial decisions, our options with dealing with creditors including tools such as the Fair Debt Collection Practices Act, and if necessary, bankruptcy tools.

After dinner, the night concluded with members of the Native American Hopi Nation teaching participants the art of making dreamcatchers which they believe catch the negative energy in the web while allowing the positive thought and energy to pass through. The tribal elder also shared stories of his nation and others.


Key to Happiness
"The Comfort Zone"

A FEW COMMENTS FROM THE PARTICIPANTS:

"Feeling stronger after the empowerment of the Men's Retreat."

"The Hemophilia B Men's Retreat is always a winning event ... new bonds are always made, old friends reunite, and you will most certainly leave with some valuable information."

"The Coalition for Hemophilia B Men's Retreat allows us to bond and share our stories with the understanding that what is said there remains with all the participants. Safe zone!"

"The power of the men's retreat is undeniable. Quality time that fosters brotherhood."

"Spending time with my blood brothers filled my cup! Allowing time to openly share what's on our minds including successes, struggles, and everything in between with people I can identify with was such a help and a treat. I'm looking forward to the next event with eagerness!"

Many thanks to our generous sponsor Pfizer, our staff and volunteers and, of course, our participants for making this special event possible.

Pfizer

BCares

THE COALITION FOR HEMOPHILIA B PATIENT ASSISTANCE PROGRAM

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

SHANNON L. ALDER

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

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

LEARN MORE hemob.org/bcares

PLEASE DONATE hemob.org/donate

The Coalition for Hemophilia B
Email: contact@hemob.org
Phone: 212-520-8272

1970
First patients ever receive gene therapy

1997
First rFIX products approved by FDA

1999
First gene therapy trial in hem B

2018
Late-stage trials for gene therapy in hem B underway

EVERY STEP HAS BEEN EVOLVING THE SCIENCE OF GENE THERAPY IN HEMOPHILIA B

We're working to make gene therapy a reality for you.

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Explore the advancing science behind gene therapy at HemEvolution.com

Biotherapies for Life®

CSL Behring

WOMEN'S EDUCATION AND EMPOWERMENT RETREAT

BY ERICA GARBER

Laughter and tears of joy were in the air this summer as women from around the country came together in person for the first time since 2019 for the Coalition for Hemophilia B's Fall Women's Retreat. The event was held at the Arizona Grand Resort in Phoenix from June 23rd to 26th.

The program was an opportunity for women in the hemophilia community, including women living with a bleeding disorder and caregivers, to share a weekend of self-care, self-love, education, and advocacy that not only impacts the women themselves but also their families.

Our daily self-care practice and morning rejuvenation began with a healthy dose of listening to our bodies, sweating, moving, and laughing with our friends. We took in the vast Arizona desert and became one with the cacti on a guided walk with community member, wife, mother, and volunteer Brittany Williams. We had the joyful pleasure of water aerobics led by Erin Dupree, a certified personal trainer and fitness coach specializing in inclusivity at all fitness levels. We also kicked off the weekend with a special presentation from new community member, holistic nutritionist, health coach, and chronic condition educator Vanessa Vitali. Vanessa taught the women her framework of natural approaches for bringing our bodies into balance.

The participants attended a variety of sessions that provided them with education and information they can use to tackle the challenges that can accompany hemophilia B. Executive coach and leadership speaker Natalie Sayer taught us practical tips to improve our communication in everyday life and identify the best ways to advocate for ourselves whether we are speaking with our significant others, medical professionals, or work peers. We learned about navigating disability, finances, work, and career in the presence of a bleeding disorder with Ellen Kachalsky, LMSW, ACSW.

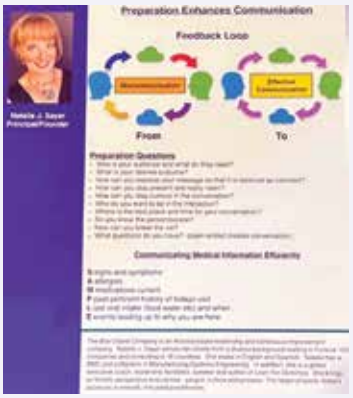
We had the great benefit of Dr. Danielle Nance's 14+ years of experience as a hematologist, patient advocate, and educator in the bleeding disorder community, and her special research interests in bleeding disorders, and in women's health particularly during the reproductive years and pregnancy. This

powerful conversation taught us so much and answered many lingering questions about recognizing excessive bleeding in women and how to ensure our voices are being heard by our healthcare providers.

Dr. Mina Nguyen-Driver joined us for a relevant and timely session on the emotional impact of being a woman caregiver in our country today. Women comprise nearly half of the workforce, yet we still shoulder a significant amount of household responsibilities. Bringing with her over 20 years of experience providing mental health treatment for patients and families with bleeding disorders she reminded us not to lose sight of ourselves as we care for our families.

Several sessions looked at ways that women can become empowered, whether physically, mentally, or as advocates. The women in attendance had the opportunity to learn from Rachel Cooper-Leal and Jackie Mosca, two Patient Affairs Liaisons with Pfizer Rare Disease. Rachel led an important discussion on the unique challenges of hemophilia with an intimate group of new moms, caregivers, and women bleeders, providing practical tips to help them become self-advocates in many areas of life. Jackie presented to us an overview of how emotional health impacts the hemophilia community, what signs and symptoms to look for, and how to encourage dialogue with caregivers and health care providers. We left the conversation with important guidance on how to balance our emotional wellness.

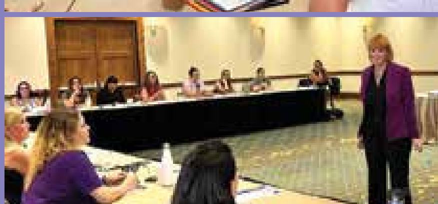
Over this weekend the women tapped into their creative side with a variety of arts, crafts, and cultural experiences. Through storytelling, jewelry making, and rock painting, Kelly Gonzalez, a patient, a parent, and spouse in the rare disease community, showed us how to build healthy habits to prioritize our mental wellbeing as we care for others. We also welcomed a new member of the CHB team and arts educator Erica Garber into the community. She led the women through a journaling exercise about our dreams and memories and then creating expressive watercolor paintings. By sharing our ideas and work with each other we told the story of our dreams as a therapeutic exploration with art and community care. On our final night we had a recognized local elder from the Sun Clan of the Hopi Nation, Palmer Lomakema, join us to share the cultural significance of the circle and dreamcatchers, the history



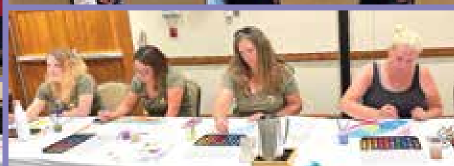






















of his people, and guide us all in making our own dreamcatchers with personal symbols and meaning.

Keeping with the theme of sharing stories and feelings in ways that are deeply empowering, the attendees gathered for several special community led sessions. In the two rap sessions, the community facilitators worked together to create a safe, nurturing space for the participants to share their stories and feelings. Farrah Muratovic and Kelly Gonzalez kicked us off with a silly game of purse bingo. On the second night Stormy Johnson and Tiffani Pokrajac led us in a women's sharing circle called Chit, Chat, and Chocolate, opening their hearts, sharing their stories, and enjoying the sweetness of chocolate and friendship. Women took advantage of these safe spaces to ask essential questions and learn from each other's unique experience in the hemophilia B community. These are the moments we have all come to look forward to and have missed the most in these past two years of social distancing and isolation.

The retreat featured many opportunities for the women to gather in small groups, make new friends, and share strength and support. Everyone left feeling empowered, refreshed, and equipped with tools and connections of a lifetime. If you have an interest in attending retreats in 2023, please check our website at hemob.org for more information and registration as it becomes available, or email farrahm@hemob.org The Coalition for Hemophilia B would like to express our deep thanks to the event sponsor, Pfizer. We would also like to thank the many presenters, volunteers, team members, and of course the participants for making this amazing program possible.

ATTENDEE COMMENTS:

"The women's retreat is an amazing opportunity to meet other women going through the same thing and moms that care for their children with hemophilia. I left feeling grateful for the new friendships and education I received at the retreat."

"Attending the lady's treat with my hemo B family is seriously one of my favorite events of the year. I love learning from each one's unique personalities and experiences. The bonds you form are more than friendships and so much more than you can explain to an outsider!"

"This year's women's retreat was a blast!!"

"I love going to the women's retreat. It is always amazing to visit those dealing with similar life events."

"Being at the Women's retreat really makes you feel part of something bigger. And it is amazing."

"This community is unmatched, and it was so nice for this group to come together and support one another to live the best quality of life possible, not only for themselves, but as caregivers for the next generations to come."

"It was a dream to spend a weekend with other women going through the same journey as me. We bonded over chocolate, bracelets, tears and amazing food. 10/10 would recommend!"

"As a first time in person attendee to the Women's Retreat, it was amazing to receive the support and self-care I needed. Thank you for making it possible."

GEN IX MENTORSHIP

BY JACOB POPE

The Coalition for Hemophilia B, along with GutMonkey and the program's sole sponsor, Medexus Pharma, hosted an experiential Mentorship learning program for Teens and Young Adults as part of the ongoing Generation IX Project. Held the first week of June, the program was hosted at the YMCA Camp Collins from May 31st to June 5th for young adults and June 3rd to 5th for teen participants.

Nestled in a temperate rainforest near Portland, Oregon, YMCA Camp Collins is the original home of the Generation IX Project Mentorship experience and offers the perfect balance of getting away and modern amenities. The reason for the choice of Camp Collins was immediately evident from the serenity participants feel walking underneath the great timber archway entrance but becomes even clearer through group and self-exploration of the grounds and in the ways, participants engage with the site's facilities during programming.

Mentors explored the camp right away by learning to fly fish on the Sandy River and by testing out the many trails used for getting down to the riverbank. GutMonkey's Margaret coached mentors through the basics and gave us plenty of time to learn by trial-and-error with helpful tips. Mentors then kicked things up a notch with a radical dance party to jump-start the creative energy needed to organize a transformative three days for the mentees, followed by a deep-dive into the program's theme – Radical! – and self-reflection on what radical meant to us. As always, GutMonkey and The Coalition came prepared with ingenious and stimulating prompts and activities. These prompts and activities nurtured values like choosing your own challenge and taking space, making space – affording mentees and mentors alike the chance to step up or to sit back and take things in as they please every step of the way.

As someone who has a fear of heights, I arrived in Oregon with some apprehension about the high-ropes course and an adrenaline-packed "secret activity." However, this fear became an unexpected highlight of the program for me thanks to the patience, kindness, and expertise of the program facilitators. Learning how to engage safely and with more kindness toward myself in that scenario – 30 feet off the ground, harnessed from waist to shoulder with a helmet – taught me how to re-engage that fear and other fears with better outcomes back home.

The best part about GenIX Mentorship is just that – mentors and mentees learning from each other and growing because of the support afforded to one another. To paraphrase another memorable program takeaway: healing and growth do not happen in isolation, but within the context of relationships. I witnessed and was moved by the friendships teens formed with each other, the joyful conversations and plentiful laughter each minute of the day, and the sense of community that blossomed out of the adventure education challenges and communal living aspects of GenIX Mentorship. It was radical to witness.

















For those who are on the fence about attending Mentorship next year, I would certainly recommend reaching out to The Coalition for Hemophilia B for additional information. Everyone was given the help that they need and even received a call from medical staff in advance to help participants create and stick to their plan of care while on-site. Traveling with hemophilia has gotten easier over the years, but I appreciated knowing that skilled and experienced medical professionals were available leading up to and throughout the duration of the program for those unexpected bleeds so many of us have experienced. Parents and teens can also feel at ease while traveling far from home knowing The Coalition takes every step available to make sure teen participants are in safe hands from the moment teens land in Portland to the moment they touchdown back home.

None of this would have been possible without Medexus, the sole corporate sponsor of this amazing program. I have deep gratitude for Medexus, as well as the speakers, facilitators, and The Coalition for Hemophilia B staff that do so much for everyone in attendance. Many more programs are planned for the year and into 2023, so please check the Coalition's website at www.hemob.org to register for the programs that are most meaningful to you and your family. See you soon!

Some of the things participants had to say about the program:

"The thing I like about the Gen IX Mentorship is that all the people in the group get to share what it is like for them to have hemophilia and get how hard it can be sometimes to treat it. What the Gen IX program means to me is that you're not the only one in the world that has a bleeding disorder, and that you can have people that can understand how hemophilia works and how it affects you."

"Gen IX means everything to me. Ever since the first one in October of 2014, something that keeps me coming back is the educational element of the programs. Each time there's something new to be learned and the way they teach it to us never gets old and always a new twist to it."

"I enjoyed how the programs bring us all together as a community and give me an outlet to possibly pass on some experiences to teens/young adults while those memories are still fresh."

"Generation IX Mentorship 2022 was RADICAL! It brought about many new friendships that were bonded through conversations about how people with bleeding disorders can exit societal norms and how we can choose to live our most authentic lives. We stepped into our growth zone climbing high ropes courses, visiting a farmer's market in Portland, and hunting for public art. We even saw "RENT" at a local theater! The nurses led a thoughtful and educational discussion based on questions us mentors and teens asked about our bleeding disorder. Gen IX is incredibly important to me, and I live my life more and more genuinely after every trip!"

Emerging Therapies

BY DR. DAVID CLARK

There is a huge amount of new product development going on in hemophilia B. The potential new products can currently be separated into three categories, 1) improved factor products, 2) rebalancing agents and 3) gene therapy. These updates are divided into those three categories. Within each category, the entries are generally listed in order of the names of the organizations developing the product.

A number of the studies described below were presented at the annual meeting of the International Society on Thrombosis and Haemostasis (ISTH), July 9–13, 2022. Abstracts (summaries) of the studies are available for free on the ISTH website: https://www.isth.org/

IMPROVED FACTOR PRODUCTS

These are improved versions of the factor products that most people with hemophilia B are currently using. The improvements include longer half-lives and delivery by subcutaneous injection.

What's Happening at Catalyst Biosciences?

8/15/22 Catalyst Biosciences has been developing three products for hemophilia B: 1) a higher-activity longer-lasting subcutaneous factor IX product, 2) a higher activity longer-lasting subcutaneous factor VIIa product for inhibitor treatment and 3) a gene therapy. All have been getting promising results, some of which were reported at ISTH. However, it appears that Catalyst is on the road to closing the company. Their hemophilia products are for sale, but it is unclear whether anyone will buy them. [ISTH abstract OC 40.5 and Catalyst 2nd Quarter Report]

Genentech/Roche's Hemlibra for Hemophilia B?

7/9/22 Genentech/Roche produces Hemlibra for hemophilia A. It's been a blockbuster product for patients with or without inhibitors that has taken over a lot of the hemophilia A market. In theory, Hemlibra shouldn't work for hemophilia B – or does it? A study from Children's Hospital of Philadelphia and the University of Pennsylvania presented at ISTH provides some very interesting results.

Hemlibra is a bispecific antibody that binds to both activated factor IX (FIXa) and factor X (FX). It mimics the action of activated factor VIII (FVIIIa), which does the same thing so that FIXa can activate FX to carry on the clotting process. Since most hemophilia B patients have normal FVIII, Hemlibra shouldn't add anything to their ability to clot. But that's taking a bird's-eye view of the situation.

Down to earth, we have to look carefully at what's really happening with FIX in Hemophilia B. Not all FIX gene mutations are alike. Some mutations affect the reactivity of FIX; the ability of the molecule to activate FX. Other mutations affect the regulatory part of the gene; the part that controls how much FIX is made. Some people have large mutations which keep the body from being able to make anything that is even similar to FIX; they've lost the recipe. However, some people have mutations in the part of the FIX molecule that affect binding to FVIIIa. Since Hemlibra binds to a different part of FIXa than FVIIIa does, maybe it could still help bring the mutated FIXa into contact with FX to form FXa and continue the clotting process.

Well, it turns out that maybe it can! These experiments haven't been done in humans yet, but with hemophilia B patient blood samples in the lab it looks like Hemlibra can actually help correct the clotting deficiency for patients with FIX mutations in the section of the molecule that affects binding to FVIIIa.

Now this wouldn't work for all Bs – only those with certain mutations. Since many patients have now been genotyped (their FIX gene has been analyzed to determine their mutation), and since we know enough about the FIX molecule to be able to determine whether that mutation affects FVIIIa binding, we can guess pretty well which hemophilia B patients might be helped by Hemlibra.

Since Hemlibra is a licensed product and a physician can prescribe any licensed product for any indication, somebody might just try this. Stay tuned. [ISTH abstract OC 50.3]

Novo Nordisk Receives Approval for Rebinyn for Prophylaxis

7/29/22 Novo Nordisk announced that the FDA has approved a prophylaxis indication for Rebinyn, their extended half-life factor IX product. Some people may already be using Rebinyn for prophylaxis. Doctors can prescribe any licensed product for any indication, but manufacturers can only market/advertise them for indications that have been approved by FDA. [Novo press release 7/29/22]

Rebinyn and PEG

8/27/22 Novo Nordisk's Rebinyn is an extended half-life factor IX that uses polyethylene glycol (PEG) to increase its time in circulation. The long PEG chains attached to the factor IX molecule wrap around the molecule, hiding it from the cells that want to break it down. PEG has been used with a number of drugs and has a good safety record. However, Rebinyn is one of the few PEG-tagged products to be given repeatedly over a number of years, so there is more concern about possible risks.

A group of mostly Danish scientists (Novo Nordisk is a Danish company) has published a study of the effects of Rebinyn on juvenile rats. They found that there was no effect on the rats' neurodevelopment, growth, sexual maturation or fertility and there were no clinical or histological abnormalities seen. This all helps to support the safety of Rebinyn for prophylaxis in children. [Jensen VFH et al., Int. J. Toxicol., online ahead of print 8/27/22]

REBALANCING AGENTS

Rebalancing agents tweak the clotting system to restore the balance so a person clots when they should and doesn't clot when they shouldn't. The clotting system is a complex of clotting factors that promote clotting and anticoagulants that inhibit clotting. In a person without a bleeding disorder, the system is in balance, so it produces clots as needed. In hemophilia, with the loss of some clotting factor activity, the system is unbalanced; there is too much anticoagulant activity keeping the blood from clotting. Rebalancing agents mainly reduce or inhibit the activity of the anticoagulants in the system. Most of these agents work to help restore clotting in people with hemophilia A or B, with or without inhibitors.

Novo Nordisk to Submit BLA for Concizumab by the End of 2022

7/9/22 Novo Nordisk is developing concizumab, a monoclonal antibody that binds to and inhibits the anticoagulant tissue factor pathway inhibitor (TFPI). This reduces the amount of anti-clotting activity in the coagulation system and helps to rebalance the system. Concizumab is a daily subcutaneous injection for treatment of people with hemophilia A or B, with or without inhibitors. Novo has completed the Phase III clinical study and plans to submit their Biologics License Application (BLA) to FDA by the end of 2022.

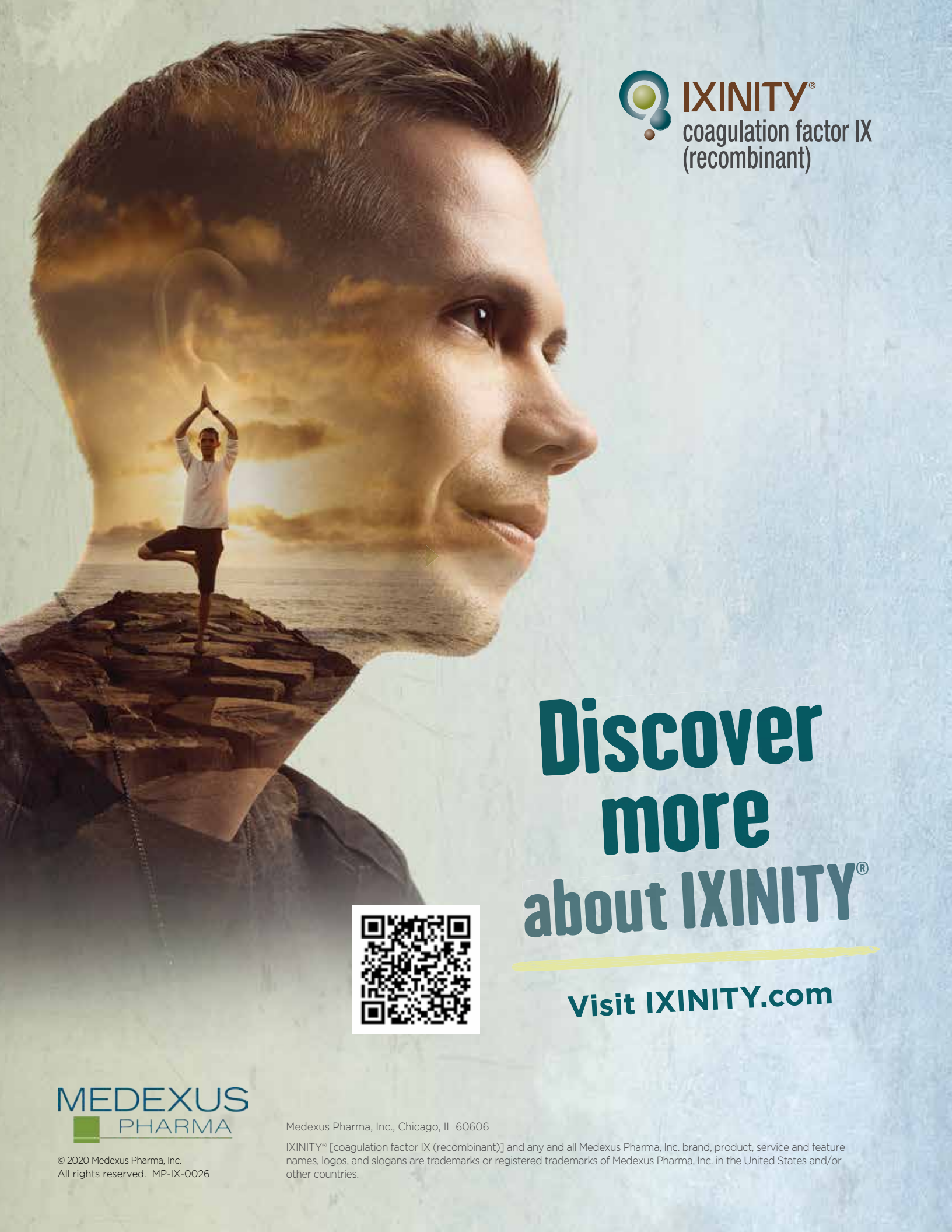
At ISTH, Novo presented the results of their studies on A and B inhibitor patients, which showed a mean (average) annualized bleeding rate (ABR) of 1.7 after 24 weeks, compared to an ABR of 11.8 for those receiving no treatment, in 133 subjects with inhibitors. The product was safe and well-tolerated and there were no thromboembolic complications (instances of internal clotting). Similarly positive results were reported previously for patients without inhibitors. A second study assessing treatment burden showed an improvement after 24 weeks on concizumab. [ISTH abstracts LB 01.2 and OC 30.3]

Sanofi Reports Updates for Fitusiran Development

7/9/22 Sanofi is developing fitusiran, a drug that reduces the amount of the anticoagulant antithrombin being made by the body. Lowering antithrombin levels appears to rebalance the clotting system. Fitusiran is a monthly subcutaneous injection for treatment of people with hemophilia A or B, with or without inhibitors.

Previously in their Phase III clinical studies, two subjects had developed thrombosis (dangerous internal clotting), one of the potential side effects of reducing anticoagulant levels. To reduce the risk, Sanofi decided to reduce the dose of fitusiran and thus leave a somewhat larger amount of antithrombin in the bloodstream, around 15 – 35% of the normal level. The studies have continued at the lower dose with positive results. However, because of the delay, Sanofi now expects to submit their BLA in 2024.

Sanofi presented four papers on fitusiran at ISTH. Two studies reported the results from hemophilia A and B subjects with (60 subjects) and without (120 subjects) inhibitors,. Both showed about a 90% reduction in ABR versus on-demand treatment. Another paper showed that both groups achieved about a 95% reduction in the consumption of clotting factor or bypassing agents. The last paper gave an interim analysis of the current Phase III study, showing good results. [ISTH abstracts PB1152, OC 50.2, OC 40.3 and LB 01.1]



Medexus Pharma, Inc., Chicago, IL 60606

Two other non-Sanofi studies looked at the effects of lower antithrombin levels. One study from Poland found that lower antithrombin levels produced a denser, more compact clot structure that was less susceptible to fibrinolysis. Fibrinolysis is the process that dissolves the clot as the injury heals. These stronger clots might be a benefit for patients with hemophilia, but they could also predict more difficult treatments for patients that develop thrombosis.

The other paper from researchers in Italy and The Netherlands showed that people with lower antithrombin levels have a lower risk of death from cardiovascular disease but a higher risk of death from cancer. Overall, death from any cause was not associated with antithrombin level. The reasons for these results are not currently known. [ISTH abstracts PB0547 and PB0539]

GENE THERAPY

Gene therapy is the process of inserting new, functional factor IX genes into the body to allow it to produce its own factor IX.

First-Ever Hemophilia Gene Therapy Approved in Europe

8/24/22 BioMarin's Roctavian (valoctocogene roxaparvovec) gene therapy for hemophilia A received a conditional approval in the European Union (EU). This is the first gene therapy for any type of hemophilia approved anywhere, so it is a major milestone. Conditional approval means that the treatment fulfills an unmet need for patients, but that additional information is still needed before a full approval is granted. Patients on Roctavian will be followed for a number of years to confirm the safety and effectiveness of the treatment.

BioMarin is proposing a cost of about $1.5 million for the treatment, which is about half of the $3 million previously discussed. However, Europe has strong controls on drug prices, so the cost will probably be higher once it is licensed in the U.S. They plan to launch the product first in Germany and then in France. Roctavian was also granted Orphan Drug Designation (ODD), which will give it ten years of market exclusivity in the EU. ODD is supposed to encourage development of drugs for rare diseases. The FDA has a similar program, but ODD programs are controversial. Roctavian's ten-year exclusivity could also discourage other companies from developing similar products during that period. [BioMarin press release 8/24/22]

GeneVentiv Developing Factor Va for Hemophilia Gene Therapy

8/5/22 Scientists at the University of North Carolina (UNC) and their spin-off company GeneVentiv are studying the potential of a gene therapy to produce activated factor V (FVa) as a treatment for hemophilia, both A and B. FVa is a cofactor for activated factor X (FXa). A cofactor is a molecule that enhances the activity of an enzyme. For instance, activated factor VIII (FVIIIa) is a cofactor for the enzyme activated factor IX (FIXa). Without FVIIIa, FIXa has a very low activity. That's why if you're missing either FVIII (hemophilia A) or FIX (hemophilia B) you have hemophilia – it takes both to do the job.

FVIIIa and FIXa together activate factor X (FX). The UNC investigators propose that if a hemophilia patient has enough FVa, the lack of FVIII or FIX won't matter much. This is another kind of rebalancing where instead of reducing anticoagulant activity, they are increasing clotting factor activity. This could also work for inhibitor patients.

The UNC researchers used an AAV8 vector to insert a FVa gene in hemophilic mice (both A and B, with or without inhibitors). They were able to completely correct the bleeding in the hemophilia B mice and got a substantial improvement in the hemophilia A mice. The presence of inhibitors did not make a difference. There were no safety issues and no evidence of thrombosis. Their work is continuing. [Sun J et al., Front. Med., 9:880763, 2022]

Hemophilia News

BY DR. DAVID CLARK

A number of the studies described below were presented at the annual meeting of the International Society on Thrombosis and Haemostasis (ISTH), July 9–13, 2022. Abstracts (summaries) of the studies are available for free on the ISTH website.

IS R.I.C.E. RIGHT?

7/3 and 7/10/22 Hemophilia patients are often counseled to employ R.I.C.E. (Rest, Ice, Compression, Elevation) to treat a joint or muscle bleed, but with what we know today, is that still the best advice? I first encountered this question in 2013 in an article by Angela Forsyth, who was then a physical therapist at the Rush HTC in Chicago. (Among her co-authors is Len Valentino, now the head of NHF.) She pointed out that ice might not be the best thing for a bleed because cold could slow down the clotting reactions.

R.I.C.E. has been recommended for over four decades since Dr. Gabe Mirkin, a sports medicine physician, coined the term in 1978. However, later research showed that ice can actually slow the healing process. Dr. Mirkin changed his mind in 2015 and now advises against icing an injury.

Rest is also being reconsidered, but instead of going into that in detail here, I want to guide you to an excellent pair of articles written by Paul Clement on Laurie Kelley's HemaBlog™, "Time to Rethink RICE?" The articles were published July 3 and July 10 at https://www.kelleycom.com/blog/. HemaBlog™ is an excellent resource that is worth reading regularly. [HemaBlog™ 7/3/22 and 7/10/22]

FACTOR IX AND THE EXTRAVASCULAR SPACE

7/10/22 We now know that factor IX exists not only in the bloodstream (intravascular space) but also inside the walls of the blood vessels (extravascular space). In the Winter 2021 issue of Hemophilia B News we published an article titled "*Where is the Factor IX and What Does It Do There?*" that gave an introduction to the subject. We might not even know about this except for the dogged determination of Dr. Darrel Stafford and his group at the University of North Carolina (UNC) who have been exploring this for years. Some of his group's results suggest that the factor IX inside the walls of the blood vessels is just as important, or maybe even more important, than the factor IX in the bloodstream.

This may be the next step in figuring out how clotting actually happens. In the beginning, people assumed that the clotting reactions take place in solution in the blood. Then, mainly in the 1970s and 80s, they realized that the clotting reactions actually take place on surfaces such as activated platelets and the walls of the broken cells at the injury site. In fact, many of the molecules that participate in clotting have sections that allow them to bind to these surfaces. This makes sense because that localizes the reactions at the site of the injury. If the reactions took place out in the bloodstream, the clotting factors would float away from the injury site. Now it may be that some of these reactions actually take place inside the walls of the vessels, which are exposed when the vessel is torn open.

We know that factor IX binds to a protein called collagen IV inside the vessel walls. Collagen is the main structural protein in the body. It's a component of bone, skin, blood vessels and many other body structures. At the 2020 ISTH meeting, a group from the UK showed that factor IX binding to collagen is important for clotting. At the 2022 ISTH meeting, they continued this work showing that collagen may cause the activation of factor IX and that the activation of factor X might actually take place on a collagen surface (parts of the blood vessel wall) instead of on a phospholipid surface (platelets and the broken walls of the injured cells). [ISTH abstract PB0187 and ISTH 2020 abstract PB0341]

One of the biggest questions about this whole idea is how does factor IX get into the wall of the blood vessel? Blood vessels are lined with endothelial cells, which form a tight barrier to keep anything from leaking out of the bloodstream. An additional clue might be contained in another paper at ISTH. A group of US researchers has shown that factor XI, which also activates factor IX, has a role in controlling the permeability of the endothelial cell layer. Could factor XI be involved in getting factor IX inside the wall of the vessel or is there another mechanism that pulls in both molecules? The paper doesn't address that, but provides food for thought. [ISTH abstract OC 28.5]

This is how science usually works. Once in a while, there is a big discovery that immediately answers an important question, but most of the time it just a long slow slog finding one little clue after another and then fitting them together like a jigsaw puzzle.

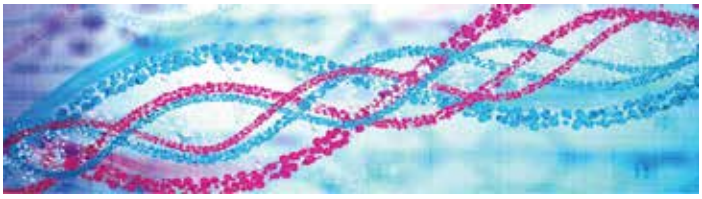
MASAC RECOMMENDS GENOTYPING

7/6/22 The Medical and Scientific Advisory Committee (MASAC) of the National Hemophilia Foundation (NHF) now recommends that most people affected by hemophilia undergo genotyping. Genotyping is the process of analyzing the makeup of one's factor gene to identify the mutation. That can give us a lot of information about what might be specifically causing a person's hemophilia.

Until we started actually analyzing people's genes, we used to basically lump everyone together, only separating them into mild, moderate or severe disease by their level of factor activity. Yet, we now know enough to look at specific abnormalities based on the genetics. For instance, hemophilia B patients might have a severely mutated gene that doesn't allow them to make anything that looks like factor IX. Others might have one small change that affects how their factor IX binds to surfaces, to factor VIII or to factor X. They might have plenty of the protein but it just doesn't work as well. Other people could have mutations in the regulatory part of the gene that controls when and how much factor IX is produced. They could have "good" factor IX, just not enough. Some people even have more than one mutation.

Knowing a person's genotype can help in planning their treatment. It is also the best way to determine a woman's carrier status, that is, whether she carries a mutated copy of the gene that she could pass on to her children. In an unusual case, in the Emerging Therapies column, we talk about how some hemophilia B patients could benefit from using Hemlibra, which is a treatment for hemophilia A. Those patients were identified by genotyping.

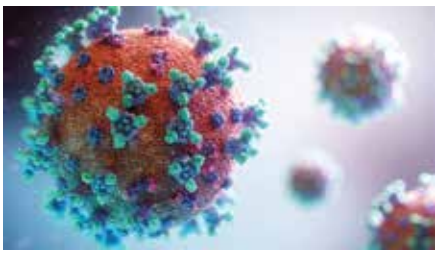
Genotyping used to be an expensive proposition, but it is now much less costly. Many patients had their genes analyzed for free in the *My Life, Our Future* (MLOF) program that ran from 2013 to 2017. In fact, much of what we now know came from the genetic databases compiled by MLOF. Now many HTCs are offering genotyping to their patients. MASAC points out that an important part of genotyping is genetic counseling to make sure that the patient understands the results. [MASAC Document 273 from the NHF website]



HEMOPHILIA AND DIABETES

3/3/22 A group from the US and Canada looked at the risk of diabetes in people with hemophilia. They found that younger people with hemophilia actually had less risk of developing diabetes than either the general population or a group of veterans who have similar mobility issues. In older subjects, the risk seems to stay low, except for those infected with hepatitis C. Hepatitis C is a significant risk factor for diabetes. Even heavier hemophilia patients seemed to have less tendency to develop diabetes, so it's not just a matter of weight. The take-home message is that hemophilia patients with hepatitis C infections should be monitored for diabetes. [Pandey B et al., Haemophilia, online ahead of print 3/3/22]

HEMOPHILIA AND COVID



7/10/22 Several papers at ISTH looked at hemophilia patients and COVID. A group from Italy (Italy was hit hard by COVID) presented a study that showed that there was no difference in the management of hemophilia patients with COVID compared to those without hemophilia. [ISTH abstract VPB0696]

Another Italian group looked at vaccination of HIV-positive hemophilia patients in their HTC. In spite of HIV's potential effects on the immune system, they found no difference in the responses of these patients to the vaccine. No one reported bleeding at the injection site and there were no serious adverse effects. [ISTH abstract PB1133]

A group from Germany reported on intramuscular injection (IM) of COVID vaccines. Patients with hemophilia are sometimes encouraged to get vaccines by subcutaneous injection (SC). However, the COVID vaccines are only licensed for IM injection. The group looked at 461 patients, both As and Bs with all severities. They found that less than 3% of the group bled after IM vaccine injection. That is comparable to the rate in the general population. Most of the subjects received factor infusions prior to vaccination. [ISTH abstract OC 70.2]

So it appears that COVID doesn't add significant additional challenges for those with hemophilia.

GENOTYPE VS. PHENOTYPE VS. PLATELETS

7/10/22 We usually divide the bleeding tendency of people with hemophilia into classifications of severe, moderate and mild based on their factor level. However, not everyone fits. There are patients whose factor IX levels put them in the severe category (<1% of normal factor level) who don't bleed that much, more like moderates. Conversely, there are moderates (1 – 5%) who bleed more like severes. The same goes for all the categories – milds who bleed more and moderates who bleed less... The reasons for these differences are currently unknown. Studies in the last few years have suggested that the differences could be due to other genetic differences besides just mutations in the factor IX gene. But genetic differences in what?

At ISTH, a group from Italy and Germany presented data that suggests that the "what" might be platelets. Platelets are the smallest blood cells and are part of the clotting system. When an injury occurs, platelets are activated and become sticky. They stick together to form a "platelet plug" that plugs the hole in the damaged blood vessel. Historically, researchers have studied platelets separately from clotting factors. However, we are learning that separating the two areas might not be a good idea. The surfaces of platelets are covered with a number of protein molecules that interact significantly with the clotting factors. These are called receptors because other molecules in the blood bind to them to cause an action.

The Italian/German group showed that small changes (mutations) in the receptors on the platelet surface can significantly affect clotting in hemophilia. If you have hemophilia B, you have a mutation of your factor IX gene that is significant enough to affect clotting. That's not the only mutation in your body. Humans have many other gene mutations in our bodies. We call the proteins that are made from the mutated genes "variants." Many variants are insignificant and seem to have little effect on our health, at least as far as we can tell. We know that there is a range of variations from person to person in the receptor variants on the platelet surface. In people with a "normal" clotting system, the different variants may only have a minor impact on clotting times, causing the usual person-to-person variation that we always see in medicine.

However, when you have hemophilia, your mutated clotting factors might not interact as well with some of the variant receptors on your platelets. The researchers measured bleeding scores for 55 subjects with hemophilia A or B, and also analyzed the receptors on their platelets. They found a consistent set of variants on the subjects' platelets that seemed to increase their bleeding scores (poorer clotting). Subjects that had those platelet receptor variants did not clot as well as subjects with similar factor IX levels who did not have the variants.

This may explain some of the variation between how we expect a person to clot based on their factor level and the way they actually bleed. The authors suggest that if this pans out with more research, physicians might need to also do genotyping (determining the structure of a gene) on a hemophilia patients' platelet receptors as well as their factor IX gene. [ISTH abstract VPB0204]

NHF'S 2022 BLEEDING DISORDERS CONFERENCE

NHF's 74th Annual Bleeding Disorders Conference 2022 was held August 25th–27th, both virtually and in-person in Houston, Texas. Wayne, Rocky, Farrah, Fel, and Jibin had a great time representing The Coalition for Hemophilia B! Thank you to everyone who visited our booth. It was so great to see you and to participate in the event!

Take Care

"Take care" is a phrase commonly used by connected people. It is usually intended to convey that the person cares for you and wants you to be okay. Given the additional stress resulting from recent events, it is time to revisit that simple phrase. What does it mean to take care of yourself? The following is an abbreviated list of some common strategies to help you cope with personal adversity.

- Get a good night sleep, eat right, and exercise regularly
- Be intentional about creating a balance between work, rest, and play
- Create realistic expectations of yourself and others
- Focus on what you can control
- Practice deep breathing coupled with soothing mantras

While all the aforementioned concepts make sense intellectually, it is quite another thing to put them into practice. Have you ever wondered why it is so hard to do things that are good for you? The answers to that question are sometimes very apparent. We feel we don't have personal time, or we feel depleted and the idea of adding one more thing to our plate seems daunting and impossible.

There are also some answers that are not so obvious. In fact, they are locked away from our conscious mind and take the form of lessons learned a long time ago. Here are some possible culprits keeping you from acting in your own best interest:

- You were raised to put yourself last
- You were told that "self care" is selfish and/or unnecessary
- Your sense of self and your self-esteem is invested in being seen as productive or heroic by others
- You were raised in a family where your needs were not met or seen as important, so you internalized that sentiment and eventually became unaware of your own needs

If some of these statements resonate with you, I would like to offer a bit of hope. There is a widely-accepted term called "neuroplasticity." In the simplest terms, it means that our brains can form new connections which, in turn, help us to form new thoughts about ourselves and the world we live in. So, what does this mean for you?

Like any personal changes, it takes deliberate attention; a commitment to look inside and evaluate where these messages came from and what you would like to do about the "truths" that are guiding your life. Here are a couple of questions which can help you get started:

- What did I learn about my self-worth, personal needs and taking care of myself?
- Is that narrative working for me in my adult life?
- Can I make a new decision on who I am and how I take care of myself?
- What can I do today that can lead to a positive personal change?

The recipe for personal change can be summed up as follows:

Awareness of what is not working for you and taking small, intentional steps that lead you in a self-loving, self-accepting direction.

Take care, friends!

Go Inside a Chrysalis, Come out a Butterfly: A Mother/Daughter Story

BY ALICIA COOK

Kathie's daughter Virginia "Belle" has moderate/severe hemophilia B, inherited from her father. Their road to navigating hemophilia B has been a rough, bumpy journey, starting the very day they realized Belle had hemophilia B.

"Belle was involved in a serious four-wheeling accident when she was only three," Kathie began. "She had an obvious head injury that the doctors struggled with addressing, then they didn't realize she also had a major muscle bleed happening in her right leg, her femur was bruised."

Kathie knew right away that this could be connected to Belle's father's hemophilia. Though the doctors brushed it off, as some often do when it comes to female bleeders and the misconceptions around them.

"We mentioned in the hospital that her father had hemophilia, he even mentioned how she was healing just like he did. The doctors of course brushed us off, telling us we didn't need to worry about that until she reached childbearing age. Well, they were wrong."

Belle was set on a path of being in and out of the hospital for her head wound that would not heal. Her father demanded the doctors run her factor levels.

"They fought us every step of the way," Kathie noted. They did not stop advocating for their daughter though.

After being in the hospital almost two weeks, it was discovered that Belle's levels were significantly low, and the doctors did administer her Factor.

That's not where this story ends though. It would take about another year before Belle would be formally diagnosed with hemophilia B. They fought tooth and nail the whole time, fighting for their daughter's health and wellbeing.

"Doctors would tell us we were wrong or misinformed!" Kathie said. "Even worse, I was even accused of being a 'drug seeking parent' and had Child Protected Services (CPS) called on me numerous times."

For the record, Kathie is not a "drug seeking parent." What Kathie is, is a protective mother who knew something was going on with her daughter and she was not going to stop applying pressure to the medical

professionals until they listened to her. A mother's intuition is rarely wrong. Even all this time later though, doctors are still rolling their eyes at her.

"We still struggle with dealing with undereducated doctors in the hemophilia community when it comes to a female that is not a symptomatic carrier," she said.
Kathie stepped her advocacy work up to extend even beyond just her own daughter. She joined the Women's Hemophilia Advisory Board in Northern California in 2015 to help bring awareness for young women like Belle. She knows there are a lot of young women out there who need people in their corner.

"I love my hemophilia community and look forward to having more young girls/teen events!"

Notably, she was the Executive Pastry Chef for Google up until right before the pandemic. She created programs that still exist on all their campuses around the country.

Kathie is a force of nature who was hit with more unfortunate news. She recently learned that she has spinal radiculopathy in her upper cervical spine and lower lumbar spine. She suddenly found herself being limited, much like members of the hemophilia B community, but in a different way. She can no longer drive or work in a kitchen, two big losses to Kathie. She can't lift, can't hold small objects, can't stand or walk for more than 15 minutes.

"It has completely changed my life. I've had a really hard time dealing with this change," Kathie admitted.

There is a stunning set of photos of Kathie, draped in butterfly imagery. She took these photos for a special reason.

"I have been followed by butterflies my whole life," she explained. "I was reading about what they go through to become who they are meant to be. These beautiful creatures literally turn themselves into mush before having to eat their way out of a cage they put themselves in."

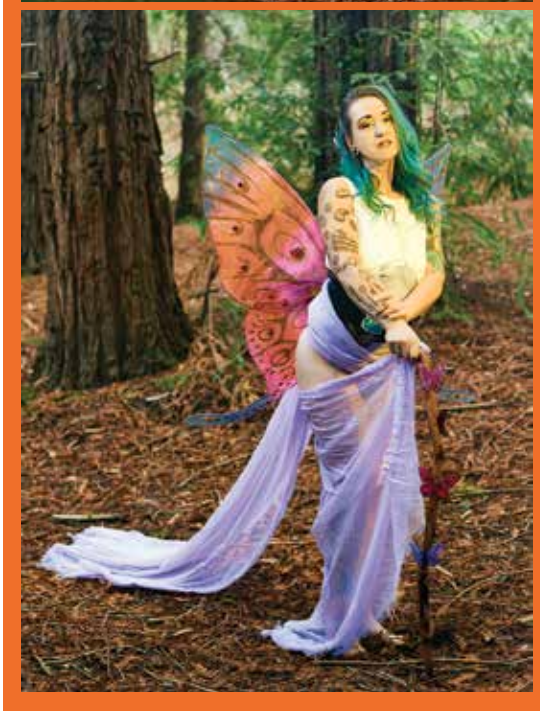
"I kind of saw my situation like this. I am eating my way through my cage to embrace the beautiful butterfly I feel like I am. Trying to embrace all the difficulties I have faced and will continue to face with patience and compassion for myself first and foremost," she continued.

Like butterflies, Kathie has faced brutal challenges that will lead her where she is destined to go.

"During this process of transition, their wings get torn in the process sometimes, but they remain determined to continue," she shared. "They are still beautiful with their kind of broken wings. I see such truth in that. It's okay to have injuries, visible or not. You can still be beautiful and get to where you are destined to go."

A mantra she now embodies, alongside her daughter.

Keep up with Kathie's cookie page Cooky's Baked Goods on Facebook, and @itsjustkathie or @cookysbakedgoods on Instagram.



women & girls with hemophilia

articles to support, educate, and empower

The Birth of a Mother: Part 2

BY CASSANDRA STARKS

Content Warning: This article contains a birth story which may be triggering to some. It also contains content regarding spiritual beliefs that not all may agree with.

One often falls into the trap of thinking that when they have experienced an event once, if that same event happens again in the future, it will be the same. However, this is absolutely not true. Every moment of life we are a new person. Like a gentle stream, life is constantly moving forward into a future. We learn and grow and change with each experience and therefore will never experience the same thing exactly the same way twice. This is true of the pregnancy and birth of my second child.

While my own hemophilia did not cause an issue during my first child, Clyde's, birth, another "factor" was added to the mix shortly after. As a woman with mild hemophilia, I developed an allergy to the factor I had been on and began having mild anaphylactic reactions each time I infused. Almost two years after Clyde's birth, a shoulder bleed gave me the opportunity to test out a new factor, but I had the same allergic reaction to it.

My reactions at this point were fairly mild and while they were very uncomfortable, they went away on their own after several hours without any lasting effects. However, my HTC nurse warned me that during any infusion in the future, the reactions could become a full anaphylactic event that would be life-threatening without intervention. We agreed that any future infusions would need to be under strict supervision in a hospital setting.

When I became pregnant with Edith, I was ecstatic. I loved being a mother and couldn't wait to bring another baby into our family. My spirituality, meditation practice and faith in a newly found guru grounded me in a way of living that allowed me to focus on what was truly important and to have a greater understanding of my own purpose in life. While I have always considered myself of the spiritual nature and had been led down some incredible paths already, the depth of my devotion and love for God and life grew immensely as I navigated the challenges of motherhood and hemophilia with my guru. Prayer and developing a relationship with a higher power became fundamental for me. I know that it was because of my guru and my daily practices that my pregnancy was physically and emotionally very easy and went by without any of the typical challenging symptoms.

While I wanted to have a homebirth, I knew it would be too risky, so, I chose a midwife instead and planned on having Edith at the closest hospital, which was 45 minutes away from our house in remote Montana. I was forced to advocate for myself frequently: explaining to multiple medical personnel what hemophilia was and was not, refusing intervention after intervention, and creating a very detailed and clear birth plan to ensure that once at the hospital I would have minimum disturbances to allow for the peaceful and quiet environment that a successful childbirth requires.

I learned to face each medical decision with patience,

trust and courage. A decision-making process emerged where I would refuse to make any decision and wait until I became completely clear that it was the right one. Often this stage took a great deal of research, praying, talking it over with the HTC, talking it over with my husband, Paul, and then listening deeply to God. Then once the decision became clear to me, and I felt really good about it, I had to trust the knowing within myself that it was the right decision to make. Finally, I had to gather the courage to implement my decision, which at times meant refusing what was recommended by the midwife or doctor because it wasn't what was right for me.

During the month before my due date, I found myself faced with two additional challenges. The first was that I was finally approved to test a plasma-derived factor to see if I would have the same allergic reaction to it. The second challenge was that without warning my midwife handed off my case to an OB/GYN who I had never met before. Both shook me. I faced the possibility of having a life-threatening allergic reaction while pregnant and then the whirlwind of anxieties brought about by my care being handed off so abruptly to someone I didn't know. In the moment, I knew I just had to trust that it would all work out.

I kept up my daily prayer and meditation practice to stay calm and centered and focused on taking one day at a time. My test with the new factor went smoothly, and I had no side effects whatsoever after the infusion. Along with this, my new OB/GYN ended up being a perfect fit for me. Upon seeing my case and meeting me she gave me the option to have either her or my previous midwife for the birth. With both challenges behind me, I knew my faith had been tested.

Exactly one week before my due date, I was finally fully prepared to give birth. I had my strict and detailed birth plan ready for the hospital, my labor bag fully packed, and my mom had just arrived to help with Clyde during the birth. I also laid out a very detailed plan for both Paul and my mom to follow in preparing to leave for the hospital so that all I would need to do when the time came would be to get in the car.

The next evening, around 9:30 at night, I began to feel what I suspected were contractions. Remembering to breathe deeply with them while relaxing my body, I found they were much less painful than what I remembered with Clyde. Because of this I told Paul to start getting everything ready slowly. I wasn't completely sure if I was in labor yet and thought that by the time everything was ready for us to leave, I would know for sure whether Edith was actually coming or if it was a false alarm. In the meantime, I laid down in bed and rested, focusing on breathing deeply and completely relaxing my entire body.

As the contractions continued, I remembered a few key points that I had read about, including keeping the mind focused on the excitement of the baby coming rather than allowing it to enter the fear of the childbirth experience. As I did this I also began praying and could feel the presence of God and my guru with me, supporting me and holding me during this time.

The contractions continued to come with intensity but with no pain and as the intensity continued to pick up, it crossed my mind that we needed to leave soon. A little while later, Paul came in to get me and in between contractions I peacefully and quickly got into the car. I was fully alert and energized by the notion that our baby was coming.

As we drove 45 minutes to the hospital, I found a way to lay down, partially propped up into a position where I could relax as much as possible. While it was very awkward, I was able to maintain complete relaxation and continued to feel no pain during the contractions.

When we finally arrived at the hospital, I had to stop and hit the floor twice before Paul and I made it to the delivery wing so that I was able to be fully relaxed during contractions. Paul handed me off to the nurse and headed back down to our car to get the rest of our things, as well as my mother and Clyde.

The nurse brought me into the triage room where she asked me some questions, conducted a COVID test and then left to get my midwife. As she was leaving, I was suddenly overwhelmed by an urge to push. I continued to push on my own, so relaxed and in the moment that I couldn't even bring myself to speak. I was in my own

world of focused relaxation and also a bit shocked that I could be entering this stage so quickly. Just in time, Paul re-entered the room as Edith began to emerge and called for help.

Both my midwife and OB/GYN happened to be on call that night. My midwife arrived into the room as Edith's body was just beginning to come out. I reached down and grabbed Edith and pulled her up to my chest while the midwife took care of me to ensure I didn't have any excess bleeding.

A thrill of amazement swept through my entire being. The endorphin rush of setting a new college record in pole vault and being ranked #1 in the nation did not even compare to the thrill of what I'd just experienced. Fully energized and amazed at what had just happened, I gazed upon my second child lovingly as she began to nurse.

Edith Louise Sever was born at 11:43 p.m. on February 27, 2022, weighing 7 pounds 12 ounces. I gave birth to her after just over two hours of labor and had barely been in the hospital for 15 minutes before she arrived. Her birth was completely pain free and one of the most incredible spiritual events I have ever experienced.

I could feel the presence of my guru and God so strongly with me the entire time. To be able to experience giving birth while feeling everything fully, without any pain, was also incredible. I know without a doubt that this is the way nature intended childbirth to be like for every woman.

After all my prep and planning and decision-making during the pregnancy, I ended up not needing my birth plan at all! Being at the hospital for such a short amount of time, I never once had to fight for privacy or what I wanted during Edith's birth. It initially crossed my mind that all that effort was a waste and not needed, but I know that there was something deeper and more important about it all.
In the process of all the decision-making and challenges, I learned a great deal of trust, patience and how to take each step slowly with the presence of mind that God was with me all the time.

My spirit gained strength each time I followed my own heart and God's will rather than just going along with what the doctors wanted. But most importantly, the whole experience carved a deep and profound relationship between me, my guru and God that I know I will continue to rely on throughout the rest of my life.

Life is mysterious. While it is often fraught with challenges and a sense of repetitiveness, we are always being moved in a direction of greater joy, love, peace and harmony. While hemophilia and my two children can easily encompass my whole world, as long as I have God and guru with me, I can remember the purpose of this life. And the purpose is not to make life easier for ourselves or to live more comfortably, but to learn to face each challenge courageously and with the right attitude, to love ourselves and others unconditionally, to discover who we are in this world and what our true purpose is and then to chase it so single-mindedly that it cannot be replaced by any other goal or desire. But above all else our purpose is to awaken to the reality that we are never really alone in our journey. This is how we overcome the challenges of life. This is how we overcome the challenges of hemophilia.

Here Comes the Fun!

AN INTERVIEW WITH MARIE
BY RENAE BAKER

She's a Mama Hen. You may have found yourself under her wing at some vulnerable point in these last 20 or so years. Coalition members describe her as a "fun" person to be around. You may have heard the story of her dressing like John Travolta, in GREASE, and dancing with Dr. Clark at a Coalition event. Her name is Marie.

I sat down with her over Zoom and got to witness, first-hand, that Marie is a fun lady! As a fan of Lily Tomlin's, I assure you it is high praise of Marie when I say that her spirit and personality reminded me of the legendary comedic actor. Her whimsical turns of phrase and buoyant expressions gave my cheeks a workout!

In some people, challenging childhoods create in them a steely, protective armor. Marie, at 64, continues to choose humor to get her through. More than once, during our interview, she said, "I like to have fun!" Now residing in Beach City, Ohio, with her husband of 20 years, Chan, and their four Chihuahua "children," Babi, Sissy, Zoe and Ruby, Marie is originally from Akron. She knew, from an early age, that she was a carrier of hemophilia B, because her father suffered greatly from it.

"It was really bad," Marie admits. "He was crippled by it. He was in a lot of pain. It was real scary seeing the ambulances come take him away, and I was the oldest of four kids." Marie became a caregiver at an early age for her father and younger siblings, and she has continued to not only care for others, but to enjoy the practice. Marie is a strong Christian. "Jesus is a big part of my life," she states with - to quote a hymn - "blessed assurance." She met her dear husband at church, and I am charmed to learn that she named their children Mary and Joseph!

Although Marie knew she was a carrier, she looked forward to having children. She thought that her childhood experience living with her father, as he navigated life with severe hemophilia B, would be sufficient preparation to have a baby boy with it. She thought she was tough. "But no," she concedes. "With Dad, he was hurting, but the little boy is screaming, 'Help me, Mommy! Help!' And that is bad…" The memory of it seems to squeeze her heart all over again. She snaps out of it quickly, "So that's the difference with that!"

When her son Joey was born, the doctor advised her that she didn't need to have testing done on her baby; that within a couple of months she would just know. "And didn't I know!" she says like a punchline. "He started crawling, he hit his head, and there goes a big knot. He started screaming because of the knee bleeds." Joey was diagnosed with severe hemophilia B with a level of less than 1%. We touch on the guilty feelings that carrier mothers often experience when seeing their children suffer. "Yeah! I never would've wanted him to hurt," she states, and then pivots, "but even Joey said, 'It's not your fault, mom. You gave me life!'" As challenging as all of that was, the most harrowing parenting experiences she has had occurred after Joey grew into an adult.

"About 18 years ago, he was in a bad car accident," she begins. "A big Mack truck side-swiped his car." At the time, Marie was working as an administrative assistant for the Akron Metropolitan Housing Authority. "They called me from work, and it was just horrible." Joe was about 24 years old. Marie was told that he was alive, but that he would likely be "a vegetable." He recovered much better than that, but he is living with a Traumatic Brain Injury.

They have also learned that he has an eye condition called retinitis pigmentosa, which is a progressive vision loss which might include blind spots and loss of peripheral vision.

"It's genetic!" She blurts out. "I had no idea! The eye doctor said that people with hemophilia get it. I said, 'Get outta here!' I'd never heard that before in my life." Humor intact, Marie makes a face and says, "Ya go, 'Hey, what's up with this genetic stuff?'"

Their eye doctor is conducting a study with a DNA panel. They signed up and are expecting to learn more when more participants have signed on. Marie and Joe were stymied by the news and questioned how it could be genetic when they've never seen the condition in

the family. They were told it could go back hundreds of She's a Mama Hen. You may have found yourself under her wing at some vulnerable point in these last 20 or so years. Coalition members describe her as a "fun" person to be around. You may have heard the story of her dressing like John Travolta, in GREASE, and dancing with Dr. Clark at a Coalition event. Her name is Marie. I sat down with her over Zoom and got to witness, first-hand, that Marie is a fun lady! As a fan of Lily Tomlin's, I assure you it is high praise of Marie when I say that her spirit and personality reminded me of the legendary comedic actor. Her whimsical turns of phrase and buoyant expressions gave my cheeks a workout!

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years. “DNA is DNA.”

“Wow,” I say. “He must feel like he won the wrong lottery.”

“He’s come along quite well,” Marie assures me. “He lives in his own apartment and has five cats.”

I turn the conversation back to Marie. “You knew you were a carrier, growing up, but when were you actually diagnosed with hemophilia B?” I ask.

“So, I’m gettin’ older, right?” she starts. “We’re all gonna die. We’re gonna die when God decides we’re gonna die. But then she remembered her scriptures. “Then I said, ‘Hey, let’s not be foolish. We’re supposed to be wise. I’m gonna get tested.’”

Marie had been tested in her twenties and her clotting factor result was 30%.

“As I got older, I said to myself, ‘What if I have a heart attack? What if I have to have my guts or gallbladder taken out? Or a hysterectomy? Now, nothing is wrong with me. I’m pretty healthy, but better to be safe than sorry. So I got tested, and they said I was 50%.” She was shocked to learn that people’s levels can change. “So! They’re calling me ‘30-50’ now and told me that if I ever need an operation, to call the HTC. Well, here it was time to do my leg, whoo hoo!” she feigns celebration. “I had never had factor until last year, because nothing was that bad.”

Marie briefly explains that the nurse administered the factor for her knee replacement surgery, which she describes as “not fun.” Afterward, the nurse said, referring to her reaction to having been treated with factor, “Now, wasn’t that better?” Marie, not having anything to compare it to, didn’t know how to answer.

“But I had gotten a tooth pulled before. It bled like sump’m! For days! But I thought, ‘Well that’s what happens when you get your teeth pulled.’” Marie had a second tooth pulled recently. “But this time, I had factor!” She says with an undertone of “Aha!” “I was so shocked! I didn’t hardly bleed at all, and I said, ‘There ya go!’ So now I know what factor really does!”

Marie recalls infusing Joey as a child, and then again when he was an adult, healing from injuries. “Now I’m gettin’ ready to go to ‘Butterfly School’ myself! I need to learn to self infuse,” she says with a bit of enthusiasm. Shout out to Nurse Hope. Marie has seen you teach self-infusion at Coalition events and is impressed. You may be getting a call! I ask Marie for how long she’s been involved in The Coalition For Hemophilia B.

“I didn’t know the Coalition existed. I was at a smaller, local chapter event, and I saw Kim and Dr. Clark sitting there! I didn’t know them, and I said, ‘Oh! Look at this!’” They told Marie about The Coalition for Hemophilia B, and how it had been in existence for several years. Marie and her son Joe have learned such a tremendous amount of life-saving and quality-of-life-enhancing information through the Coalition that, “I was in awe!” she exclaims. “And then started a lot of good friendships, and I was like, ‘Where’ve you been all my life?’ It’s too bad we weren’t introduced long ago.”

Marie is especially moved when she remembers older Coalition men playfully interacting with their blood brothers at an event. She wished her father had had those relationships. “Having a bleeding disorder can make you feel real isolated. The Coalition is so good at bringing us together. I just wish I’d known about them while my dad was still alive.”

Marie sees young Coalition mothers and their children. She marvels at how these children will likely not face the same joint damage as the older members. “I’m so happy for them!” she says with seriousness.” They shouldn’t have to.”

Marie thinks about her experiences with mild hemophilia B and her son’s and father’s lives with severe hemophilia B. Her passion ignites when she considers the value of the generations of sufferers, on whose bleeds, ravaged joints and organs and deaths scientists have based their research, and how the younger generation, who benefits so greatly from the research, may be uneducated about what came before and could come again.

“I think they’re forgetting that,” Marie worries. “They should never forget those older guys dying. They should never forget.” She is referring, of course, to the blood scandal in the 1970’s and 80’s, in which thousands of men with hemophilia contracted HIV and hepatitis C from contaminated blood products, horrifying and breaking the hearts of the community with the untimely deaths of multitudes of loved ones and compounding

the pain and suffering of others with nightmarish, sometimes insurmountable health challenges. Marie believes that the documentary Bad Blood should be required viewing for every member of the bleeding community.

It is quickly becoming a different landscape for hemophilia sufferers, with kids and adults alike having access to prophy, allowing them to play sports and other activities not dared just a few years ago. Maternal hearts still ache for their children's misery of receiving treatment through a port or from crawling across the floor. However, just as we are seeing reversals in human rights happening in our "land of the free," it is not out of the realm of possibility that access to the treatment that has made it possible for today's youth to enjoy more active, less painful lifestyles, might also become threatened.

Marie senses that much of today's youth look at these older men with hemophilia B and don't realize how special, rare and brave they are. It is their suffering and advocating for the community that have made advancements in treatment a priority, making it possible for today's "young bleeders" to live more active lives with less suffering. Marie wants to encourage the younger generation to really consider the major contributions these people have contributed to their lives.

"I think they look at them and think, 'They're old. That's how old people are,'" Marie supposes. Then she asserts this uncharacteristically grave caution; "Be aware of what could have been or what could be! Just think about kids on the other side of the world, running around, screaming with no factor. That could happen here."

I get the idea that that was a rare serious moment for Marie, but it was an important idea that she needed to express. Marie's appreciation for the men who have lived through such tribulations to ages far beyond what the doctors told their mothers to expect is reciprocated. I have talked to many of these men for whom it is a front-burner issue that women bleeders are not being taken seriously enough by all hematologists. They are incensed that their blood sisters are being denied the same rights to prophy as their own sons only by virtue of their sex. I ask her how she feels about the men advocating for the women.

"It's good! We need that! They've already lived through it where no one was listening to them," Marie nods in solidarity.

Marie thinks about the stories she's heard from women bleeders, and she launches into one of her determinations; that more people should be extending themselves to others who may not be connected enough to the resources that will give them a higher quality of life. She starts by considering unsuspecting women having what they will later describe as "bloodbaths" for birthing experiences.

"Why should there be a bloodbath?" She asks, incredulously. "I think they [the doctors] should tell women where to go." With her inner light flaring like a Fourth of July sparkler now, she coaches us to be on the lookout for people who may not realize they have hemophilia yet. "Maybe you've heard someone say, 'I think she has hemophilia.' I think - it doesn't matter what state - someone should take them under their wing. Give them people to call. Especially when people are of childbearing age. They might know they have hemophilia B, but not know about the Coalition. Everybody should be telling them about the Coalition. If the HTC doesn't tell you about the Coalition or FHS or National, they aren't going to know. Just like I didn't know."

Additionally, Marie urges, "Get out there. Get tested. Talk to people. Go to conferences. Be educated." But she doesn't stop there. She adds something I haven't heard before, "Invite people to conferences; even if it's a promotional dinner. Go to it. Learn."
"So, you're all about extending yourself," I reflect back to her. "Are you saying, 'Don't wait for an invitation to reach out to people?"

"Yes. I like to help people. That's one of my passions," Marie jumps in. "I'm a caregiver to many people. It makes me happy. It's what I've done all my life. Any way I can help anybody, I do." She uses me as an example. "You're a writer, and you can also tell somebody.

Indeed, I am, Marie. I'm happy to help you get the word out, so more people may join you in the fun!

ADVOCACY NEWS

BY GLENN MONES

The Coalition for Hemophilia B at the Hemophilia Alliance Gene Therapy Town Hall Meeting

The Coalition for Hemophilia B (CHB) had the privilege of representing our members at an invitation-only Gene Therapy Town Hall Meeting on June 20 and 21. The event was hosted by the Hemophilia Alliance, a not-for-profit organization that comprises federally funded hemophilia treatment centers (HTCs) that either have, or are seeking to have, pharmacy programs under Section 340B of the Public Health Service Act. CHB was represented by Advocacy Director Glenn Mones.

The main purpose of the Town Hall was to learn about a reimbursement model for gene therapy in which the HTCs take the principle role in providing access to eligible patients who want one of the new treatments. The model has many advantages including consistency in the way the treatment is administered and in appropriate follow-up over time.

In addition to the national patient organizations who opened the meeting, the more than 80 attendees included representatives from ATHN (the American Thrombosis and Hemostasis Network) and 44 HTCs including 25 doctors, nurses, pharmacists, and administrative staff.

There will be future discussions in the months to come on this and other import related topics. The Coalition for Hemophilia B will work to keep our members informed as these discussions progress.

Cost of ACA Plans May Increase for Those At Higher Income

An important feature of the Affordable Care Act (also known as ACA or Obamacare) is subsidies made available to Americans opting for the plans. The impact of these subsidies has varied from state to state depending upon how the plans have been implemented in each state. However, the amount of subsidy is generally keyed to income, with those above four times the Federal Poverty Level Federal (FPL) receiving substantially less or even no assistance.

That was the case until the passage by Congress of the American Rescue Plan Act (ARPA), part of the many bills designed to address the cost of the COVID crisis. ARPA expanded subsidy eligibility, now capping what people with higher incomes pay for a silver plan premium at 8.5% of their income. However, ARPA is due to expire at the end of the year, again making ACA plans "less affordable" for many Americans. There is strong support for extending the subsidies for at least another year.

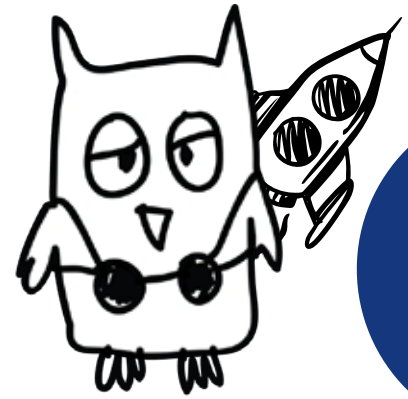
You can learn more about this issue in a post from the Kaiser Family Foundation at Falling off the Subsidy Cliff: How ACA Premiums Would Change for People Losing Rescue Plan Subsidies | KFF. The Coalition for Hemophilia B will also provide additional information as it becomes available.

Preliminary Injunction May Restore Plasma Donations by Mexican Nationals

United States District Court has issued a preliminary injunction preventing the US Customs and Border Protection (CBP) from continuing to enforce its ban on plasma donations by Mexican nationals with B-1/B-2 visas. This was reported in a press release from CSL Behring, one of the parties to the suit. CSL is a major collector of plasma and manufacturer of therapies for the treatment of hemophilia and other conditions.

For more information on this important story, please refer to the original press release at https://www.cslplasma.com/newsroom/preliminary-injunction-of-plasma-ban

Inflation Reduction Act Extends Obamacare
Among the provisions of the Inflation Reduction Act of 2022, signed into law recently by President Biden, is the extension for three years of the enhanced Affordable Care Act (ACA) also known as Obamacare. This benefits people with hemophilia and other chronic conditions in multiple ways, including by increasing the amount of subsidies available for patients who want these plans. You can learn more about health provisions in the Inflation Reduction Act from the Kaiser Family Foundation (KFF) at https://www.kff.org/medicare/understanding-the-health-provisions-in-the-senate-reconciliation-legislation/



TEEN EVENT WITH NICK

RAFFLES AND FOOD VOUCHERS!

AGES 13-19

Thursday, November 17, 7:00-8:30pm Eastern

Come hang out with other teens for an incredible night of fun!

REGISTER TODAY:
hemob.org/upcoming-events

Hosted by The Coalition for Hemophilia

Sponsored by sanofi

The Coalition for Hemophilia

WIN FREE GROCERIES FOR ONE MONTH!

- Donate to The Coalition for Hemophilia B between November 21, 2022- November 29, 2022 to earn raffle tickets:
  - **Donate $20: 1 Raffle Ticket**
  - **Donate $50: 3 Raffle Tickets**
  - **Donate $100: 6 Raffle Tickets**
- There is no limit on how many tickets you can earn
- The raffle will occur on November 30, 2022
- Winner will receive a $500 Visa Gift Card!

Questions: contact@hemob.org

GIFT CARD

DONATE TODAY

GINGERBREAD HOUSE DECORATING + TRIVIA NIGHT

CONTEST OPTIONAL

Saturday, December 17, 4pm Eastern

questions?
contact@hemob.org

FIRST 50 TO REGISTER BY NOVEMBER 18 WILL RECEIVE A GINGERBREAD KIT

REGISTER TODAY: HEMOB.ORG/UPCOMING-EVENTS/GH-CONTEST

Submit your gingerbread house photos to contact@hemob.org

Prizes for Trivia + Winning Gingerbread House

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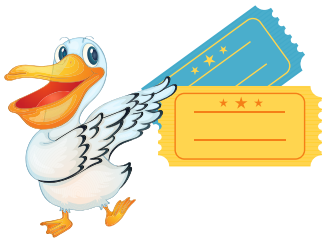
THE COALITION FOR HEMOPHILIA

NEW MEMBER/FIRST TIME ATTENDEE SCHOLARSHIP

2023 COALITION FOR HEMOPHILIA B ANNUAL SYMPOSIUM MARCH 16-19 IN ORLANDO, FL

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



THE APPLICATION DEADLINE IS DECEMBER 17, 2022

APPLY TODAY: hemob.org/annual-symposium

ADVOCACY EXPERIENCE

For folks with hemophilia B

ADVOCATES WELCOME!

January 26-29, 2023 in sunny San Diego!

applygenerationixproject.com

Hone your advocacy skills. Share community wisdom across generations. Welcome nearly all ability levels aged 20 and older residing in the US.

Participation and travel at no cost to you

COVID-19 vaccination required

WHAT IS THE GENERATION IX PROJECT?
The Generation IX Project was launched in 2014 as a program uniquely designed to educate, empower and engage individuals with hemophilia B. Since then, Gen IX has grown to hundreds of participants of all ages from across the country.

NO COST TO ME?
Thanks to the generosity of Medexus Pharma, participation and attendance at any of the Generation IX Project is provided at no cost to participants.

WHO CAN PARTICIPATE?
Anyone with a diagnosis of hemophilia B within the age range for each program is welcome to apply. Past participants of other Generation IX events and new folks are encouraged to apply!

APPLY BY NOV 30!

genix@gutmonkey.com contact@hemob.com factorix@medexus.com

BROUGHT TO YOU BY THE COALITION FOR HEMOPHILIA
SPONSORED BY MEDEXUS PHARMA
ORGANIZED BY GUTMONKEY

EMERGING THERAPIES 101

VIRTUAL ZOOM MEETING | JAN 12, 7:30–9:00PM ET

REGISTER TODAY: HEMOB.ORG/UPCOMING-EVENTS

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

RAFFLE PRIZES AND MEAL VOUCHERS!

THE COALITION FOR HEMOPHILIA

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Biotherapies for Life™

SAVE THE DATE: 2023 SYMPOSIUM

Applications Due December 17, 2022!

Everyone at the Coalition for Hemophilia B cannot wait to see you at our Annual Hybrid Symposium 2023 from Thursday, March 16, 2023 to Sunday, March 19, 2023. You will have the option to join us in person in Orlando, Florida at the Renaissance Orlando, or participate virtually!

The Coalition for Hemophilia B's Annual Hybrid Symposium is the largest regular gathering exclusively for families and individuals affected by hemophilia B. Learn more about applications, travel scholarships, and scholarships for first–time attendees at:
https://www.hemob.org/annual–symposium

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 23, 2022**
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 23, 2022**. 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

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

Name: _____

Street Address: _____

City, State, Zipcode: _____

Phone: _____ Email: _____

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

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

THE COALITION FOR HEMOPHILIA

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:

Website: www.hemob.org
Facebook: www.facebook.com/HemophiliaB/
Twitter: https://twitter.com/coalitionhemob
Instagram: www.instagram.com/coalitionforhemophiliab
Linkedin: https://www.linkedin.com/company/coalition-for-hemophilia-b/

SCAN ME

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

LESSONS LEARNED: A TEEN ADVOCATE STORY

BY JC

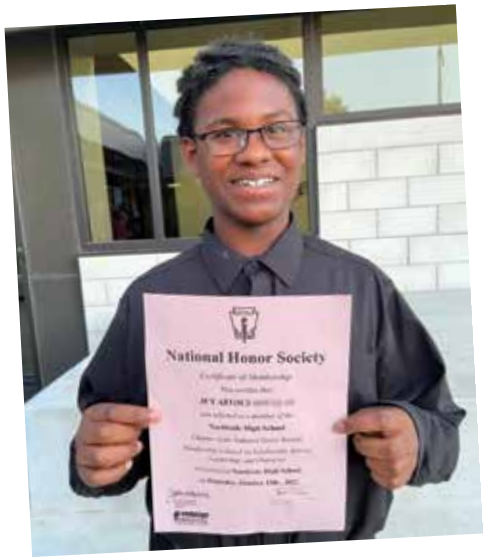
Hi, my name is JC. I was born and raised in Fort Smith, Arkansas. My connection to the hemophilia B community is that I was diagnosed with hemophilia B at just nine months old. My mom, a carrier for the hemophilia gene, passed it along to me. I have no family members with hemophilia living but I did have a distant cousin, who had it along with HIV, but he died several years ago. I am currently the only person in my family with hemophilia.

The first time I went to The Coalition for Hemophilia B's annual Symposium, about three or four years ago, we chose not to infuse before getting on the plane. By the time we made it to the hotel and started walking, I experienced a groin bleed. I ended up having to use a scooter to get around most of the time. The lesson I took away from this was to infuse before we leave so that I can be comfortable throughout the trip.

Another time, when I was little, my mom and I got into a car accident and my head hit the back seat, hard, upon impact. I had to infuse at the emergency room. Luckily, I did not have a head bleed because medical professionals were not familiar with hemophilia at that time or how to care for me.

Having hemophilia has affected me to where I could not play contact sports. My family and I worry about a lot of safety measures and how it will affect me at the same time. Although it has given me other options to look at that I may be able to participate without being too hard on my body. I am more aware of how to take care of myself through my circumstances without being frustrated and scared.

When I was in elementary school though, I didn't want to wear my protective helmet to recess all the time. None of the other kids had hemophilia and many didn't understand why I had to wear a helmet, at my mom's insistence. My mom worried because recess saw a lot of hard play or horseplay. I wore the helmet, and my friends would watch me carefully with what little bit of information they knew.



I feel confident and stronger when I do my medicine now because I know how it helps me. I try my best at everything I do and want to make my family proud.

I have several hobbies, like being a part of the marching band for my high school. I have been playing the French horn since the seventh grade and made "All Regionals." In my free time, I play Xbox, and my favorite game to play is Marvel Avengers. I like to battle my Beyblades with my best friend DeVaughn. I also like spending time with my aunt and cousins.

My passion is to educate my friends and family and be an advocate to help other teenagers with hemophilia.

In three years, I see myself graduating from high school and attending college, not sure on my major yet, but I would like to be an actor or a chef.

I am very passionate about knowing that I am not alone, and I am the best advocate for myself because I know what I like and dislike. I do have a great support system to help me through hard times including support from the Coalition. In which I get to meet people from different states and share my story with them or hear their stories at a camp or a Coalition meeting. I would like to teach other kids how to infuse and encourage them to look after each other.

It has been an honor to join The Coalition for Hemophilia B at events and on advocacy initiatives.

SHARE YOUR STORY

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

XIANKANG: COMPUTER PROGRAMMING EXTRAORDINAIRE

INTERVIEW BY ALICIA COOK

Denzel is a 16-year-old with hemophilia B.

"My first severe knee bleeding happened when I was about three and a half years old," he recollected. "I don't remember how it happened, but I could see my knee getting more and more swollen to the extent that I could not walk normally."

His parents took him to see the orthopedics doctor who drew a lot of blood from knee joint with a 50-mL syringe. But after a few days, his knee appeared to be swollen again. His parents sought help from many doctors until a hematologist suspected Denzel had hemophilia B. His diagnosis was confirmed once they checked his factor level.

Being the only person in his family with hemophilia B has not slowed down any of Denzel's life experiences. He's been to Disney, Universal Studios, Hole in the Wall Gang Camp, and enjoyed a vacation on a cruise. Though he can't play contact sports anymore, he has a mild case and does not bleed spontaneously.

One major passion of his is computer programming. "I use it to cheat in video games, automate simple tasks, and more," he quipped.

He has been studying this skill since he was in the second grade, after one of his friends bought a book called Hello World! Computer Programming for Kids and Other Beginners. By the third grade, he had already designed an online PC game called Crazy 8.

Ever modest, he said, "I did a lot of reading, searching, and self-teaching about how to computer program. It's not difficult as long as you are interested and determined to do it."

"It's pretty safe to develop a hobby like this for hemophilia people," he added. "There is no bleeding risk. On the other hand, this is sedentary activity which is not good for hemophilia people who need to maintain certain degree of muscle, joint and bone strengthen."

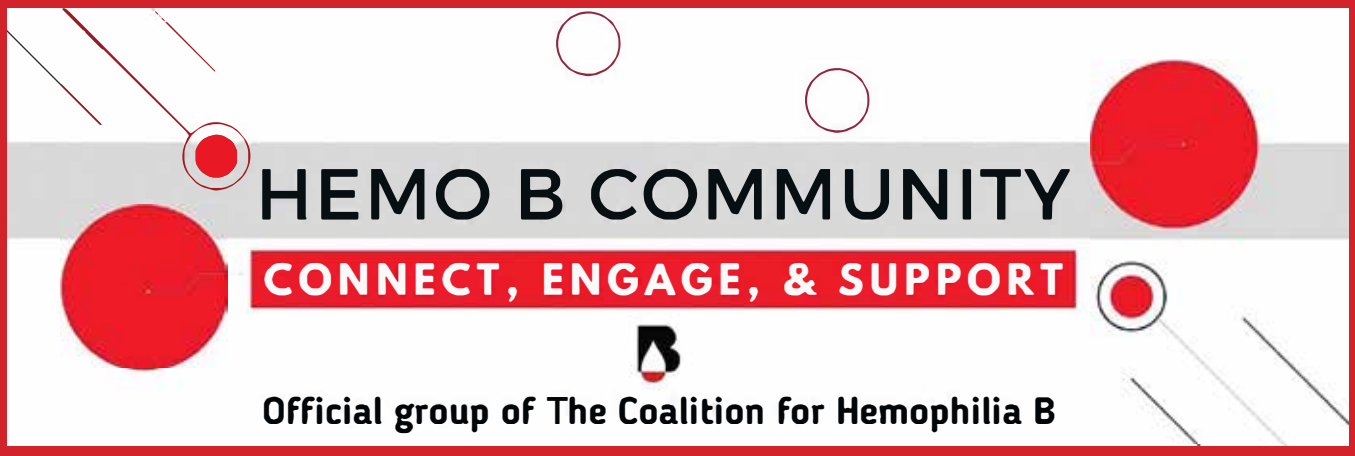
While he is not sure where he will be or what he will be doing in 20 years, he knows he will graduate from high school in two years and might choose to major in a computer-related program in college.

Hemophilia B did reroute the direction of some of his other interests, and a lot of his time is spent doing activities and advocacy work related to hemophilia. In addition to being a part of The Coalition for hemophilia B community, he used to be connected to HACA and HFM, and is currently part of the Eastern Pennsylvania Chapter of Bleeding Disorder.

Since discovering he had hemophilia B, he learned more about the rare disease, and he has some thoughts.

"I've definitely gathered more of an understanding about this rare disease. But it does not seem to me to be very rare at all!" he said. "I saw a lot of people, more or less severe than I, with this disease since childhood. There seems to be a lot of us."

COALITION FACEBOOK GROUP!



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

B inspired!

Stories and artwork from teens in the Hemophilia B Community

SUMMER 2022

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LESSONS LEARNED: A TEEN ADVOCATE STORY

XIANKANG: COMPUTER PROGRAMMING EXTRAORDINAIRE

WANTED: TEEN CONTENT CREATORS!

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

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