

THE COALITION FOR HEMOPHILIA B

HEMOPHILIA B NEWS

NATIONAL NONPROFIT ORGANIZATION

FALL 2022

MEN'S EDUCATION & EMPOWERMENT RETREAT



GEN IX LEADERSHIP EXPERIENCE



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to be empowered*

**SAVE THE DATE:
2023 SYMPOSIUM**

**HISTORIC FDA
APPROVAL**

**EMERGING
THERAPIES**

FAMILY MEETINGS ON THE ROAD



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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.

MEN'S FALL RETREAT

BY SCOTT HAYES



The 2022 Men's Fall Education and Empowerment Retreat was held from Saturday, September 24th to Monday, September 26th at the Hyatt Regency Grand Cypress Resort in Orlando, Florida. The beautiful grounds of the resort provided a perfect location with stunning views for the event.



The 2022 Men's Fall Education and Empowerment Retreat was held from Saturday, September 24th to Monday, September 26th at the Hyatt Regency Grand Cypress Resort in Orlando, Florida. The beautiful grounds of the resort provided a perfect location for the event, with stunning views.

I continue to be grateful for our online community gatherings, but they simply cannot compare to the in-person experience of being with our hemophilia B community brotherhood. This was my first in-person Men's Retreat in about 3 years, after the COVID-induced hiatus. Every participant and speaker were tested for COVID before the event to ensure everyone's safety.

Lunch at the Lake House restaurant provided beautiful views of the lake through its large windows, which flooded the room with natural light. After lunch we were treated to a 15-minute chair massage by skilled professionals, which was so relaxing it felt like a power nap!

Saturday afternoon, Coalition President Wayne Cook led a breakout session on life transitions as men living with hemophilia B get older. He shared his own personal life experiences, which were challenging and transformative. His openness encouraged other men

to open up and share their own experiences with life transitions. I am grateful that the Coalition, and Wayne in particular, put so much effort into creating a safe space for men to discuss these important issues. Wayne also spoke passionately about the need to include women with low Factor 9 in the bleeding disorder community and the challenge of men struggling with depression.

Saturday evening, an artist from Disney studios taught the men how to draw Mickey Mouse. The artist customized the image of Mickey Mouse for the occasion, giving him a superhero appearance with a unique logo that looked like a drop of blood on his chest! We followed his instructions and guidance as we all learned to draw our one-of-a-kind Mickey. Line by line, we sketched in the "Super Blood" Mickey with pencil. When finished, we inked it in with black marker. It was a great exercise, and we had a lot of laughs trying to follow along and keep up with a professional artist.

On Sunday morning, before breakfast, we had a morning snack followed by a nature walk. Some of the brothers did stretching exercises on an open pavilion overlooking the lake on the hotel grounds, while others of us walked around the lake together. The walk also provided an opportunity for us to talk and get to know





one another better in smaller groups.

Fernando Reyes shared an engaging session on the connections between physical health and mental health. He walked us through different types of stress and stressors, and shared practical tips for self-care, exercise, and nutrition.

Cosimo Costa from Pfizer updated us on the latest developments in gene therapy and clinical trials. He explained the differences between gene editing, gene therapy, and cell therapy, and discussed how hemophilia, as a disease caused by the mutation of a single gene, is a good candidate for gene therapy. It's exciting to think that gene therapy could provide a long-term treatment for hemophilia B that could raise Factor 9 levels for years or even a lifetime!

Mark Zatyorka shared his journey using medical cannabis as an alternative form of pain relief. He explained the different types of cannabinoids and their effects on the body and discussed what to consider in states where medical cannabis is legal. He also shared his personal experience using cannabis for pain related to his severe hemophilia.

Social workers Dave Rushlow and Karen Boyd facilitated a conversation about relationship challenges for people living with hemophilia and its impact on their families. They observed that most men never experience the

kind of brotherhood and bonding that occurs when men in our hemophilia B community openly share about the challenges of living with the condition. They also talked about the importance of seeking support from family, friends, and professionals to overcome these challenges.

Before supper, attendees enjoyed the friendly competition of the *Bleeder Olympics* outdoors. These included old favorites such as beanbag toss and ladder toss, as well as a new one I hadn't seen before where you use a frisbee to try to knock a bottle off a pole.

The best thing about the men of the hemophilia B community is their ability to serve as a brain trust, imparting their collective experiences, knowledge, and wisdom with each other. The unique characteristic of our hemophilia B family is that we can be vulnerable with each other in a way that we aren't free to with anyone else. It is a place where we can both come to understand and to be understood. This is the most powerful feature of the *Men's Retreats*!

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





learn from the programs, and play in the *Bleeder Olympics!*"

"The benefits of attending a hemophilia B men's retreat are truly lifelong if you use the information provided to better your life or the life of your loved one."

"Exchanging ideas, providing support, teaching and learning; all work together in a positive and enjoyable gathering. Well done."

"The men's retreat gives you that drive to see things in a different perspective and being with all the guys helps us share our emotions to get back home with a relaxed mental health."

"The biggest takeaway moments from men's retreat happen in conversations. These are the times we get to connect with our fellow bleeders - swapping stories about life and commiserating over our shared experiences."

"After attending the men's retreat, I took away many lessons on how to live a healthier life for my physical and mental health."



COMMENTS:

"The Men's Retreat is an awesome program to connect and share experiences with other blood brothers. I hope to attend every year!"

"The brotherhood was strong at the fall Men's retreat. There were great topics and chances to see old friends and make new ones!"

"What a warm reception of people! The positive energy left a huge impact!"

"The men's retreat allowed me to refocus and recenter. Brothers uplifting each other."

"This was an amazing opportunity to connect with other men and fathers in the hemophilia B bleeding disorder community. What an amazing combination of education and recreation. It was like summer camp for adults!"

"It was great to share experiences with the community,





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PURE JOY GEN IX LEADERSHIP

BY JACOB POPE

As I sit to write this debrief of the Gen IX Leadership program, I can't help but feel overwhelmed with happiness. Just a few hundred yards down the beach from YMCA Camp Surf, a young kid shouted to his family, "Look at the sunset! Look at the sunset!! Look at the sunset!!!" We all looked at each other and giggled at his enthusiasm, but I couldn't blame him - it was a beautiful thing to witness.

If you haven't experienced the sunset in San Diego, let me tell you, it's a spectacular sight. The sun seems to pull the whole sky around its arc as it sets, and if you're lucky enough to be barefoot in the sand, leaning back in an Adirondack chair next to new friends who you know will be a part of your life for years to come, the feeling is indescribable. It's moments like these that make the Gen IX Leadership program worth signing up for.

I have so many wonderful memories from the program, and I'm sure everyone else who attended does too. As I think back on those 72 hours of smiling, I've compiled a list of the moments that made me happiest. For those who attended, I hope reading these memories brings a smile to your face too. For those who didn't attend or couldn't attend this year, I hope this list gives you a taste of what the program has to offer and inspires you to join us next time.

Here are just a few:

- Dave riding in the SkyTram at the San Diego Zoo and letting out a high-pitched "AHHHHH!!!" as the tram picked up altitude, surprising the group of school field-trip goers below.
- Casey shredding the gnar her first time surfing and gliding to shore on gentle

waves time and time again.

- Mohammad engineering an ingenious solution and guiding a group through a notoriously challenging puzzle and learning the secret of the puzzle is to teach us to ask for help.
- John walking into the Institute for Contemporary Art and walking right back out with a "yeah, not for me" - which was completely okay, because Balboa Park was filled with other free-choice activities for us to enjoy and spend a balanced Friday with friends.
- A gaggle of adults glued to a big screen TV for a "wind down" movie that ended up keeping most of us through the whole thing, some of us popping out of our seats to cheer, and inspiring others to come up with creative Halloween costumes.
- Embracing the season of fall by mastering the art of the *Fabled PSL* ("Pumpkin Spice Latte" for the uninitiated).
- Damon going full-out Jackson Pollock and splattering paint on his Halloween pumpkin.
- Sipping on Italian ice and fresh berries while soaking up the sun.
- Ron doing the best Carlton dance down a runway with 30 other people cheering him on.
- Learning how to balance exercise into your life, no matter your mobility restrictions, from a physical therapist from the UCSD Hemophilia and Thrombosis Treatment Center.

The theme of our first live Gen IX Leadership program since 2020 was *Balance*. Throughout the long weekend, we explored this theme through a variety of activities and conversations. At the beach, we literally engaged with balance on surfboards and boogie boards. Camp Surf staff supported us as we tried surfing, boogie boarding, and body surfing. In the ocean, we learned





that balance can be hard to gain and maintain, but once we do, we can find a sense of calm control as we ride the waves.

On land, we participated in games, field trips, and activities that focused on balanced leadership. We played a camp-wide game where participants were invited to step into leadership roles and develop skills like problem-solving and creativity. We discussed our perceptions of ourselves and of each other, and how that affects our views on leadership. We visited the San Diego Zoo, where we observed animals living, leading, and existing in balance with one another, and considered how we can learn from them.

We were grateful to have the opportunity to think, discuss, and dream about balance during our last Gen IX program of the year.

A special Thank you to our Sponsor MEDEXUS PHARMA.



COMMENTS

"An experience of many firsts that I'll never forget!"

"Gen IX Leadership taught me about many different things, but the most important was how to be a leader and how I am looked up to [by others]. I got to spend time getting to know many wonderful individuals during my time at Gen IX Leadership and they're

now a part of my Gen IX Hemo Hana family. I think my favorite part is having my accountability buddy hold me accountable to my goal and I will reach it! The last night at Gen IX Leadership was powerful. It showed me that a lot of people look up to me and also showed me that everyone is inspiring and has their own story. I cannot wait to cut my paracord bracelet off once I reach my goal of getting my drivers license."

"Leadership was all about balance. Whether that meant getting on the board or simply balancing life and the people around us."

"As I reflect on the time at YMCA Camp Surf for Gen IX Leadership, I feel grateful for the opportunity to share a space with amazing individuals who have shown their hemophilia who is boss. Their resilience, energy, and passion are truly inspiring. I owe part of who I am as an individual and as a professional to programs like these! I look forward to continuing to be part of this program and to help expand it so more of our community members get to enjoy it! To the Coalition for Hemophilia B, Medexus, and GutMonkey, thank you for making this a reality for us!"



THE COALITION FOR HEMOPHILIA B FAMILY MEETINGS “ON-THE-ROAD”

BY ERICA GARBER

Over the course of six weekends this fall, the CHB team visited 12 cities to host their first in-person *Family Meetings on the Road* since 2019. This is our series of one-day programs in cities across the country designed to provide education, support, and empowerment to members of our “extended family” in an intimate, family-oriented, local setting. Sessions featured distinguished speakers and members from the hemophilia B community providing information and tools that improve health outcomes and maximize quality of life. More than 200 members attended these events, which focused on mental and physical health and the impacts of the pandemic on our community.

CSL Behring sponsored meetings in St. Louis, Fullerton, Houston, Charlotte, Pittsburgh, Richmond, Atlanta, and Auburn Hills. Patricia Amerson, Honey Blankenship, Amber Casey, Betsy Koval, and Tyra Holland joined us as expert speakers in five states to share important new information. They dove into the topic of gene therapy for hemophilia B and led attendees through an interactive program to help them think about the condition and what optimal control looks like for each person.

Novo Nordisk sponsored meetings in Minneapolis, Denver, Chicago, and Cincinnati. Hemophilia

Community Liaisons Judy Doyle, Natalie Kukla, Craig Price, and Brittany Slossberg shared sessions on advocacy and physical fitness. They explored the topic of identifying needs while living with a bleeding disorder and how to effectively communicate those needs to others using six powerful tools of self-advocacy. In their *Guide to Fitness*, attendees learned new tips and tricks for maintaining a healthy lifestyle with a bleeding disorder.



Many of the expert speakers at these events had personal connections to hemophilia B, either living with the condition themselves or caring for someone who does. This allowed attendees to hear a variety of perspectives and experiences. Timothy Whitehead, who has severe hemophilia B, shared his story and discussed the importance of self-advocacy. William Patsakos, a clinical pharmacist and father to three sons with factor 9 hemophilia, discussed the impact of nutrition on bleeding and shared tips for healthy eating. Dr. Lisa Hensley, a virologist and mother to a child with hemophilia B, shared her son’s challenging medical journey and the importance of self-advocacy.





Lisa Littner, who has served on the board of directors for the Tristate Bleeding Disorder Foundation for 14 years and is currently the president, led a workshop on how to navigate the healthcare system like a pro. She discussed the importance of health literacy and shared essential tips for being your own advocate, including a method for discovering your unique learning style. Aaron Hansz, a financial planner who coaches individuals through the seasons of life with a spiritual foundation, explored the potential impacts of hemophilia on relationships and finances. Douglas Stringham focused on promoting proper ergonomics and overall better health and wellness. Lucy Ramirez, a clinical social worker with over 20 years of experience, presented on crisis management and easing the trauma of emergency rooms. She discussed ways of preparing for crisis events and how proactive thinking about emergency rooms can help. The session provided attendees with tools to better prepare for their next visit to the ER.

Matthew D. Barkdull, a certified medical family therapist and severe hemophilia B patient, presented new research and topics to the community. In his session on the science of change, he discussed the six principles that fuel change and how a paradigm shift from limiting thoughts can create a more desirable outcome. In other workshops, he shared research-based interventions for improving relationships and dispelled myths about money and highlighted economic principles. Jasmine

Brett Stringer is an uplifting keynote speaker, award-winning author, on-air TV personality, and host of the "Carpe Diem with Jasmine" podcast and lifestyle blog. In her talk, "Seize Your Life," she motivated us to live a vision-driven life and bet on ourselves to achieve personal success. She provided guidance on unlocking barriers to living the life we are intended to have and building a vision to take life to the next level.

Mosi Williams, who has severe hemophilia A and an inhibitor and has been involved in the bleeding disorders community for 30 years, presented on the importance of mental health in the hemophilia journey. He discussed the normal ups and downs of living with a bleeding disorder in the effort to address bleeds and other acute physical challenges and provided accessible strategies and resources for maintaining mental wellness. Mental health is an aspect of our well-being that is too often overlooked. Mosi shared with us an abundance of accessible strategies and resources, to find and remain in balance embracing wellness.

Mark Zatyryka, who lives with severe hemophilia and longtime advocate for the community, joined us for a presentation on mental wellbeing in the community. In this targeted session, he highlighted the significant impact of mental health challenges on caregivers and individuals living with bleeding disorders. He led us in exploring the challenges and effects on mental health, both as individuals and as a community. The session



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ended with a discussion on how to support one another and ourselves on our mental health journey.

Dr. Mina D. Nguyen-Driver, a therapist with over 20 years of experience treating patients and families with bleeding disorders, led a session on healthy relationships. She explored the power of connection and close personal relationships as a key aspect of mental health care and support, and discussed topics such as love languages, healthy communication, and building a supportive inner circle. Debbie De La Riva LPC, a licensed professional therapist and certified Mental Health First Aid instructor, has been active in the bleeding disorders community since her son was born with severe hemophilia in 1994. In 2018, she founded Mental Health Matters Too (MHMT) to raise awareness of mental health issues within the community. In her workshop, *"Got Triggers? Let's Talk About Them,"* Debbie explains that triggers are reminders of adverse or traumatic experiences that can create heightened emotions and unhelpful behavior. She provides tools for identifying and managing triggers to prevent them from causing havoc in personal and professional life.

Robert L. Friedman, Ph.D., author, international speaker, trainer, and therapist, has provided workshops, training programs, and keynote presentations for the past 35 years. Based on his book *"How to Relax in 60 Seconds or Less,"* he presented a multimodal "immediate-need" program that teaches relaxation techniques that can be completed in one minute or less. Attendees learned instant mental, behavioral, sensory, and physical relaxation techniques, as well as tools for creating a more relaxing home and work environment. Another longtime speaker and community contributor, Ellen Kachalsky, LMSW, ACSW, CCM, joined the presentation to explore the physical and emotional impact of COVID on various bleeding disorder populations, disparities, and mental health. The group discussed the importance of coping and caring for themselves as we come out of the pandemic.

Each of our meetings this year included one session that modeled one form of hands-on healing experiences and attention to our physical bodies. With certified yoga instructors, Erica Garber, Bianca Davis, and Douglas Stringham, we explored gentle yoga sequences, guided meditations, and breathing



exercises. We also learned the value of combining quality breath work and movement together. In recent years, many of us have struggled with mental, physical, and emotional health concerns. These short workshops were designed to show us some techniques that are useful in any setting to lift spirits, minds, and bodies. Our own Rocky Williams also did a great job of bringing the fun of camp to our meetings, with many of us up on our feet, moving, stretching, and laughing.

Another leader in our community, Rick Starks, diagnosed with hemophilia B at birth, taekwondo champion, and Tai Chi instructor, joined us for several

of our Meetings on the Road. Rick shared the Tai Chi techniques that taught him a sense of mindfulness and body connectivity that he hadn't experienced before. This ancient Chinese martial art is known for its slow, gentle movement, which lures participants into a deep sense of relaxation while achieving physical fitness. It is one of the highest recommended forms of fitness in the hemophilia community.

While the adults learned and shared with each other, our children were out exploring the sites with our chaperones. We took kids trips to several major zoos, adventure parks, and a variety of enriching science and



discovery museums. There were science experiments, art projects, sharks, turtles, and wild cats, to name a few of the experiences and new friends made. But the adults had their own fun too. The CHB team ended every meeting with our own family-style trivia game, "Are You Smarter Than Your Hemophilia B?" Families and teams matched their knowledge and wits for trophies and prizes, but everyone ended up a winner. In each city, we ended the day with a wonderful evening meal and fun arts and crafts. We had a great time making spooky lanterns and orange pomanders. Thanks to Medexus for the memories we made painting rocks and playing games, and for generously sponsoring our dinners.

The exhibit tables hosted by our extended family of local chapters, pharmaceutical companies, and healthcare services are a major attraction for our families. We would like to thank all of our exhibitors for sharing their resources and time to make these gatherings more enriching and informative. It is

through that extra personal touch and face-to-face time to ask important questions with experts that makes this series and all of our meetings like it so important to our community. In the six weekends of meetings, we hosted over 60 tables filled with resources, materials, and gifts that were supported by over 150 industry professionals. The need for this kind of education and community building is more vital than ever, and we are proud to have offered so many opportunities for interaction and bonding between participants.

This year's Family Meetings on the Road series provided an invaluable opportunity for education, support, and connection for those living with hemophilia B. From workshops on navigating the healthcare system to discussions on mental health and wellness, there was something for everyone. The CHB team is grateful for the support and participation of our expert speakers, sponsors, exhibitors, and attendees. We extend our thanks once more to our two event sponsors, CSL

Behring and Novo Nordisk. The interactions and connections made at these meetings are crucial for building a strong and supportive community. The events were a success, and we look forward to continuing to provide educational and support opportunities for those living with hemophilia B in the future.

CSL Behring



COMMENTS

"It was warm and welcoming being greeted by local volunteers. It was like receiving a hug from a family member"

"The Denver *Meeting on the Road* was our first hemophilia B event as a family. We had a great time and learned a lot. We are kicking ourselves that we waited so long to get involved in this great community."

"It was excellent to catch up with the Hemo B families. It is always great learning something new even though attending these meetings for a while. Keep them coming!"

"I had a great time at *Meeting on the Road*. It is a great feeling to get together with others in the Hemo B community."

"I love getting together with my Hemo family!"

"Great to see everyone again!"



"The Coalition always puts on a good show while encouraging interaction among our blood brothers and sisters as well as caregivers."

"Great chance to get together with our CHB family. Informative."

"The meetings on the road are a great chance to meet up with old friends, make new friends, learn some useful information, and relax!"

"Thank you for the *Meeting on the Road*. It allowed us an in-person meeting with some one on one time with friends and an educational experience to remember. Thank you for all you do for our Hemo B family."

"HEMO B is the place to be!"

"The *Meeting on the Road* will always hold a special place in our hearts. The Michigan MOR was our very first gathering, right after our son's diagnosis six years ago. We didn't know what to expect, and were nervous, not knowing anyone yet. Fast-forward to last weekend, we got to spend time with some people we consider family! Plus, we had a chance to meet a newly diagnosed family in Michigan to welcome them to our close knit B Community. We are so grateful for this opportunity to learn and grow together."



"This was our first time attending any of the CHB meetings. We enjoyed it all and Rocky, he is awesome, he kept us all laughing."

"We met a lot of wonderful new friends at the meeting."

"The *Meeting on the Road* help families who might not be able to travel to larger events keep up with the Coalition and what's happening in our world. Thank you for being here for us."


"The meeting was very helpful and informative, and it was great seeing family."

"Everything ran so smoothly, all attendees were so engaged and appeared to truly learn from the speakers and laugh and enjoy themselves. I was able to see people I haven't seen for some time and sit in on some sessions."

"The love and fellowship in the room from your coalition team and the fellow attendees and vendors was a much-appreciated experience and just what makes the coalition the special bunch of folks that it is."

"My mom and I attended the *Meeting on the Road* in Cincinnati. We met some awesome people and learned a lot. It was the first time I had attended one in person. I loved talking/networking with others who "understand" what we are going through. Would definitely recommend it to others and look forward to attending the next one!"





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FUELING CHANGE: 50 AND OVER

BY CHAD STEVENS

On November 17th, I had the pleasure of hosting, along with my friends Wayne and Carl, a gathering of blood brothers and sisters in the 50 and older age group. This wasn't just another Bingo or Yoga event for us 50-plus folks! It was an opportunity to get together and spend time discussing what concerns us. We hope this will become a regular event, both virtually and in person.

At our inaugural event, we were honored to have a great presentation by Matt Barkdull on the topic "The Science of Change". Before his presentation, Matt asked the group, "Who likes change?" This question revealed differing opinions in the group, with some people liking change, some being indifferent, and others not caring for it. Regardless of our preferences, we all agreed with the old saying that "change is inevitable" and many of us agreed that change can be both good and bad. We also agreed that when we have control over change, it can be good, but change that we can't control may not always be good. Many of us shared our concerns about the decline in our physical and mental health that is a natural part of the aging process and its resulting loss of independence.

To help us understand change better, Matt went through the Six Principles that Fuel Change: Identity (who we are and how we think of ourselves), Purpose (the central motivating aims of our life), Truth (the cold hard facts that don't change regardless of the future, present, or past), Momentum (the pace at which we move in a positive direction in life), Synergy (the need for the strength of others in going through life changes), and Transcendence (the ability to perceive ourselves differently and achieve what we're trying to achieve).

Throughout the meeting, we had some great conversations about the good and bad aspects of aging, what the future may hold, finances, healthcare, and more. It was great to see familiar faces as well as some new ones. Thanks to the Coalition for Hemophilia B for making it happen and helping us move forward with change.

Stay tuned for details in January about our next 50-Plus event.

50 AND OVER GATHERING
WITH WAYNE, CARL, & CHAD
LET'S WRITE
THE NEXT CHAPTER

- ✓ Virtual Zoom Meeting
- ✓ Raffle Prizes
- ✓ Meal Vouchers

THE COALITION FOR HEMOPHILIA

COMMENTS:

- "It was great to see and hear the older group again since we don't see each other in person as much now."
- "The Over 50 session was great! Being able to address largely unexplored issues is something that is needed in our community..."
- "I found the 50-and-over event to be a great way to meet others in my age group; I found their willingness to share their experiences to be helpful and interesting; I enjoyed the presentation on the Science of Change because change is usually something that I am not comfortable with."
- "I greatly enjoyed the 50-and-over event. I appreciated everyone's participation in the group chat and I look forward to seeing the group again."
- "Genuine connection and support"
- "I am glad that we are addressing the age factor of individuals with hemophilia because it seems like a lot of activities are geared towards our youth."
- "Loved being able to check in with people in my age bracket who understand what it involves being "senior citizens."
- "Felt like I am at home, very casual, and friendly. Obviously, it was very informative."
- "Great way to keep us connected without the difficulties of travel."
- "The over 50 session was great for reconnecting with family and learning something new!"

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.

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. Nothing to report.

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 system 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.

Pfizer Reports Phase II Results for Marstacimab

10/11/22 Pfizer is developing marstacimab, an inhibitor of the anticoagulant tissue factor pathway inhibitor (TFPI). Inhibiting TFPI rebalances the clotting system, restoring the clotting ability for people with hemophilia A or B, with or without inhibitors. Marstacimab is a subcutaneous once-weekly injection. They recently published an article on their Phase II clinical study, which is the first report on long-term (one year) safety, efficacy and tolerability as a prophylactic treatment.



The treatment was generally well-tolerated, although there were some mild adverse events such as injection site reactions, injection site hematoma and hemarthrosis (joint bleeding). There were no thrombotic effects (unwanted clotting), no allergies to the treatment and no inhibitor development. The annualized bleeding rate (ABR) on marstacimab ranged

from zero to 3.6, compared to ABRs of 14.0 to 22.0 pre-treatment. [Mahlangu J et al., Br J Haematol, online ahead of print 10/11/22]

Freeline Halts Development of Gene Therapy for Hemophilia B



11/15/22 Freeline Therapeutics has been developing a gene therapy for hemophilia B. Their product, FLT180a, is an AAV-delivered high-activity factor IX gene, similar to others under development. They are in Phase II studies in patients. The advantage of Freeline's product is that it increases factor IX activity into the normal range. However, Freeline has been having financial difficulties and has decided to stop development of FLT180a in favor of two other gene therapies they believe will produce a quicker payoff.

They are interested in finding a partner for resumption of FLT180a development. [Freeline Q3 Corporate Update]

Study Suggests that Misfolded Proteins Might Cause Liver Cancer with Some Gene Therapies

10/13/22 A group from California recently published a study that suggests that misfolded proteins produced by gene therapy may cause liver cancer. Proteins fold into a specific shape when they are made in cells. The shape gives the protein its activity. For instance, a misfolded clotting factor protein would have little or no clotting activity. The study focused on factor VIII, the protein missing in hemophilia A, but is potentially applicable to any protein made in liver cells by gene therapy.

The factor VIII proteins made by gene therapy are a shortened form of the normal protein because the complete factor VIII gene does not fit inside an AAV vector. The shortened form deletes part of the molecule called the B-domain, which does not appear to be involved in clotting. The resulting protein is called B-domain deleted factor VIII, or BDD-FVIII. Note that many of the recombinant factor VIII products also use

BDD-FVIII, so we know that it works well in hemophilia A. However, BDD-FVIII is prone to misfolding.

These studies were done in mice. Proteins are made in a portion of the cell called the endoplasmic reticulum (ER). It is known that extensive protein misfolding in the ER, coupled with a high-fat diet can cause hepatocellular carcinoma (liver cancer). The researchers treated the mice with one of three types of gene therapy using direct DNA delivery to liver cells to avoid any reactions to AAV vectors. The mice received either: 1) DNA that caused them to produce DHFR, a protein that folds easily, 2) DNA for BDD-FVIII or 3) DNA for a modified factor VIII called N6-FVIII that is less prone to misfolding. The mice were then put on a high-fat diet for 65 weeks.

After 65 weeks, the mice that received the BDD-FVIII gene therapy had all developed liver tumors. Only 58% of the mice that received N6-FVIII gene therapy and none of the mice that received DHFR gene therapy developed liver tumors.

The research suggests that the misfolded proteins place a lot of stress on the liver cells that produce them. That stress itself might not be enough to cause the cells to become cancerous but combined with other stresses could lead to cancer. Other stresses include a high-fat diet, excessive alcohol intake or an already-damaged liver among others.

Note that these studies were done in mice, not humans. Although mice are often used for gene therapy studies, they don't completely replicate human behavior. Also, the study was done with factor VIII, a much larger protein than factor IX.

At this point, we don't know whether factor IX gene therapies have this same problem. In gene therapy for hemophilia B, the whole factor IX gene is used, although it is modified in several cases. However, the Padua factor IX variant used by CSL/uniQure and many of the other groups developing gene therapies, only has two different amino acids and has a structure very similar to normal (also called wild-type) factor IX. That may keep it from misfolding.

This should not scare you away from gene therapy, especially if you have a healthy liver. It does point out that there is still a lot we don't know about the effects of gene therapy. In a real sense, anyone who tries gene therapy now is still part of the ongoing experiment testing how it actually works in the long run. Having gene therapy is not a decision to be taken lightly, but so far there are a number of patients who are glad they did choose it. The bottom line may be that if you are interested in gene therapy, take care of your liver! [Kapelanski-Lamoureux et al., Cell Mol Ther, online ahead of print 10/13/22]

ICER Analysis Shows Gene Therapy to Be Cost-Effective



11/3/22 Does a price tag of \$3.5 million seem crazy for a gene therapy treatment? Well, the Institute for Clinical and Economic Review (ICER) suggests that it is not. They looked at pricing for both HEMGENIX, the recently approved gene therapy for hemophilia B, and Roctavian, a gene therapy for hemophilia A that has been approved in Europe but not the U.S. They collaborated with the Coalition, HFA and NHF as well as a number of other organizations.

Based on the fact that over a decade a hemophilia B patient on prophylaxis spends \$5 - 6 million on factor, a price of \$3.5 million for gene therapy would recover the cost in about six years. This, of course, depends on the durability of the treatment, that is, how long it lasts. That's an issue for Roctavian and hemophilia A because it seems that its effect may fade after about eight to twelve years. At this point, HEMGENIX for hemophilia B seems to have a much greater durability, but we don't know yet how long that will actually be. Of course, it also depends on the cost of factor, which is probably overpriced in the U.S., but that's just how our system works. [ICER Report: Gene Therapy for Hemophilia B and An Update on Gene Therapy for Hemophilia A: Effectiveness and Value, updated 11/3/22. Available for free online at icer.org.]

OTHER PRODUCTS

Tremeau Discontinues Study of Rofecoxib for Pain in Hemophilia



9/13/22 Tremeau Pharmaceuticals has been developing rofecoxib, a COX-2 inhibitor, for treatment of joint pain in hemophilia patients. Rofecoxib, marketed as Vioxx, was on the market for a number of years as a pain medication. Many hemophilia patients found that it worked very well for joint pain, but it was taken off the market because some patients developed heart disease. Tremeau believes that it can be used safely in a more controlled environment like hemophilia. They have been performing a Phase III study to get it re-licensed.

However, with the pandemic, the Ukraine war and other significant events, they have been unable to enroll enough patients in their study, so they are discontinuing the project. They are now starting a Phase III study using rofecoxib to treat migraine. They feel that a migraine study would be completed in a much shorter time and lead to quicker re-licensure. Note that once a product is approved by FDA for any indication, it can be prescribed by physicians to treat other conditions. This may end up being the path to availability of rofecoxib for hemophilia. [Private communication from Tremeau, 9/13/22]

GENE THERAPY HISTORICAL APPROVAL

BY DR. DAVID CLARK

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 Gene Therapy for Hemophilia B Approved by FDA

11/22/22 The U.S. Food and Drug Administration (FDA) approved CSL Behring's gene therapy for hemophilia B. The drug name is etranacogene dezaparvovec-drlb, and the trade name is HEMGENIX®. The treatment was originally developed by uniQure and will be commercialized globally by CSL. We want to congratulate them for their years of work and the success of this exciting breakthrough.

HEMGENIX consists of an adeno-associated virus, type 5 (AAV5) vector that delivers the high-activity Padua factor IX gene to cells in the liver. The transformed liver cells can then produce the Padua version of factor IX along with the mutated factor IX that they usually produce.

Although HEMGENIX was only tested clinically in adult males with severe or moderately-severe hemophilia B, the FDA gave it a fairly broad indication:

HEMGENIX is an adeno-associated virus vector-based gene therapy indicated for treatment of adults with Hemophilia B (congenital Factor IX deficiency) who:

- Currently use Factor IX prophylaxis therapy, or
- Have current or historical life-threatening hemorrhage, or
- Have repeated, serious spontaneous bleeding episodes.

That means that it can be used in adult (18 and older) men who fit the above criteria, not just in those with severe (<1% FIX) or moderately-severe (up to 2% FIX) disease. However, it is not indicated for inhibitor patients.

The clinical studies showed a wide range of responses to the treatment with factor IX levels ranging from factor IX levels of 4.9% of normal to 99.2% after 24 months in 50 patients. The average factor IX level after 24 months was 36.7%. Thus, the treatment will move many patients up into the mild hemophilia range, with some patients even obtaining normal factor IX levels.

Such a widespread in results, 4.9 to 99.2%, would normally doom a product. Manufacturers want to know that a product can be depended on to work for as many patients as possible. However, the clinical study results suggest that the product will work well in many patients, so it was probably worth approving for those patients' benefit.

The approval was actually based on the decrease in annualized bleeding rate (ABR) rather than factor level. The average ABR during the lead-in portion of the study while the subjects were still on prophylaxis (months 0 to 6) was 4.1 bleeds/year. The average ABR during months 7 to 18 after treatment decreased to 1.9 bleeds/year. All but two of 54 subjects in the studies were able to discontinue prophylaxis.

Pre-testing is required for patients considering HEMGENIX. Patients will be tested for inhibitors and for liver health. It is also recommended, but not required, that potential recipients be tested for pre-existing antibodies against the AAV5 vector. The clinical studies showed that the treatment still works in people with pre-existing antibodies, except for those with extremely high levels.

Presence of an inhibitor will preclude using HEMGENIX. We don't know what would happen if an inhibitor patient were given gene therapy, but there is a potentially significant risk. The inhibitor patient would start producing factor IX, but the immune system would also still be producing inhibitor antibodies. This could set up an ongoing war between the immune system and the transformed liver cells that now make factor IX. That could be a possibly fatal situation.

Patients with liver damage can still potentially receive HEMGENIX. FDA only requires that a liver specialist be consulted before going ahead. If the specialist thinks the patient will still do all right with the treatment, they could still be treated.

Possible adverse reactions include infusion-site reactions, liver toxicity, immune reactions against the AAV vector that could render the treatment ineffective

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and liver cancer. Other common reactions include headache, flu-like symptoms, fatigue and malaise.

After treatment, regular testing for factor IX level, new inhibitors and liver enzymes will continue. It can take several weeks for the treatment to take hold, so factor IX infusions may need to continue during the first weeks after treatment. Patients with elevated liver enzymes (ALT and AST) after treatment may be given corticosteroids to manage the liver inflammation. In patients with liver conditions, periodic ultrasound and tests for alpha-fetoprotein will continue at least annually for five years.

One real question is how long the treatment will last. This is a one-time treatment that is intended to last a lifetime, but we don't really know for sure – only time will tell. Last year uniQure reported results from a series of patients who had had the treatment for at least five years. They still had sustained production of factor IX, reductions in ABR, and were still off prophylaxis. However, those subjects had been treated with an earlier version of the product that did not use the Padua factor IX gene. So, this provides some assurance, but not proof that the treatment will last a substantial amount of time.

Much of the media coverage of the approval of HEMGENIX overlooked the fact that this is a real breakthrough treatment for hemophilia B and only

focused on the cost. HEMGENIX is now the most expensive drug in the world at \$3.5 million per dose. That could be a real burden. We will have to see how payers react. CSL will also want patients to use their new product, so they might provide some financial incentives as have become common for other high-priced drugs.

We don't yet know how HEMGENIX will be marketed and administered. There has been talk of only providing the product through a few major medical centers and HTCs. If you are interested in being treated, talk to your hemophilia provider or HTC. You should also explore what is known so far about HEMGENIX before you make a decision. Much of this article is based on the FDA-approved Package Insert (also called Prescribing Information or Direction Insert), which can be downloaded for free at <https://www.fda.gov/vaccines-blood-biologics/vaccines/hemgenix>. In addition, there will probably be ongoing evaluation of HEMGENIX as the product is rolled out to patients, and we get more real-world experience with it.

This is an exciting development for hemophilia B treatment. It is the first gene therapy approved anywhere for treatment of hemophilia B. It represents a major leap in the development of an eventual cure for all patients with hemophilia B. [FDA approval information and press releases from CSL and uniQure]



**WHAT I
WISH I HAD
KNOWN...**

Uncensored & Uncut

**REAL-LIFE
LESSONS
FROM
YOU-
THE EXPERT**

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story to help
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MAKING DECISIONS UNDER STRESS: KEEPING THE FLAME WHILE ENDURING THE STORM

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

In today's fast-paced society, change and speed are the norm—high speed internet, fast food, express lanes, and instant messaging are all part of our daily lives. However, life's stressors can also come upon us quickly and unexpectedly, leaving us feeling vulnerable and unprepared. In order to be ready to make critical and objective decisions in the midst of a crisis or change, we must be prepared for the unexpected and take steps to manage fear and stress. By doing so, we can increase our sense of control and make better decisions during challenging times.



Dealing with bleeding disorders can be a difficult and stressful experience, whether you are a patient, a parent, or a caregiver. The fear of making poor decisions and the potential consequences, both physically and emotionally, can be overwhelming. In these situations, it is natural to wonder how to make important decisions when faced with fear and stress. Here are three pieces of advice that may be helpful in preparing to make significant decisions during times of crisis or change:

Principle 1: You can only critically think of one thing at a time.

Some people pride themselves on their ability to multitask under high-pressure environments. While they may be good at juggling multiple tasks, this is different from critical thinking. In reality, human beings are often terrible multitaskers, especially when under stress. In these situations, important details can be lost, consequences can be considered but not properly weighed, financial details may be ignored, and the potential repercussions of decisions may not be fully thought out.



So, what's the solution? I call it *weeding the garden*. Church leader and statesman LeGrand Richards once said:

*For every worry under the sun
There is a remedy or there is none.
If there is a remedy, hurry and find it.
If there is none, never mind it.*

This analogy can be applied to the problem of multitasking. In a garden, there are plants that produce a yield, offering the grower a bounty of fruits and vegetables. However, there are also plants that offer nothing of value, such as weeds and thorns that can choke and destroy a crop. Similarly, we must clear out the pressing influences from our minds that serve no purpose. These can come in the form of petty distractions, saying yes to too many requests, and other issues that should be put on hold or eliminated altogether.

To help with this, I find it helpful to draw a line down a blank page and label one side "control/important" and the other "no control/

not important." Write out your worries, concerns, and issues that you're facing, and sort them into these respective categories. You may be surprised at what falls under the "no control/not important" category. Focus on and act upon those things that you have control over and that are most important.

Principle 2: You can't do it alone.

Have you ever cooked with charcoal or briquettes? Nothing beats the taste of grilled vegetables, shish kabobs, fish, hamburgers, steak, or chicken cooked over a charcoaled grill. Once the coals are all fired up after applying lighter fluid, they eventually turn from black to glowing red and coated with a light-gray ash.

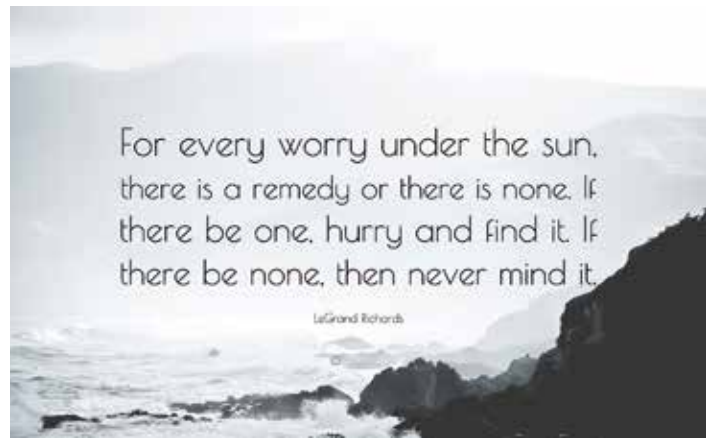
At this point, the fluid and fire that originally set them ablaze have long since died out. So, what's keeping them burning? Grab a pair of tongs, remove a single coal from the grill, and let it sit out in the air for a while. What happens to it? It eventually burns out. Why? While a single piece of coal can sustain its own heat for a while, it won't burn nearly as long as others in the grill. The agent that keeps coals' heat sustained is not just their own internal burning mechanism—it's each other.

This same principle applies to humans. We cannot sustain our own "heat" very long on our own. Although some may possess grit and endurance, "burnout" is still more likely to occur without the support, guidance, and love of others. Trying to make stressful and even life-changing decisions without support is like trying to keep a match lit in a hurricane. It just doesn't work. We must invite others to rally around us (e.g. doctors, family, friends, groups, co-workers, clergy, etc.) in order to feel empowered by their heat and support.

All too often, people complain that they have no support system. Let me share a little secret that many find hard to believe, but it actually works: speak out! Try it. Get to know your neighbor, express your concerns with a doctor, or seek counseling. When somebody you trust asks how you're doing, tell them the truth. You're struggling. You don't have to go into an enormous amount of detail, but expressing how you're feeling can be therapeutic. It may surprise you that others may be going through something very similar. By opening up, you may just find your new best friend!

Principle 3: You can't ride a dead horse.

As life changes, we must adapt and conform to our new circumstances. With each new major milestone and crisis, life takes on a different dynamic, requiring a change in course. A biblical text explains this principle: "When I was a child, I spoke as a child, I understood as a child, I thought as a child: but when I became a man, I put away childish things" (1 Corinthians 13:11). As much as we may wish that our present circumstances would revert back to what was familiar and comfortable, our present reality demands a different approach.



For example, say you inherited a beautiful stallion. From a foal, the horse seemed perfect in every way. It responded to its training, learned commands, and respected your authority. Over time, you came to know its behaviors and cues well enough to anticipate any problems and respond to its needs. But as the horse gradually declined and died, you were left with its offspring. You begin to train one particular horse that seems promising, using the same training formula that worked so well with the previous horse. However, to your shock, the new horse is not as responsive and is even downright stubborn! Frustrated, you continue to use the "proven" principles of horse training, but to no avail. Attempting to train from the saddle is like canoeing upstream. Finally, you give up and sell the horse for only a few hundred dollars.

To an extent, all of us attempt to ride a "dead horse," assuming that one method of practice that once worked governs and applies to all situations. "Johnny was so easy, but Billy! He's as stubborn as a mule! What did I do wrong?" Mental health professionals can help us objectively break old patterns that don't work and define new ways of thinking through and navigating changing tides. It is a liberating feeling when old habits are broken and new, effective actions are taken that help achieve better solutions.

As a closing thought, it's good for us to remember that anxiety and stress are specters that all of us will face. A lack of stress in life is more the exception than the rule. To an extent, stress can be highly beneficial as it can serve as a barometer for how much work we need to put forth to accomplish a goal. However, too much stress skews our ability to *see things as they really are*, diminishing our ability to make effective solutions.

If the degree of stress you're enduring is making it difficult to make critical decisions, please know that you're in good company. In fact, if you're not experiencing some stress, I'd be worried about you. If you can keep these three principles in mind as you're making decisions, I'm confident that you will have the mental and physical energy to be successful.

women & girls with hemophilia

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Don't Give Up on Living Your Best Life!

Heidi's Story

BY RENAE BAKER

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

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

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

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



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

Once diagnosed, Heidi was instructed to infuse one day

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

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

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

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

Heidi is actively involved with the Coalition. The Coalition's acknowledgment and support of female bleeders have been a tremendous help to her because as Heidi shares,



"One of the most frustrating things has been having people tell me to my face that I can't have hemophilia, that it's *impossible*." Indeed, she has even heard this from her own father.

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

"Some days, I might have an elbow bleed and be in so much pain I feel the weight of the world on my shoulders



and then blow a vein while trying to infuse. That's the worst," she continues. "Thankfully, I have such an amazing husband. Jacob encourages me and says I've got to get the infusion done. If I just can't, he will do it for me in spite of the fact that he hates needles. He's such a blessing!"

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

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

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

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

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

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

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

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#morethanaperiod

Bridging the Gap Between Diagnosing and Treating Women

BY RENAE BAKER

"I knew that my family had something wrong with their blood, but I didn't know what. Everybody in my family bruised and had bleeding issues, and they just called themselves 'free bleeders,'" Stormy says with a laugh. She didn't realize that her frequent pain and swollen ankles were caused by something more than her childhood play. "We lived in the country, so I was always falling into holes. I remember limping around a lot, but it was just like, 'Whatever!'"

Stormy grew up in North Florida and was one of seven daughters. Their mother hemorrhaged after every birth and ended up back in the hospital. Most of the daughters had terrible periods and early hysterectomies. Stormy had her hysterectomy at 33. "When I look back, I can remember every time I would lose a molar, I'd wake up, and my hair would be plastered to the pillow from the dried blood. I thought, 'That's just what happens.' I remember my very first period," she laughs. "I was at Disney. I was exhausted, not feeling good, and we had one of those old-fashioned photos taken. I was just like [she makes a miserable face that doesn't reflect the "magic" of Disney."

Stormy reveals that her periods were always bad. Even on hormone pills, she never bled for less than ten days each month. 45-day stretches of bleeding were not uncommon. As she looks back at the extensive periods, pain, and gum bleeding, and continually being told that these were "just female things" and that "some women just bleed like that," Stormy is infuriated. Her severe endometriosis led to a laparoscopy and blood transfusion at the age of 18. After a few more of these procedures, her doctor put her on male hormone injections and a two-year course of a contraception pill that would put her into a state of menopause by the age of 21. "Back then, I was so desperate and so young that I didn't ask questions. If they said, 'Do it,' I said 'OKAY!'"

Stormy married Craig, and they moved to Germany where he was stationed in the US Army. While still newlyweds and living overseas, their doctor advised them that because of Stormy's endometriosis, they would have to act quickly if they wanted to have children. That wasn't their plan, but they followed the doctor's orders. After two miscarriages, their daughter, Whitney, was born. Five years and a third miscarriage



later, their son, Collin, was born in 1999. After yet another miscarriage and enduring almost non-stop bleeding and excruciating pain, Stormy and Craig decided they were done trying for more children, and

Stormy had her hysterectomy. "I always said I wanted six kids, and I got six; just not all here on earth with me."

Once Collin was diagnosed with mild hemophilia B at age three, Stormy became heavily involved in the bleeding disorder community. She homeschooled Whitney and Collin, and as a busy mom, she noticed that her ankle had swollen to an alarming size. She consulted a doctor about it, but was told that she was not taking care of herself, given her son's hemophilia. Stormy then saw an orthopedic doctor, who showed concern for her ankle but Stormy felt that the extent of his concern was the too-familiar "Whatever." Due to other joint pain she was experiencing, the doctor referred her to a rheumatologist. This specialist told Stormy that all she needed was Prozac and that there was nothing wrong with her. Stormy knew that her pain was not caused by clinical depression and that she was not imagining it, but the doctors were not taking her seriously.

One day, a nurse friend noticed her swollen ankle and asked if it hurt. Stormy replied that it did, and her friend validated her pain, affirming finally that it was in fact not normal. She recommended that Stormy see a podiatrist, who she said had recently treated her husband. Stormy saw this doctor and learned that she had been walking around with three tears in her tendon for three years!

After Collin started going to camp, Stormy began volunteering on a leadership team in the Georgia bleeding disorder community and at camp. She said she enjoyed working with the girls and remembered telling them to take care of themselves and learn to infuse. One of the girls asked her if she had ever been tested, and Stormy replied that she was a carrier. This question spurred Stormy to see a private hematologist at Emory University Hospital, who told her that her levels were around 42. When Stormy said she thought this meant she had hemophilia, the doctor said they didn't know. Stormy replied that she would take care of it and called the Hemophilia Treatment Center (HTC), where she was finally diagnosed with mild hemophilia. She remembered that for the first time at the HTC they did not brush her off by saying she was a carrier and felt excited that she was finally being taken seriously.

But that excitement would soon turn to frustration and hurt as the doctors refused to prescribe a factor for her to have on hand when she needed it. "I said, 'Look, y'all recommend that my son have some on hand. I need some on hand just in case, too.' When something would happen to me that I knew I would infuse my son for, I would call them and they would say, 'It's not traumatic. You don't need to worry about it.'"

One day, Stormy suffered a bad ankle twist. She was infused with medication by the doctor and noticed that her hip and neck felt better as well. Stormy called her



doctor to ask if she could try infusing a few more times to see if it would continue to help her. However, the doctor dismissed her by saying, "It's the placebo effect. There's no reason other parts of you should feel better." Stormy recalls this moment with frustration. "That really upset me! I said, 'Don't tell me it's the placebo effect! If it feels better, it feels better. I know that for a fact!'"

Stormy's encounter with the dismissive doctor motivated her to seek a second opinion. She asked to see a different doctor, who told her that her symptoms were due to aging and likely arthritis, and advised her against infusing. Stormy challenged this diagnosis, pointing out that the infusions seemed to help her pain. In a conversation with an HTC nurse, Stormy asked if it was possible that she was having microbleeds in her hip. The nurse responded that microbleeds typically only occur after an injury, to which Stormy replied, "Well, I've had two babies. That was pretty traumatic on my hips!" Stormy eventually started infusing on her own and letting the doctors know afterwards. She felt that she knew her body better than they did.

After a couple of surgeries, for which Stormy was allowed to infuse, she found her third doctor. "I was really excited, because she agreed to let me start doing prophylaxis before I went hiking or did stuff I knew aggravated my hip or ankle." But once again, Stormy's excitement was short-lived as the prophylaxis was never prescribed. Stormy called and was told by the nurse,

"Well, your level was 60 this time. She's not giving you factor." Stormy challenged the nurse, "So last year, I had a genetic condition, but this year I don't?" "Well, your levels weren't high enough. You shouldn't be having any bleeding." "But I am!" Stormy persisted. "I know the difference." The lack of respect Stormy was feeling was creating a mounting sense of indignation. She started calling private doctors until she found one who would see her. It is a sad commentary on the state of women's health care at the institutions which specialize in bleeding disorders, but Stormy has left the HTC and is now being treated by a private doctor. "I realize that this doctor probably doesn't know enough about hemophilia, but I do, and I feel confident that, as long as he'll give me factor, I can take care of myself. I'm on prophy now, and it's amazing!"



After a couple of surgeries, for which Stormy was allowed to infuse, she found her third doctor. She was excited to work with this doctor because they agreed to let her start prophylactic treatment before engaging in activities that could potentially exacerbate her hip or ankle pain. However, the prophy was never prescribed. When Stormy called to inquire about this, the nurse told her that her factor levels were not high enough. Stormy challenged this, arguing that she was still experiencing bleeding despite having normal levels.

Frustrated by the lack of respect and support she received at the HTC, Stormy started calling private doctors until she found one who would see her. It is a sad commentary on the state of women's health care at the institutions which specialize in bleeding disorders. "I realize that this doctor probably doesn't know enough about hemophilia, but I do, and I feel confident that, as long as he'll give me factor, I can take care of myself. I'm on prophy now, and it's amazing!"

Stormy's mission is to raise awareness about the lack of treatment that women with bleeding disorders often receive simply because they are not male. This incongruity is highlighted by her experience volunteering at camp, where pediatric doctors would

examine her and immediately recommend infusion if she twisted her ankle. In contrast, her adult doctors at the HTC would not allow her to infuse, even though it had proven effective in the past. Stormy believes that women with bleeding disorders deserve the same level of care and respect as men.

Stormy recently checked in with the HTC during one of her son's visits to let them know about her progress on prophylactic treatment. The doctor asked her, "I hear you're on prophy now, so why are you here? What do you want?" Stormy replied, "The same comprehensive care that my son gets. I think I deserve that too." The doctor responded, "Well, I can tell you right now

that no 'milds' get prophy from this office. So if you have a doctor doing that for you, I don't know why you're here." Stormy tried to engage the doctor in further discussion, but he cut her off, saying that he would only prescribe PRN treatment and not prophylactic treatment. Stormy decided that there was no longer any need for her to continue seeing this doctor, and she stood up to leave. She pointed out that her son, who is also a "mild," was receiving prophylactic treatment and had never been denied the ability to infuse. She made it clear that she would no longer be seeking care from this office.

This recent exchange with the dismissive doctor took place only a week after a leading hematologist had encouraged Stormy by telling her that more hematologists are showing an interest in female bleeders and educating themselves about the topic. The hematologist had not anticipated that Stormy would have trouble getting the necessary prescription from her local HTC. Stormy described the experience as a "gut punch" and said that it made her feel like she did not matter as much as a man.

Stormy believes that doctors should be more open to the idea of the placebo effect. "If it is the placebo effect - so what? It's not their insurance. They aren't paying a dime for it. In fact, they're making money off of me," she says. She understands that doctors are concerned about the increased risk of clotting as women get older,

but she points out that women in labor often have factor levels that rise to 200-250 without experiencing clotting. She believes that even at 100% levels, women should be okay.

Stormy has also sought the opinion of a well-respected former hematologist who shared her expertise with her. The doctor acknowledged that older men often report feeling better all over after infusing, and that the medical community does not fully understand all the ways in which factor affects the body. Stormy concludes that it is possible that factor is helping more than we know.

Stormy's experiences echo those of many other women in the community. She explains that women with bleeding disorders often feel like they are getting nowhere with their doctors, who often dismiss their symptoms as being all in their heads or tell them to exercise more. Many women eventually stop seeking treatment because they are tired of feeling like they are not being taken seriously. Stormy has been aware that her own joint problems would only get worse without proper treatment, and she has been outraged by the lack of support she has received from the medical community.

As she has become more involved in advocating for female bleeders, Stormy has become increasingly grateful for the men who fought for better care for people with bleeding disorders. Because of their efforts, her son is receiving better treatment. She is determined to continue advocating for women and girls with bleeding disorders, even if it means enduring difficulties herself. She participates in every committee she can and speaks up about the gaps and shortcomings she sees in the existing support programs for women. Stormy wants national program leaders to understand that, despite their claims of supporting women, many women walk away from these programs feeling disappointed and unsupported.

Stormy knows that advocating for better care for women with bleeding disorders is not easy, but she believes that it is necessary in order to bring about change. She is motivated by her own struggles and her desire to prevent others from experiencing the same pain and frustration. Stormy has started using the hashtag #morethanaperiod to call attention to the fact that doctors often only want to talk to women about their menstrual periods, even though many women with bleeding disorders have had hysterectomies and no longer have periods. She believes that doctors should focus more on treating the symptoms of bleeding disorders, rather than just discussing factor levels.

Women in the community often feel hopeful when they hear about doctors who support prophylactic treatment for female bleeders, only to be disappointed when their



own doctors refuse to prescribe it. Some women are even willing to fly across the country to get the care they need. Stormy finds it unacceptable that women with bleeding disorders have to go to such lengths to get the treatment they deserve. She points out that every state has a treatment center, and there is no good reason why women should have to go without care. She shares stories of women who are so afraid of bleeding to death that they take their son's factor in hospital parking lots before surgeries. Stormy believes that it is time for the medical community to take the needs of women with bleeding disorders seriously.

Stormy became aware of The Coalition for Hemophilia B, when Collin was around 15. "As a woman, just being able to know that there are people who believe us, who listen, who support us, who give us opportunities to get involved and to be heard is life-changing," Stormy says. "I look at myself as this small, country girl. I never in a million years dreamed that I'd be standing on a stage, giving a presentation and an award to a doctor!" She is referring to last March's Eternal Spirit Award, which she was honored to present to Dr. Sedonia at the Coalition's annual dinner. Stormy is determined to help other women with bleeding disorders and is willing to do whatever it takes, even if it means facing her fears.



ADVOCACY NEWS

BY GLENN MONES

PRELIMINARY INJUNCTION MAY RESTORE PLASMA DONATIONS BY MEXICAN NATIONALS

United States District Court has issued a preliminary injunction preventing the United States 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.

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.

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TOGETHER

**CHB 2023 SYMPOSIUM
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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.



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VISIT OUR SOCIAL MEDIA SITES:

Website: www.hemob.org

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



Deep Dish or Thin Crust?

BY ROCKY WILLIAMS

This fall, three CHB community members - James, Gabby and Aaron - stepped up to codesign, promote, and host virtual events for their fellow teens. The results were truly amazing! Each event boosted hemophilia and advocacy trivia, an entertaining game, an impassioned rap session, and time to just connect.

On October 12th, James kicked off the series with an evening of events centered around the *Wheel of Enormous Proportions*. After being welcomed by James, myself, and our sponsor, the teens beheld the *Wheel of Enormous Proportions*! This epic game of trivia and chance was hosted by an immortal, all-knowing wheel from a mountaintop in the sky. This brainy game had everyone competing, guessing, laughing, and having a blast!



Licensed therapist Matt Barkdall hosted the rap session at each of these teen events. In each case, he encouraged teens to share a piece of themselves with their peers and, on this night, also sought to answer the immortal question of who makes the best pizza: Chicago or New York? This debate was lively and one for the ages! However, being from Chicago, we all know the answer is Chicago deep dish.



"It was spectacular to co-host and create an event with CHB," said James. "I learned a lot about the process the people at CHB go through to host these awesome events for us. I would 100% suggest that others go and create an event with CHB. I enjoyed getting together with everyone. I would like to say, 'If you don't think you would be good at creating an event with CHB, there will be a great co-host to help you along the way.'"

A couple of weeks later, on October 27th, Gabby joined us to welcome a group of teens with icebreakers and a night of educational, fun activities: Word Art, Wordle, Fishbowl, and hemophilia trivia. "I enjoyed playing word games with Gabby and the other teens" said one attendee. Others mentioned it was "amazing!" and "very relaxing." The rap session, led by Matt, featured a lively conversation about sports team allegiances and who we root for. Everyone had so much fun talking up their teams! #GoCats #Rams #Cardinals



In November, Aaron stepped up to join us in welcoming a group of teens to have some fun and get to know each other. In perhaps the most heated rap session yet, the teens discussed the coolest thing they could think of: ice cream! This frosty debate seems to have crowned coffee as the most polarizing ice cream flavor. The energy intensified in the best way for the evening's main event, *Roblox: Natural Disaster Survival*, in which the teens attempted to survive through various disasters. Everyone came out great, but none wanted the evening to end.



After the event, Aaron said, "It was great. I loved the idea and that I helped create it. I learned that taking ownership requires lots of responsibility. I was surprised to see lots of people from all around America and of all ages. I would definitely recommend this to other teens. It was fun, and interactive. What I liked most about my particular event was how everybody was debating about best restaurants in the chat". After this night, everyone wanted to visit Gordan Ramsey in one of his kitchens. The event was fantastic!

Each teen program has newly designed interactive questions in a captivating game of "Are You Smarter Than Your Hemophilia B?" As I write this article, I'm so proud of this game because learning can be fun! I love to see the enthusiasm pouring into the zoom chat as we discuss hemophilia and what it means to be an advocate.

I also love how teens come together not just to banter about the best restaurants or baseball teams, but also to engage with each other and create amazing bonds of friendship and support. It's a great environment where you can just be yourself. I encourage those who are not sure if this is for them to just come on and see. Everyone feels welcome, and we are excited for the next one. Check out hemob.org under events!

Calling all teens: we invite you to join us for future virtual programs like these, meet and hang with other teens, and to help us plan future teen events. Please email me at Rockyw@hemob.org if you are interested.

We would also like to give a giant thank you to CSL Behring. These incredible teen events were made possible by their generous sponsorship.

CSL Behring

THANK YOU, LET'S PLAY IX

BY JAMES

Let's Play Nine, the Coalition for Hemophilia B's golf scholarship program, introduced me to golf. Before that, I had only played on vacation with my parents. They asked me over the years if I wanted to learn, but I wasn't interested. At the time, volleyball was my favorite sport.

However, in the two years leading up to the scholarship, I had surgery on my right knee and a tumor in my left femur. The pain made it impossible for me to walk for more than 45 minutes, so I couldn't play volleyball anymore. To qualify for the *Let's Play Nine Scholarship*, you must have hemophilia B and be between the ages of 7 and 19. When I learned I had won the scholarship, I thought, "Okay, cool. I guess it could be fun." Since I was fortunate enough to get the scholarship, I decided to give golf a try. My mother offered to pay for one or two lessons, and if I liked it, we would use the scholarship for a set of golf clubs.

And that's exactly what happened. I started with lessons and joined the high school team this past fall, during their pandemic-shortened season.

The season started about six weeks after I finished my tumor treatment, so I wasn't sure if I could make it



through practice, much less a match. There were only four of us on the team, so if any of us got injured or sick, we would have to forfeit the match. But we made it through the whole season and finished by playing 18 holes at the County Course!

This year is my second year playing for the high school golf team. I had my lowest score in our first match! Despite this, I have seen overall improvements in my life thanks to the sport. For example, I have lost 30 pounds and started playing recreational beach volleyball again because golf helped my knees recover. I also have an amazing group of teammates who have become great friends. If it wasn't for the *Let's Play Nine Scholarship*, I never would have made these friends, earned a varsity letter, or discovered another great sport to love.



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FROM CAMP TO TAE KWON DO

BY ROCKY WILLIAMS

Aaron was introduced to the hemophilia community at a young age. After he was born, his family was released from the hospital like any other family, but his foot bled all through the night. Aaron had a PKU heel stick at the hospital that continued to bleed and bleed. So, they took him back to the children's hospital the very next morning where doctors ran the proper tests and Aaron was quickly diagnosed with hemophilia B.

It didn't come as a big surprise; Aaron's family knew this would be a possibility as Aaron's uncle has hemophilia and his grandmother and mother are both known to carry the gene. But having hemophilia has definitely changed his life. This gave Aaron the great opportunity to go to camp, and it wasn't long before Aaron was going and meeting other kids with hemophilia.

"Going to Camp Boggy Creek, I met other kids with hemophilia just like me," Aaron recalled. "I met my friend Emilio there and we remain friends today. I still go every year." These experiences are priceless to Aaron. They allow him to be in a safe place where having hemophilia is just normal. And these experiences continue to empower Aaron to try new things.

Attending camps and participating in the hemophilia

community has been a great source of confidence for Aaron. "It reminds me that I'm not alone," he said. Aaron has learned many new skills at camp, including fishing, archery, and the beginning steps of self-infusion.

Around the same time that he started attending camp, Aaron also got involved in Tae Kwon Do with his father and brother. "My biggest challenge with Tae Kwon Do is remembering my patterns and staying safe during sparring," Aaron shared. "My biggest accomplishment is not giving up as it gets more difficult. It has taught me discipline and respect, and it makes me feel very accomplished."

Aaron credits Tae Kwon Do with instilling in him a passion that requires discipline of the mind and body, as well as discipline to adhere to his own treatment regimes. This allows him to live out his passion and acquire the skills he needs to face challenges without giving up. "It fits in with hemophilia because it gives me the courage to face uncomfortable situations," he said. "Over the next five years, it will help me get in better shape and get stronger as it gets more difficult." Aaron plans to train for his black belt. Many years from now he hopes to be a mentor to younger students. He wants to help others just like his camp counselors and his Tae Kwon Do teachers have done for him.





inspired!

Stories and artwork from teens in the Hemophilia B Community

Fall 2022

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AARON:
FROM CAMP TO
TAE KWON DO



JAMES:
THANK YOU,
LET'S PLAY IX

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!

