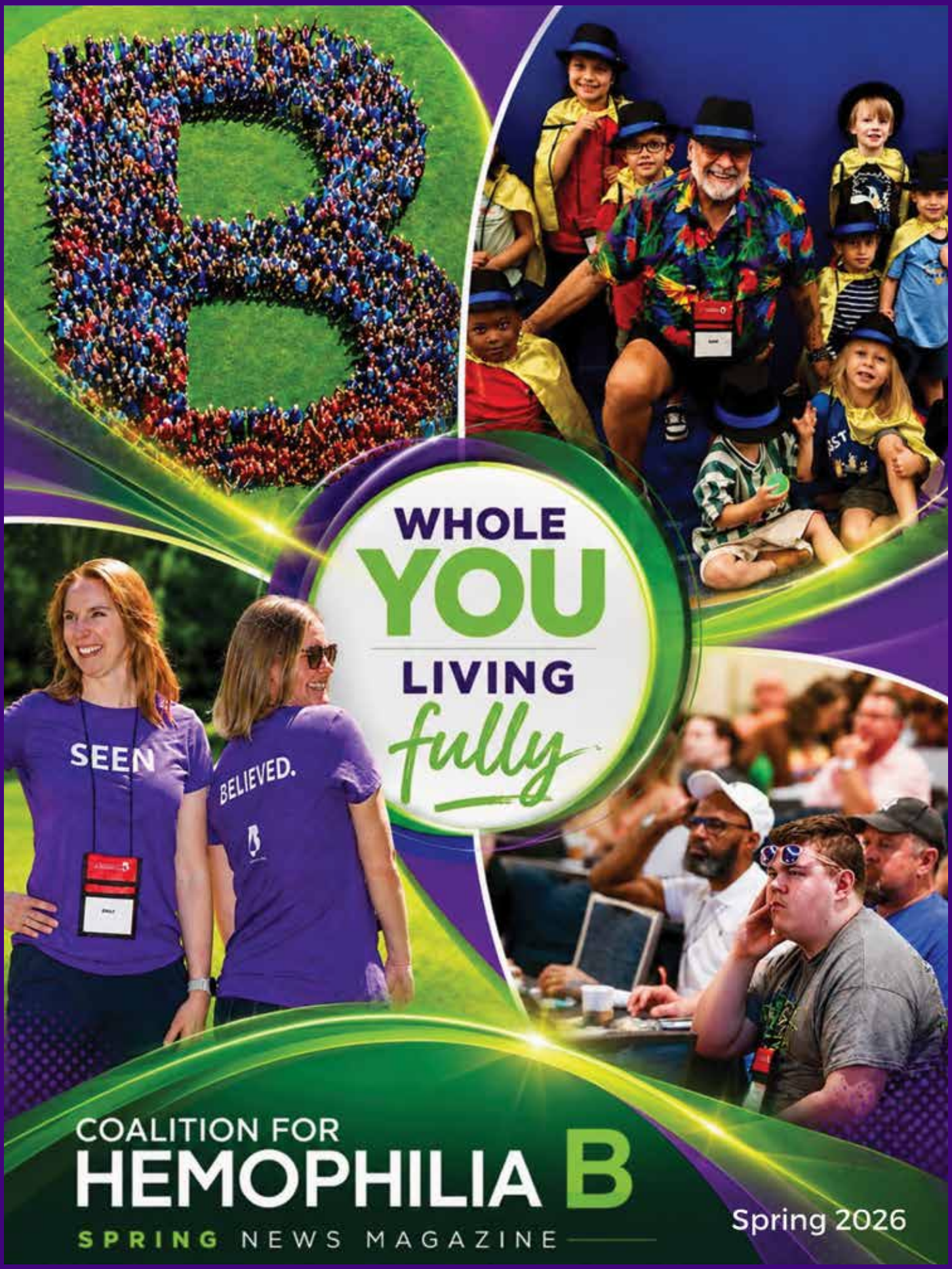
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COALITION FOR
HEMOPHILIA B
SPRING NEWS MAGAZINE
Spring 2026

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THE COALITION FOR HEMOPHILIA

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.

Whole You: Living Fully
Your Health. Your Power. Your Path.

The 2026 Coalition for Hemophilia B Annual Symposium

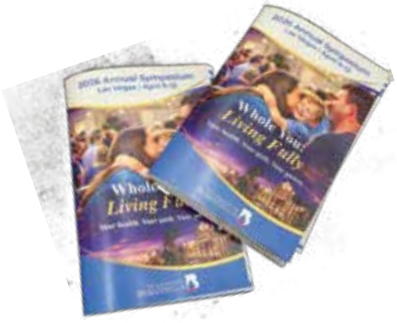
Las Vegas, NV • April 9–12, 2026

By Kim Phelan

We are living in extraordinary times.

Never before have people living with hemophilia B enjoyed such a wealth of treatment options and groundbreaking scientific advances. These new possibilities are enabling healthier, fuller lives. Yet, even as medicine evolves, our journey as a community moves forward. We continue to navigate insurance barriers, advocate for access to care, amplify our voices, support one another, and ensure that every individual and family has the knowledge and confidence they need to thrive.

That is what made this year's Coalition for Hemophilia B Annual Symposium so meaningful.



Our 2026 theme, *Whole You: Living Fully – Your Health. Your Power. Your Path.* was more than just a conference theme; it was an invitation. It encouraged us to think bigger, dream bigger, to embrace new possibilities, and to recognize that living fully extends far beyond medical treatment. It means caring for our physical, emotional, and mental well-being, forging meaningful relationships,





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advocating for ourselves and loved ones, and finding strength within a community that truly understands our journey.

Every session, conversation, shared meal, and new friendship reminded us that while treatments evolve, the heart of the Coalition remains unchanged. Whether someone arrived newly diagnosed, was navigating a life transition, exploring new treatment options, or had been part of our community for decades, everyone belonged. That spirit resonated throughout the entire weekend.

As our largest Symposium ever, we remained committed to what has always defined the Coalition for Hemophilia B: meaningful connection and the extraordinary power of community.

This year's Symposium welcomed more than 200 first-time attendees, many of whom were attending their first national bleeding disorders meeting. We understand that stepping into a room full of strangers can be overwhelming, but over the weekend, those strangers quickly became friends, mentors, and extended family. Time and again, new attendees shared that they had "found a home" with the Coalition. There is no greater compliment than knowing someone leaves feeling seen, understood, and empowered.

None of this would have been possible without the generosity of our sponsors and partners. Their ongoing commitment fosters opportunities for education, advocacy, connection, and hope for patients and families from all walks of life. We are deeply grateful for their support and shared vision.

We extend our warm appreciation to our more than 65 dedicated volunteers. Their compassion, energy, professionalism, and willingness to give their time make every Symposium possible. Whether welcoming first-time attendees, assisting speakers, supporting families, or offering a comforting smile, our volunteers are the heart of this organization.

This was our first Symposium hosted at the JW Marriott Las Vegas Resort & Spa. The beautiful grounds and spacious accommodations provided the perfect setting for our growing community. The venue offered welcoming spaces for learning, conversation, relaxation, and








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connection throughout the weekend.

Education remains the cornerstone of everything we do, and this year's program reflected the incredible diversity of today's hemophilia B community. With more than 85 outstanding speakers, 57 educational sessions for adults, 18 for teens and children, and over 35 exhibitors, the programming was thoughtfully designed for men, women, caregivers, Spanish-speaking families, children, and teens, and truly offered something for everyone.

This year also marked the launch of our new *Coalition for Hemophilia B Education Hub*, our official Symposium app, and a year-round educational community. More than simply a conference app, it provides members with an all-in-one resource for education, updates, programming, and connection long after the Symposium concludes. We encourage every member to explore all that it offers throughout the year.

The educational sessions reflected not only where we are today, but where our community is headed. Scientific presentations highlighted remarkable advances in treatment, evolving care protocols, gene therapy, subcutaneous therapies, and emerging innovations. Together, these developments continue to redefine what is possible for people living with hemophilia B.

Our keynote speaker, Dr. Christopher Walsh, did an exceptional job of meeting everyone exactly where they were. Recognizing that many attendees were new to the community, he carefully explained today's treatment landscape, reviewed available therapies, and discussed emerging options. He provided a clear understanding of where research is moving. His presentation ensured that newcomers and longtime attendees alike left with a stronger understanding of the exciting future ahead.

Advocacy stood out as a central theme throughout the weekend. While scientific advances are transforming lives, we recognize that innovation has a true impact only when patients can access it. To support this goal, sessions empowered individuals and families with practical tools to navigate healthcare systems, overcome insurance challenges, and address policy issues, ensuring their voices are always heard.

Storytelling also emerged as one of advocacy's most effective tools. In *Storytelling That Sticks*, presented by Keynote Speaker Christy Abele, attendees discovered how sharing personal experiences can educate policymakers, healthcare providers, employers, and the broader community while inspiring meaningful change. Every story holds the power to open hearts, change minds, and improve lives.

The Symposium continued to explore topics reflecting the many dimensions of living fully. Dr. Jill Johnsen offered valuable insights into the genetics of hemophilia, explaining the importance of genetic testing and its benefits for patients, families, healthcare providers, and researchers. Donnie Akers, JD,


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SUPPORT LIVE MUSIC
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covered employment, insurance, independence, and knowing your rights, empowering attendees to confidently navigate important life choices. Other educational sessions addressed inhibitor care, practical uses of artificial intelligence, iron deficiency and treatment success, goal setting, and maximizing comprehensive care visits through stronger self-advocacy.

Recognizing that living well encompasses emotional health, the Symposium featured sessions on resilience, relationships, and mental wellness. Patricia Lozano, LPC, reminded attendees that life often changes without warning. From unexpected loss to uncertainty or major transitions, her presentation encouraged participants to move forward one step at a time with hope and self-compassion.

Ashley Zebley highlighted the importance of psychological safety, showing how trust, communication, and mutual respect strengthen families, workplaces, healthcare teams, and communities. Building on this, Debbie De La Riva, LPC, inspired attendees by illustrating how helping others often becomes part of our own healing journey, reinforcing that acts of service foster purpose, resilience, and emotional well-being.

As technology rapidly becomes part of everyday life, Dr. Mina Nguyen-Driver led a thought-provoking discussion on the benefits and risks of artificial intelligence, especially as more adolescents and adults turn to AI for advice, companionship, and emotional support. The session encouraged thoughtful conversations about balancing innovation with human connection.

The Coalition continues to introduce innovative approaches to wellness and stress management. The *Nervous System Reset Sound Bath* gave attendees a chance to relax, recharge, and experience restorative healing in a peaceful setting.

One of the weekend's most memorable sessions used a menstrual simulator, allowing men to briefly experience what many women endure each month. Educational and entertaining, the session





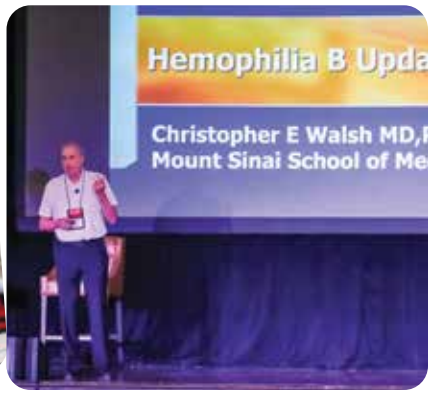












Hemophilia B Upda
Christopher E Walsh MD,
Mount Sinai School of Me

sparked both laughter and meaningful conversations. Sincere thanks to all who volunteered! You were wonderful sports and helped foster greater understanding through shared experience.

Health extends well beyond bleeding disorders, and several sessions explored whole-person wellness. Vanessa Harris, MNT, explained how nutrition directly influences energy, focus, and resilience, helping attendees better understand the biological foundations of overall well-being.

Shellye Horowitz addressed the difficult topic of rebuilding trust after medical trauma, offering practical strategies for developing healthier relationships with healthcare providers and encouraging patients to become active partners in their care.

Another inspiring presentation by Dr. April Willis encouraged attendees to transform their lived experiences into books, blogs, and other forms of storytelling. In doing so, she reinforced the idea that every journey matters and that every voice has the potential to educate, encourage, and advocate for others walking similar paths.

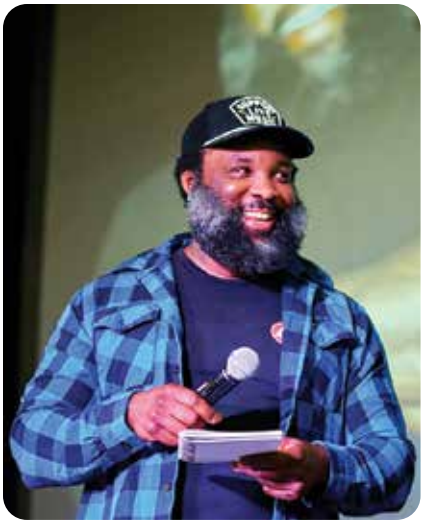
Important educational sessions also addressed stroke and head injury awareness within the bleeding disorders community, emphasizing warning signs, prevention strategies, and early recognition. Knowledge that can truly save lives.

One of the Coalition's greatest strengths has always been recognizing that education must be accessible to everyone. Throughout the weekend, multiple educational sessions were presented in Spanish to ensure clear communication and meaningful engagement for our Spanish-speaking families. The weekend opened with a dedicated *Bienvenida Para Familias Latinas*, welcoming Spanish-speaking families into the Symposium community.

A full slate of Spanish-language breakout sessions followed, covering topics from treatment access and equity to mental health, stress management, and physical wellness. For many families, this was a milestone: for the first time since attending four years ago, every breakout session provided a complete Spanish-language option. As one volunteer and parent noted, these sessions did more than deliver information; they created space to connect, share experiences, and strengthen support networks among Latino families, reaffirming that every family deserves to feel heard, represented, and accompanied, no matter the language they speak.

Our children's and teen programs provided age-appropriate education, leadership development, confidence-building activities, and opportunities for lasting friendships while allowing parents to fully participate in Symposium programming.

This year's Symposium offered daycare and robust programming for young attendees, with dedicated *Childcare* (ages Newborn to 6) and *Youth Camp* (ages 7–9) tracks running





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every day from morning to evening. Activities ranged from music-making, face painting, and outdoor games to more meaningful moments like the *Gratitude Project Pinwheel* craft, storytime, and a kid-friendly, needle-free infusion lesson that helps young children build comfort with treatment in a playful way.

Special guest presenters, including a bucket drum performance centered on resilience and self-respect, and an EMS visit with a fire truck and ambulance tour, rounded out a schedule designed to spark creativity, teamwork, and confidence.

Beyond the fun, families say the impact runs deeper. A parent described the program as giving her children their first chance to meet others facing the same challenges, building self-esteem and a sense of belonging as lasting friendships form.

Some of the moments that touched me most this year were seeing parents whose children have grown return as volunteers. Many believe they are no longer needed once their children become adults, but nothing could be further from the truth. Their wisdom, experience, and willingness to mentor younger families are invaluable. Equally inspiring were the young adults, many now graduating from college, building successful careers, and creating fulfilling lives, who returned to mentor our teens. Watching one generation lift up the next so beautifully reflects the spirit of our Coalition.

This year's group photo was unlike any we've ever taken. Looking out across the crowd, I jokingly remarked that it looked as though we could fill an entire football stadium. The image perfectly captured just how much our community has grown while still feeling like family.

Perhaps one of the most meaningful moments of the weekend was the presentation of our new purple shirts honoring women living with bleeding disorders. The front simply read *Seen*, while the back read *Believed*. Those two words carry enormous meaning for women who have spent years fighting to be heard, properly diagnosed, and appropriately treated. We hope these shirts become more than apparel; we hope they become a movement. Our wish is that one day every woman who should be diagnosed will be recognized, believed, and receive the care she deserves.

The Exhibit Hall remained filled with energy throughout the weekend as attendees connected with industry partners, nonprofit organizations, and healthcare professionals. Our Wellness Area offered a welcome opportunity to relax with chair massages after packed days of learning and travel, reminding everyone that self-care is an important part of living fully.







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Each morning began with opportunities to energize both body and mind through beach volleyball, gentle yoga with breathwork, and Tai Chi before attendees gathered with our incredible Master of Ceremonies, Elec Simon, whose contagious enthusiasm had everyone dancing, singing, laughing, and ready to embrace each day's learning.

The evenings brought their own special moments. The *Bleeders Band* had the room dancing, and our Open Mic gave attendees a chance to share their musical talents and creativity.

Our *Volunteer Awards Celebration* recognized remarkable individuals, Lisa Hensley, Jennifer Marlatt, and Shad Tulledge, whose selfless dedication continues to strengthen our community year after year (read more about them on page 17).

As always, one of the most anticipated moments was our final evening *Gala*. After three days filled with education, inspiration, and advocacy, attendees came together to celebrate. The entertainment was outstanding, the energy was contagious, and seeing friends laugh, dance, reconnect, and enjoy one another's company reminded us that joy is an essential part of healing.

The Symposium concluded with *Infuse with Hope: The Power of Kinesiology*, generously sponsored by the Montana Hart Boys and presented by Hope Woodcock-Ross, RN, BSN, and Douglas Stringham, MSL, AT, ATC, leaving attendees encouraged, inspired, and optimistic about the future.

As we reflect on the 2026 Coalition for Hemophilia B Annual Symposium, one message rises above all others. Living fully is not defined solely by the treatments we receive, but by the lives we build, the relationships we nurture, the knowledge we gain, and the courage we discover within ourselves. Together, we continue to advocate, innovate, educate, and support one another with compassion and determination.

The future of hemophilia B has never been brighter. And no matter where your journey begins, the Coalition for Hemophilia B will continue to walk beside you,

empowering every individual and every family to live with greater confidence, greater purpose, and greater hope.

Because together, we are living fully.

Symposium Comments

"Thank you for the experience of meeting more hemophilia B patients. I am glad to know there are older men with hemophilia living a good quality of life. It gives me peace of mind for my son."

"I feel that the Coalition has really set the bar very high for these types of events. Excellent in every way!"

"*Infuse with Hope* was really amazing! My husband performed his first IV stick, something I never thought he would do!"

"All the sessions were really great. I continue to learn more about living with hemophilia and raising children with hemophilia, and how to better our health overall."

"I was surprised at how much I learned at the *Iron Deficiency* session and how important it is to track levels, especially as a woman with a bleeding disorder."

"The *Speak-Up* session with Lee Hall surprised me because I didn't realize how much of a role advocacy has played in healthcare for hemophiliacs, and how much is yet to be done."

"The Symposium feels like a family reunion. I can be completely myself without the concern of being judged."

"I liked that the sessions were not just about products but provided important information I can use in my daily life. I left feeling more knowledgeable about the newest information."

"Connecting with our hemophilia family, learning and growing, and seeing our boys forge connections that will give them a lifetime of support and opportunity are all wonderful benefits of the Symposium."

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Celebrating Our CHB Volunteers!

One of the most meaningful moments of our Symposium came during our final evening celebration, a gathering filled with joy, gratitude, and community spirit. We honored three extraordinary volunteers whose unwavering dedication, boundless generosity, and deep compassion have truly touched the lives of everyone within the Coalition for Hemophilia B family. Their commitment is a bright reminder that the strength of our organization lies not only in our programs but also in the remarkable individuals who give so freely of their time, talents, and hearts.

Lisa Hensley received the ***2026 Impact Award*** in recognition of her lasting contributions to the bleeding disorders community. Whether supporting our educational outreach efforts, Meetings on the Road, or Symposium, Lisa always goes above and beyond to serve others with kindness and empathy. She has a remarkable ability to translate complex scientific information into clear, practical knowledge, empowering patients and families to make informed decisions and feel supported.

Jennifer Marlatt was presented with the ***Extraordinary Service Award*** in honor of her exceptional dedication and unwavering selflessness. She is always the first to lend a helping hand, whether supporting community outreach and *Meetings on the Road*, or ensuring every detail of our Symposium runs smoothly. Jennifer's cheerful spirit, tireless work ethic, and genuine care for others make her not only an invaluable member of the CHB family but also a trusted friend and source of inspiration to so many.

Shad Tulledge received the ***Community Champion Award*** for his extraordinary ability to bring people together and nurture the sense of connection that defines our community. With his welcoming spirit, sincere encouragement, and ever-present willingness to help, Shad creates a space where everyone feels seen, valued, and supported. His kindness and commitment remind us that building community is about making every individual feel like they belong.

Please join us in congratulating Lisa, Jennifer, and Shad on these well-deserved honors. We are deeply grateful for their extraordinary service, leadership, and the countless ways they continue to inspire hope, strengthen connections, uplift others, and enrich the Coalition for Hemophilia B community. Their kindness and dedication continue to brighten our community and remind us of the power of coming together.

More Than a Symposium: A Mother's Perspective

By Danelie Rivera

Volunteering in the Youth Program at the Coalition for Hemophilia B (CHB) Symposium and experiencing it as the mother of a five-year-old boy with severe hemophilia B and a seventeen-year-old daughter without a bleeding disorder has allowed me to appreciate the event from two uniquely meaningful perspectives. If I had to summarize our experience in a single word, it would be *extraordinary*.

A Place Where Children Discover They Are Not Alone

I witnessed firsthand the care and dedication poured into planning each activity. The program is thoughtfully crafted to blend fun, education, and meaningful interaction, empowering children to build confidence as they connect with others living with hemophilia B.

For many children, this is their first opportunity to meet peers facing similar challenges. Realizing they are not alone and that they can safely participate in activities tailored to their ages and individual needs strengthens both their self-confidence and sense of belonging.

Interacting with children from diverse countries, cultures, and languages teaches invaluable lessons in inclusion, diversity, equality, and empathy from an early age. The program is thoughtfully developed by professionals in child development, ensuring a safe, engaging, and enriching experience for every participant.

Volunteers from within the bleeding disorders community are another invaluable asset. Their understanding of the condition complements the childcare staff's expertise, providing additional support when situations arise and ensuring that safety protocols are implemented quickly and effectively. For parents, this offers tremendous peace of mind, knowing their children are cared for by compassionate and well-prepared individuals.

Young People Building a Community That Lasts a Lifetime

The Teen Program is equally impactful. I saw how this program fosters inclusion and helps young people recognize their essential role in our community.

Over the years, we have watched genuine friendships blossom and lifelong connections take root. During a stage of life that is often challenging, these teens consistently choose compassion, encouragement, and mutual support. They learn that community extends beyond a diagnosis and that everyone has a vital role to play.

One memory that stands out occurred during an off-site group activity. Some participants faced physical limitations due to surgeries, yet the other teens instinctively adjusted the pace so everyone could participate. No one was left behind. Throughout, they encouraged each other with simple but powerful words:

"If you want to do it, you can do it." That moment perfectly captured the spirit of inclusion, empathy, and solidarity that defines this community.

A Growing Commitment to the Latino Community

The 2026 Symposium marked a significant milestone for the Latino community. For the first time since our family began attending four years ago, every breakout session featured Spanish-language programming, leading to noticeably greater participation from Latino families. The selected topics reflected the evolving needs and priorities of our community, addressing issues such as living with hemophilia B, challenges faced after a diagnosis, caregiver support, mental and physical health, unmet needs, and the unique realities and healthcare challenges across Central America, South America, and the Caribbean. Beyond educational content, these sessions created meaningful opportunities for Latino families to connect, share experiences, and strengthen a supportive network built on mutual understanding.

Over the years, we have witnessed the steady growth of the Latino community at the Symposium. Simultaneously, CHB has shown an unwavering commitment to breaking down language barriers by expanding Spanish interpretation services, increasing Spanish-language sessions, and providing educational materials specifically designed for Latino families.

These efforts go far beyond improving access to information. They reinforce the Symposium's core message: every family deserves to feel welcomed, represented, and supported regardless of the language they speak.

Teens Explore at Symposium

By Jennifer Marlatt

Our teens had an awesome time during this year's symposium outing! The afternoon began at All American Park, where everyone dove into interactive group games that strengthened communication, leadership, and problem-solving skills while fostering friendship and fun. Later, the group embarked on an unforgettable adventure at Meow Wolf's Omega Mart at AREA15, exploring interactive exhibits together and uncovering hidden secrets in one of Las Vegas's most unique attractions.

This special trip offered a chance to connect and spend time together outside the conference setting, and it was filled with excitement, discovery, and lasting memories!

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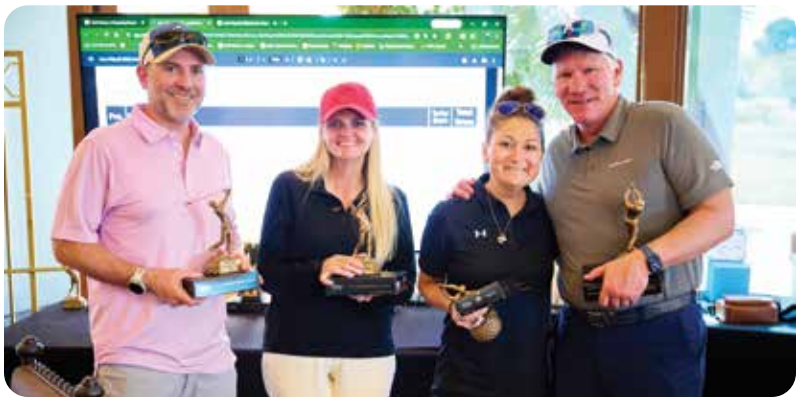
Let's Play IX Golf Tournament Tees Off Another Year of Fun, Friendship, and Giving Back

By Hope Woodcock-Ross

One of the Coalition for Hemophilia B's most cherished traditions unfolds each year on the eve of our Annual Symposium: The ***Let's Play IX Golf Tournament***. More than just a day on the course, this special event unites our community, industry partners, sponsors, friends, and families. It's a day filled with laughter, friendly competition, and meaningful connections before the symposium officially begins.



Held on April 8 at the beautiful Angel Park Mountain Course in Las Vegas, golfers welcomed sunny skies and perfect weather, with temperatures reaching a pleasant 90 degrees. The day kicked off with one of the annual highlights: a golf clinic led by professional golfer Perry Parker on the driving range. Perry graciously shared his expertise, techniques, and practical tips with participants of all skill levels, helping both first-time and seasoned golfers enhance their game before heading to their starting holes.

We are deeply grateful to Perry for generously donating his time and talent every year. His commitment to mentoring attendees, sponsors, patients, caregivers, and friends has become a treasured tradition. This spirit of sharing knowledge, encouraging one another, and making everyone feel welcome truly embodies our community.

This year, we had another wonderful reason to celebrate Perry. We extend our heartfelt congratulations on his February induction into the

UC Irvine Athletic Hall of Fame, one of the highest honors for former student-athletes. Reflecting on the experience, Perry shared, "This past week with my friends and family has been amazing! It was one of the greatest honors I have received in my life to be inducted into the UC Irvine Athletic Hall of Fame." We couldn't be happier for him and are honored that he continues to share his passion for golf with the Coalition for Hemophilia B family.

Once everyone made their way onto the course, the competition was spirited and fun. Congratulations to Brian Rhodes, who won the *Closest to the Pin* award, and Andrew O'Connor, who claimed the prize for *Longest Drive*. Kudos also to our first-place team from CVS – Brian, Kevin, Bill, and Wayne III – for their outstanding performance.

While there were winners on the leaderboard, the true victory was sharing a day together in support of an important cause. The camaraderie, encouragement, and friendships formed throughout the tournament are what make this event such a meaningful tradition year after year.

We extend our sincere appreciation to all the golfers, sponsors, volunteers, donors, and supporters who made this year's tournament another tremendous success. Your generosity fuels our expanding Let's Play Youth Golf Program, providing scholarships so children can receive golf lessons and acquire clubs, bags, and other essential equipment in their hometowns. Our hope is to introduce more young people to a sport that fosters patience, confidence, perseverance, sportsmanship, and lifelong healthy habits.

Golf truly is a game for all ages and abilities. Thanks to your support, more children will have the chance to discover the joy, confidence, and friendships the game brings. Thank you to everyone who helped make Let's Play IX another memorable success. We look forward to seeing you on the course next year as we continue to build on this cherished tradition together!

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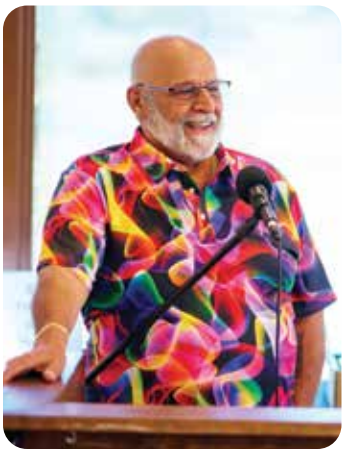

Everybody Heals: Body and Mind
Men's Educational and Empowerment Retreat

By Shelby Smoak, Ph.D.

The Coalition for Hemophilia B Men's Educational and Empowerment Retreat, held February 19–22, 2026, in Orlando, Florida, created a welcoming space for men with hemophilia B and fathers of children with hemophilia B to reconnect, form new friendships, and focus on education, empowerment, and physical and emotional well-being.

The Men's Retreat offered something difficult to find in everyday life: a protected environment where men living with hemophilia B and fathers raising children with the condition could speak openly, share experiences, and support one another. Participants did not have to explain the challenges they and their families face because they were surrounded by people who understood. Longtime friends reunited, new friendships formed, and Coalition President Wayne Cook returned for his first event following his recovery from a liver transplant.

Each morning began with opportunities to care for the body. Participants could choose Tai Chi led by Rick Starks or fitness guidance from physical therapist Doug Stringham. Men stretched their joints, strengthened their bodies, and improved their cardiovascular health. Doug also led an aqua fitness class for those willing to brave the cool pool water.

Educational sessions addressed the changing needs of men who are now living longer and healthier lives with Hemophilia B. "Transitions Through the Ages," led by Wayne Cook and Ryan Crowe, explored the different stages of life and the challenges that can come with each transition. Dr. Bill Patsakos presented "Men's Health: Hemophilia B and Co-Morbidities," emphasizing that men with bleeding disorders must also remain aware of the health concerns that can accompany aging. Physical therapist and sexual-health expert Alice Anderson led "Mechanics of Physical Intimacy," an open and engaging discussion about maintaining healthy and fulfilling relationships.

Together, these sessions reflected an important reality. Advances in treatment have helped people with Hemophilia B live longer, but longevity also brings new health, relationship, and quality-of-life considerations. The retreat gave participants a comfortable place to discuss these subjects honestly.

Treatment education was another important part of the weekend. Brad Schoenfeld of Pfizer led a detailed discussion about HYMPAVZI®. Dr. Chris Walsh provided an overview of currently available hemophilia B therapies, including subcutaneous treatments and gene therapy. Mark Zatyrka addressed the difficult and often complicated subject of pain.

The Men's Retreat also recognized that healing involves more than the body. Rap sessions led by Wayne and others gave the men an opportunity to discuss their different needs, concerns, and experiences. GutMonkey facilitated an interactive session in which Jake Trusheim shared strategies for managing the mental clutter and difficult decisions that often accompany chronic illness.

Music also became a tool for connection. During sessions led by Rick Starks and Shelby Smoak, participants played music trivia and created playlists connected to meaningful memories. The activity encouraged reflection, conversation, and laughter while demonstrating the emotional and healing power of music.

That energy continued during Saturday evening's outing to the House of Blues, where attendees enjoyed music, humor, and time

together away from the formal sessions.

Throughout the weekend, educational programming was balanced with opportunities for friendship and fellowship. Men were able to learn from medical experts, strengthen their bodies, discuss personal concerns, and spend time with others who understood their experiences.

The Men's Retreat was more than a conference. It reminded men and fathers that they do not have to face the challenges of a bleeding disorder alone. Everyone left Orlando with practical information, renewed confidence, stronger friendships, and a deeper sense of connection to the hemophilia B community.

For those who missed this retreat or have never attended, the next gathering will offer another opportunity to learn, connect, and experience the strength of the hemophilia B brotherhood.

The Coalition for Hemophilia B gratefully thanks Pfizer for its generous sponsorship of the 2026 Men's Educational and Empowerment Retreat and for helping make this meaningful weekend of education, wellness, empowerment, and connection possible.

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Living Unburdened: Travis and the New Era of Hemophilia Care

By Renae Baker

For Travis Roop, music has always been part of who he is. A lifelong drummer and passionate music enthusiast, Travis stays active and creative through hobbies such as disc golf, cooking, virtual reality gaming, home brewing, and listening to audiobooks. Whether connecting with his father across the country for a virtual round of mini-golf or discovering a new favorite book, Travis embraces life with curiosity, humor, and appreciation for the everyday moments many people take for granted.

But for much of his life, living with severe hemophilia B meant that everyday moments often came with caution and constant awareness. Every outing required preparation. Every bump, bruise, or unexpected injury carried concern. Whether going out with friends, traveling, or simply being away from home, there was always a quiet calculation in the background: Am I prepared if something happens?

"It was a general sense of always being on guard," Travis shared. "If you got injured, you had to think about how close you were to your factor or whether you had it with you."

Like many individuals in the bleeding disorders community, Travis adapted to the routines and realities of treatment. Over time, he moved from treating bleeds as they occurred to prophylactic therapy, including clinical trials of longer-lasting factor products. While these advancements helped, the mental weight of hemophilia and the routine of infusions remained part of everyday life.

Then, in 2019, a new opportunity emerged. After participating in several clinical trials, Travis was offered the chance to enroll in a gene therapy study. The decision was not simple. Gene therapy represented something entirely different, a one-time treatment with unknowns and no turning back.

"There was fear of the unknown," he admitted. "It felt a little like opening Pandora's box." Still, after thoughtful

consideration, Travis decided the potential benefits outweighed the uncertainty. He received the gene therapy infusion on August 6, 2019, and has not used clotting factor since.

Today, Travis's factor IX levels remain around 30 percent, shifting him from severe hemophilia B to a level where, in daily life, he is essentially asymptomatic. Factor would still be needed for major trauma or surgery, but the day-to-day burden of living with hemophilia has changed dramatically.

"It's been life-changing," he said. "A real weight off my shoulders." That shift brought something even greater than improved numbers; it brought freedom.

Before gene therapy, even lower-impact activities often came with hesitation or second-guessing. Now, there has been a noticeable change not only in what Travis can physically do but also in how he experiences life mentally. One particular moment stayed with him. Months after treatment, he accidentally bit his cheek while eating, something that would once have immediately triggered worry and preparation.

"This time, I realized I didn't need to worry about it," he recalled.

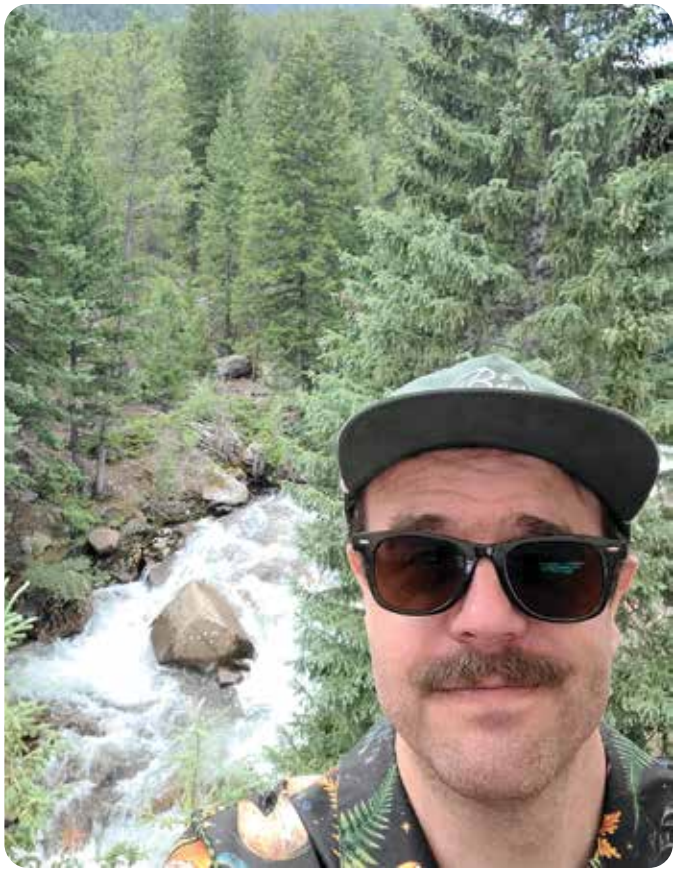
For Travis, that seemingly small moment represented something much bigger: freedom from constant vigilance. "I went from feeling like someone who couldn't do much without worrying to someone who doesn't worry about it at all."

While Travis has largely navigated his hemophilia journey independently, he understands that treatment decisions can feel overwhelming for many individuals and families, especially as therapies continue to evolve. That is why he believes education and awareness remain so important.

"I think people should at least know what their options are," he said, noting that some individuals may still be unaware of evolving therapies, including extended half-life products and gene therapy. Organizations such as The Coalition for Hemophilia B continue to play an important role in helping individuals and families stay informed, supported, and connected as treatment options advance.

Looking ahead, Travis remains hopeful not only for the future of hemophilia care but also for medicine as a whole. "It feels like we're entering a whole new era of possibilities," he said.

For Travis, gene therapy did more than raise his factor levels. It changed how he approaches everyday life, replacing constant worry with greater confidence, freedom, and possibility. And sometimes, the biggest changes reveal themselves in the smallest moments, like biting your cheek and simply moving on.



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ADVOCACY NEWS

MEDICAID PATIENT GUIDE

BY KIM PHELAN

Important Medicaid Coverage Alert for the Hemophilia B Community

Changes to Medicaid could affect access to coverage, treatment, infusion services, and specialty care for some people with hemophilia B.

The Coalition for Hemophilia B has prepared a patient guide explaining what may be changing, who may be affected, and what steps you can take now to help protect your coverage.

Key action steps include:

- Update your contact information with your state Medicaid office
- Open and respond to every Medicaid notice right away
- Begin gathering documentation of your hemophilia B diagnosis and treatment needs
- Contact your HTC, hematologist, or care team if you may need an exemption
- Reach out for help if your coverage is disrupted

CHB is actively advocating for bleeding disorders to be recognized as serious or complex medical conditions that may qualify for exemption from work reporting requirements.

Coalition for Hemophilia B

Important Health Coverage Alert for Our Community

What the One Big Beautiful Bill Act (H.R. 1) Means for Your Medicaid Coverage

Issued by The Coalition for Hemophilia B | May 2026

URGENT: Action May Be Required to Protect Your Coverage

This letter contains time-sensitive information about changes to Medicaid that could affect your ability to access treatments for hemophilia B. Please read it carefully, share it with a family member or caregiver, and take the steps outlined at the end of this letter.

What Happened

On July 4, 2025, President Trump signed H.R. 1 — the One Big Beautiful Bill Act (OBBBA) — into law. This sweeping legislation made the largest cuts to federal health programs in American history, reducing Medicaid funding by nearly $1 trillion over the next decade. Independent estimates project that between 10 and 17 million Americans will lose their health insurance coverage as a result.

Because Medicaid is jointly funded by the federal government and each state, these federal cuts force every state to make difficult decisions: they must either find new revenue, cut benefits, reduce eligibility, or lower payments to providers like hospitals and clinics.

The law does not eliminate Medicaid. But it changes who qualifies, how often you must prove you qualify, and how much funding states receive to run the program — all of which could affect your access to the clotting factor treatments, infusion services, and specialty care you depend on.

The Four Major Changes You Need to Know

1. Work Requirements (Starting January 1, 2027)

If you receive Medicaid through the ACA Medicaid expansion program and are between the ages of 19 and 64, you will be required to document at least 80 hours per month of work, job training, school, or community service to keep your coverage.

Qualifying activities include:

- Paid employment (any number of employers)
- Job training or a formal work program
- Enrollment in school or vocational training (at least half-time)
- Community service or volunteering (with documentation)
- Earning at least $580/month in states using the federal minimum wage calculation (80 hours × $7.25/hr — your state's threshold may differ)

2. More Frequent Eligibility Checks (Starting December 2026)

Currently, most states review your Medicaid eligibility once per year. Beginning in December 2026, expansion enrollees must re-verify their eligibility every six months. That means twice-yearly income checks, household size confirmation, and paperwork submissions. Missing a renewal notice — even if you are fully eligible — can result in losing your coverage.

3. Restrictions on Immigrant Eligibility (Starting Fall 2026)

The law narrows Medicaid eligibility for lawfully present non-citizens. Many immigrants who previously qualified for Medicaid — including green card holders in their first five years of residency — will lose eligibility beginning in fall 2026. This affects both Medicaid and, in some states, the Children's Health Insurance Program (CHIP).

4. Reduced Funding for Hospitals and Providers (Starting 2027–2028)

States will lose significant funding they previously used to pay hospitals and specialty providers. This may lead to lower reimbursement rates for providers, which could cause some clinics, treatment centers, or hemophilia treatment centers (HTCs) to limit or reduce Medicaid patients. This is a longer-term risk, but one our community must monitor closely.

Critical Information for People with Hemophilia B

CHB Is Fighting For Your Exemption — But It Is Not Yet Guaranteed

The law includes an important medical exemption from work requirements for people with 'serious or complex medical conditions.' The Coalition for Hemophilia B, along with the National Bleeding Disorders Foundation and the Hemophilia Federation of America, has formally written to the Centers for Medicare and Medicaid Services (CMS) and every State Medicaid Director urging them to officially recognize bleeding disorders as qualifying serious or complex medical conditions — which would exempt our community from work reporting requirements.

CMS guidance finalizing the definition of medical frailty and serious conditions is expected by June 2026. We will update you immediately when that guidance is released. In the meantime, do not assume you are automatically exempt — you may need to document your condition.

The full list of exemption categories under the law includes:

- People who are blind or have a qualifying disability
- People with a serious or complex medical condition (this is where Hemophilia B should qualify)
- People with a physical, intellectual, or developmental disability that significantly affects daily activities
- Parents, guardians, or primary caregivers of a dependent child age 13 or under
- Caregivers of a disabled family member
- Pregnant or postpartum individuals (up to 12 months after delivery)
- People currently enrolled in a substance use disorder treatment program
- Veterans with a total disability rating (note: partial service-connected disability does not qualify)
- People currently incarcerated or recently released (within 90 days)
- American Indians, Urban Indians, and Alaska Natives eligible for Indian Health Service
- Former foster youth (up to age 26)
- People already meeting SNAP (food assistance) work requirements

Even if you qualify for an exemption, you will likely need to document it. Your hematologist, treatment center, or primary care provider may be asked to complete an attestation form. We strongly recommend alerting your medical team now so they are prepared.

Your State: What's Happening Where You Live

The impact of the OBBBA varies significantly by state. States that expanded Medicaid under the ACA (sometimes called 'expansion states') face the most significant changes, including work requirements, more frequent eligibility checks, and funding cuts to hospital payments. States that never expanded Medicaid are less directly affected — but are not immune.

At-a-Glance: Key States

State	Expansion?	Budget Impact	Enrollment Risk	Primary Concern
Nebraska	Yes	Moderate	High	First state to enforce work requirements (May 1, 2026)
Missouri	Yes	High	High — est. 130,000+ at risk	Admin system capacity concerns; thin fiscal reserves
Utah	Yes	High	Very High — up to 40%	Hospital payments cut hundreds of millions/year
Florida	No	Minimal (<0.5%)	Low	Immigrant eligibility cuts; long-term provider risk
West Virginia	Yes	Very High	Severe — 20%+ loss	Sickest enrollees; fewest backup options
Kentucky	Yes	Very High	Severe	Top-ranked on all vulnerability measures
New Mexico	Yes	High	Very High — up to 40%	High poverty + high Medicaid dependence
Oregon	Yes	High	High — 20%+ loss	35%+ of enrollment is expansion population
Mississippi	No	Moderate	Moderate	Poor population health + thin state budget
South Carolina	No*	Moderate	Moderate	High poverty + limited expansion safety net
California	Yes	Severe ($112B)	Moderate-High	Largest dollar loss; provider tax reductions
New York	Yes	Severe ($63B)	Moderate-High	Major provider tax and SDP reductions
Pennsylvania	Yes	High	High	High provider tax reliance; LTC cuts
Louisiana	Yes	High	High	High poverty; top-5 on multiple risk measures
Arkansas	Yes	High	High	Waiver requests pending; may implement work requirements ahead of Jan. 2027 deadline

* South Carolina has not expanded Medicaid but has high-poverty enrollment making it moderately vulnerable.

Detailed State Profiles

Nebraska — ALREADY IN EFFECT

Status: Nebraska became the first state in the nation to enforce OBBBA work requirements as of May 1, 2026 — ahead of the federal January 2027 deadline.

What this means for Nebraskans on Medicaid: you must now document at least 80 hours per month of qualifying activity to keep your coverage. Nebraska's state budget already faces a significant projected shortfall, and Medicaid represents 47% of all federal funding the state receives. Up to 24,300 Medicaid expansion adults are estimated to be at risk of losing coverage — many due to paperwork failures, not actual ineligibility.

Action needed now: If you are on Medicaid in Nebraska, contact your state Medicaid office immediately to understand what documentation is required. Do not wait.

Missouri — Implementation Begins December 2026

Missouri expanded Medicaid through a 2020 voter initiative and now covers approximately 1.1 million residents through MO HealthNet. Work requirement tracking begins December 2026, with enforcement starting January 2027.

Missouri faces documented challenges with its Medicaid administrative systems: the state has a history of slow application processing and eligibility backlogs. Research and advocates suggest these existing capacity issues could worsen significantly when work requirement documentation begins. Approximately 130,000 Missourians are estimated to be at risk of losing coverage — most due to paperwork issues, not because they are ineligible. Missouri also has one of the thinnest rainy day funds of any state, leaving almost no fiscal buffer.

Action needed now: Stay alert for notices from MO HealthNet beginning in fall 2026. Keep your contact information updated with the state. If you have a chronic condition like Hemophilia B, begin gathering medical documentation of your condition now.

Utah — Cautious Implementation, Serious Hospital Risk

Utah is an expansion state approaching implementation carefully, but the financial picture for hospitals is alarming. Utah Medicaid estimates that hospital payments will be reduced by hundreds of millions of dollars per year once the provider tax and state-directed payment phase-downs are complete (beginning 2028). For patients who depend on specialty facilities or infusion centers, this matters.

Most strikingly, research projects that up to 40% of expansion adults in Utah could lose coverage by 2034 — one of the highest rates in the nation. Utah submitted an early 1115 Waiver request for work requirements and is seeking flexibility from CMS on implementation. The state has also applied for Rural Health Transformation Program funds.

Action needed now: Watch for outreach from Utah Medicaid beginning in summer/fall 2026. Prepare your medical documentation and ensure your address is current in the system.

Florida — Most Protected, But Not Immune

Florida never expanded Medicaid under the ACA, which means the law's most severe provisions — work requirements, 6-month redeterminations, and major hospital payment cuts — do not directly apply. According to RAND, Florida sees less than 0.5% change in its overall Medicaid budget from the provisions studied.

However, Florida is not untouched. Approximately 12,975 immigrants who previously qualified for Medicaid or CHIP lost eligibility beginning in fall 2026. Long-term, restrictions on provider taxes could put pressure on nursing home and home care reimbursement, which matters for older and disabled patients. Florida also holds one of the thinnest rainy day funds in the nation.

Action needed now: If you or a family member is a non-citizen enrolled in Florida Medicaid, verify your current eligibility status immediately. All other Florida Medicaid enrollees should monitor for any state-level changes.

Other High-Risk States to Know

West Virginia and **Kentucky** rank as two of the most vulnerable states in the country. Both are expansion states with some of the sickest Medicaid enrollees — high rates of chronic disease, disability, and poverty. KFF analysis places both states in the top five across multiple vulnerability categories. West Virginia projects Medicaid enrollment declines exceeding 20% by 2034.

New Mexico and **Oregon** face projected expansion enrollment losses reaching 40% and 20%+ respectively by 2034. Both are expansion states with significant shares of their population dependent on Medicaid.

California and **New York** face the largest dollar-value losses — $112 billion and $63 billion respectively over 10 years — primarily due to restrictions on provider taxes and state-directed payments. These funding cuts can reduce what hospitals and clinics are paid to treat Medicaid patients, which may affect access to specialty care.

Louisiana, **Arkansas**, **Mississippi**, **South Carolina**, and **Pennsylvania** all rank in the top tier for multiple risk factors including population health, poverty, and limited fiscal capacity to absorb cuts.

How to Protect Your Coverage: Action Steps

The most important thing to know is this: losing Medicaid coverage is most often caused by missing paperwork, not actual ineligibility. The steps below are designed to help you stay covered even as the rules change.

Step 1: Know Which Program You Are Enrolled In

Not all Medicaid programs are affected equally. Work requirements and 6-month redeterminations apply specifically to adults enrolled through the ACA Medicaid expansion.

They do NOT apply to:

- Children under 18
- Pregnant and postpartum women
- People enrolled in Medicare (including those dually enrolled in both Medicare and Medicaid)
- People in traditional Medicaid programs (not expansion)
- Residents of states that did not expand Medicaid (such as Florida, Texas, Mississippi, Tennessee, Georgia, Alabama, South Carolina, Wisconsin, Wyoming, Kansas, and others)

Check your Medicaid approval letter, renewal letter, or your state's online portal (usually called MyBenefits, BenefitsHub, or similar) to see which program you are in.

Step 2: Update Your Contact Information Right Now

This is the single most important action you can take today. Renewal notices will be mailed to the address your state has on file. If your address is outdated, you will not receive your notice — and your coverage can be terminated even though you are still eligible.

- Log in to your state's Medicaid portal and update your mailing address, email, and phone number
- If you have moved recently, update your address with your state Medicaid office by phone if needed
- Consider setting up email or text alerts if your state offers them

Step 3: Document Your Hemophilia B Diagnosis and Treatment

Even if the medical frailty exemption is confirmed for bleeding disorders, you will likely need documentation to prove it. Begin gathering the following now:

- A letter or note from your hematologist confirming your hemophilia B diagnosis and treatment needs
- Records showing your current treatment regimen (factor replacement therapy, gene therapy enrollment, etc.)
- Any documentation of functional limitations caused by your condition (joint disease chronic pain, infusion requirements, etc.)
- If you see a Hemophilia Treatment Center (HTC), ask them to keep a current letter on file that can be submitted quickly if needed
- CHB will communicate updates as soon as CMS releases final guidance on the medical frailty exemption (expected by June 2026). Watch for our communications

Step 4: Respond to Every Notice You Receive — Immediately

Beginning in late 2026, states are required to send outreach notices before work requirements take effect. These notices will explain what you need to do, what exemptions exist, and how to report your status. When you receive one:

- Open it immediately – do not set it aside
- Read it carefully, or ask a family member, caregiver, or patient advocate to help you
- Meet the deadline stated in the notice – missing it can mean losing coverage
- Keep a copy of everything you submit
- If you need help, call your state Medicaid office or contact CHB (see below)

Step 5: If You Lose Coverage — You Can Appeal and Reapply

If you receive a notice that your coverage is being terminated:

- You have the right to appeal. Request an appeal (also called a fair hearing) immediately – in most states you must do so within 30 to 90 days of the notice
- While your appeal is pending, you may be able to maintain coverage – ask your state office
- You can also reapply for Medicaid at any time if you lost coverage in the past
- If you need immediate help accessing treatment while coverage is disrupted, contact CHB's BCares Patient Assistance Program

Step 6: If You Are Not Eligible for Medicaid — Know Your Other Options

If you lose Medicaid coverage or are unsure of your eligibility, you may have other options:

- ACA Marketplace coverage: Visit healthcare.gov or your state's exchange to see if you qualify for a subsidized plan (note: enhanced subsidies expired at the end of 2025, so premiums may be higher than in prior years)
- COBRA continuation coverage: If you recently left a job, you may be able to continue your employer health plan
- CHB's BCares Patient Assistance Program: Can help connect you to manufacturer patient assistance programs, free or reduced-cost clotting factor, and emergency insurance navigation support
- Contact CHB directly: We can help you explore options and connect you with resources

What CHB Is Doing for You

The Coalition for Hemophilia B is actively engaged at the federal and state levels to protect our community's access to Medicaid. Specifically, we are:

- Advocating for bleeding disorders to be formally recognized as 'serious or complex medical conditions' qualifying for work requirement exemptions – in a joint letter to CMS and all State Medicaid Directors alongside NBDF and HFA
- Monitoring CMS guidance expected by June 2026 and will communicate updates immediately to our community
- Tracking state-by-state implementation decisions and flagging states where our patients face the highest risk
- Working with our network of patient advocates to provide navigation support for members who receive coverage termination notices
- Raising these concerns at our B the Voice Summit (June 22–25, Washington D.C.) during Capitol Hill Advocacy Day

We will send updated communications as CMS guidance is finalized and as states begin sending outreach notices. The most important thing you can do is stay in contact with us and keep your information current with your state Medicaid office.

State Medicaid Contact Information

If you need to contact your state Medicaid office to update your information, ask about your enrollment status, or learn about work requirement implementation:

State	Program Name	Contact / Website
Nebraska	Nebraska Medicaid	1-855-632-7633 | medicaid.ne.gov
Missouri	MO HealthNet	1-800-392-2161 | dss.mo.gov/mhd
Utah	Utah Medicaid	1-877-543-7669 | medicaid.utah.gov
Florida	Florida Medicaid	1-888-419-3456 | ahca.myflorida.com
West Virginia	WV Medicaid	1-800-642-8589 | dhhr.wv.gov/bms
Kentucky	Kentucky Medicaid (kynect)	1-855-459-6328 | chfs.ky.gov
New Mexico	NM Medicaid (centennial care)	1-888-997-2583 | hsd.state.nm.us
Oregon	Oregon Health Plan	1-800-699-9075 | oregon.gov/oha/HSD/OHP
California	Medi-Cal	1-800-541-5555 | dhcs.ca.gov
New York	NY Medicaid	1-800-541-2831 | health.ny.gov/medicaid
Pennsylvania	PA Medicaid (Medical Assistance)	1-800-692-7462 | dhs.pa.gov
Louisiana	Medicaid Louisiana	1-888-342-6207 | ldh.la.gov/medicaid
Arkansas	Arkansas Medicaid	1-800-482-5431 | medicaid.arkansas.gov
Mississippi	Mississippi Medicaid	1-800-421-2408 | medicaid.ms.gov
South Carolina	SC Healthy Connections Medicaid	1-888-549-0820 | scdhhs.gov

Contact The Coalition for Hemophilia B

If you have questions, need help navigating your coverage, or are in crisis accessing treatment:

www.hemob.org | BCares Patient Assistance Program | contact@hemob.org

We are here for you. You do not have to navigate this alone.

Disclaimer & Sources - This document was prepared by the Coalition for Hemophilia B using publicly available research from the RAND Corporation, KFF (Kaiser Family Foundation), the Urban Institute, the American Medical Association, the Center for Medicare Advocacy, and the National Bleeding Disorders Foundation, as well as state Medicaid agency communications. It is provided for informational purposes and does not constitute legal or medical advice. Medicaid rules are subject to change as CMS guidance is issued. Always verify your specific eligibility status with your state Medicaid agency. Last updated May 2026.

Hemophilia Landscape *Updates*

By David Clark, Ph.D.

Some of the items below were presented at the European Association for Haemophilia and Allied Disorders (EAHAD) Congress, February 3 – 6, 2026, in Dublin, Ireland. Copies of the abstracts (summaries) of the presentations are available free of charge at https://onlinelibrary.wiley.com/toc/13652516/32/S1.

Other items were presented at the World Federation of Hemophilia (WFH) World Congress, April 19 – 22, 2026, in Kuala Lumpur, Malaysia. Copies of the abstracts (summaries) of the presentations are available free of charge at https://onlinelibrary.wiley.com/toc/13652516/32/S2.

Hemophilia Care at HTCs Compared with Non-HTC Care

4/20/26 A group, mainly from the U.S., compared outcomes among patients with severe hemophilia treated at Hemophilia Treatment Centers (HTCs) versus those treated outside the HTC network. About 30% of U.S. patients receive their hemophilia care from non-HTC clinics and physicians. The reports are a combination of patient-reported outcomes and provider-reported data. They reviewed data from 100 patients: 65 treated at one of five HTCs and 35 at one of 39 non-HTC clinics. The patients' median ages were similar: 35.08 for HTC patients and 35.83 for non-HTC patients. The split between hemophilia A and B was also similar, with 86.2% of HTC patients and 88.6% of non-HTC patients having hemophilia A. Otherwise, many of the results were striking.

Prophylactic use was more common among HTC patients, with 84.6% receiving prophylactic treatment vs. just 40.0% among non-HTC patients. Non-HTC patients had a significantly higher average annualized bleeding rate (ABR), 7.1, compared to 2.9 for HTC patients. Joint damage and chronic pain were similar, but acute pain scores were higher in the non-HTC patients. Non-HTC patients had significantly worse health-related quality of life and higher anxiety and depression. The non-HTC patients also had more productivity loss and more activity impairment.

Then, why do so many patients receive care at non-HTC clinics? One reason is that HTC patients traveled an average of 51.6 miles to their HTC, whereas non-HTC patients traveled only 7.3 miles to their clinic. These results show the benefits of receiving care at HTCs but also highlight a major disadvantage: the distance to the HTC. Out here in the west, for instance, many HTCs hold periodic satellite clinics in other areas, yet many patients still travel hundreds of miles for care. [Grazzi EF et al., WFH abstract MP-305]

Tattoos and Hemophilia

4/20/26 Tattooing has become a very popular global trend, but it is not without risks. Possible complications include skin irritation, inflammation, swelling, bleeding, pain, and infection. Having a bleeding disorder is considered a higher risk, although there is little actual data to support that. Even so, many treatment centers discourage their patients from getting tattoos. The WFH Nurses Committee decided to explore experiences with tattooing within the global bleeding disorders community.

They conducted a survey among 188 subjects from 18 countries with 13 different bleeding disorders (70% hemophilia; 19% von Willebrand Disease). Women comprised 43% of the group, including two non-binary respondents. The rest were male. 80% had tattoos, with the vast majority of those citing personal choice as the reason. 70% did not consult their HTC before getting the tattoo. Of those with tattoos, 20% reported bleeding issues, and 1% reported infection. Interestingly, of those who reported bleeding, 40% had taken treatment (factor or tranexamic acid) before receiving the tattoo.

The group concluded that bleeding rates were relatively low. Some of the recommendations from the inked participants were 1) get to know your tattoo artist, 2) talk to your HTC, including for guidance on which parts of the body are more prone to bleeding, and 3) see if your tattoo artist will let you sit for reduced times during the process. Participants also reported that treating beforehand speeds healing. [Harrison C et al., WFH abstract PP-071]

Artificial Intelligence (AI) in Hemophilia Care

4/16/26 Artificial intelligence (AI) has been infiltrating the hemophilia world just like it has everywhere else. Although its use in everyday social life is highly controversial, its value in technical fields, especially in data analysis, is exceptional. A recent review article summarized many of the current and future possible uses of AI. AI can be employed in both technical and non-technical areas.

AI has already shown its worth in a number of technical applications in hemophilia treatment. For instance, it has shown high accuracy in analyzing ultrasound and MRI images of joints (see below). It has been used to estimate bleeding risk associated with physical activity in children with hemophilia by offering more individualized treatment recommendations. AI has identified genetic variants associated with an increased risk of inhibitor development, again with the potential to create personalized treatment strategies for individual patients. In surgical settings, AI-assisted robotic systems show promise in improving precision, reducing intraoperative blood loss, and enhancing perioperative safety.

In research, AI-based modeling has generated new insights into previously underappreciated aspects of the clotting system with potential clinical relevance. For instance, it has shown the important influence of factor V in producing thrombin and a successful clot.
In non-technical areas, AI has the potential to assist patients through multilingual, multicultural tools being developed to support education (see below), self-management, and treatment adherence. It also has applications in optimizing clinical workflows, in health system planning, and many other areas.

It is not a panacea, though; important limitations must be acknowledged. The author states, "AI systems are not consistently connected to live medical databases and may generate inaccurate or outdated information if inadequately prompted. Their outputs remain dependent on training-data quality and user input and therefore require critical supervision by experienced clinicians and educators. AI-based tools should complement, rather than replace, evidence-based guidelines, expert clinical judgment, and direct patient–clinician interactions." [Hermans C, Haemophilia, online ahead of print 4/16/26]

AI in Ultrasound Joint Imaging

3/4/26 A group in Italy is developing a point-of-care (home or clinic) AI-based ultrasound (US) system that can potentially support immediate and accurate diagnosis of acute joint bleeding followed by prompt treatment recommendations. They recently published the results of their validation of the system as the first step in developing a telemedicine system for patients with hemophilia.

Initially, the group looked only at joint effusion (fluid build-up). US scans of the knees of 158 adults with hemophilia and 66 age-matched healthy controls were evaluated by expert reviewers and by the AI system. The AI system showed 93.9% accuracy compared to the expert interpretations (which were assumed to be 100% accurate). This "represents an important step toward telemedicine in hemophilia, enabling early recognition of joint bleeding and supporting personalized, timely therapeutic interventions to prevent further joint damage." [Gualtierotti R et al., J Thromb Haemost, online ahead of print 3/4/26]

4/20/26 A group from China conducted a similar AI-based study, but in addition to joint effusion, they examined synovial hypertrophy (thickening of the synovial membrane), synovial neovascularization (development of new blood vessels), cartilage damage, and bone erosion. Their model similarly achieved a high level of agreement with expert interpretations at 89.7%. Interestingly, the model was better at detecting mild-to-moderate lesions (92.3%) than less-experienced physicians, who scored only 78.5%, compared with the expert reviewers. [Li J et al., WFH abstract MP-138]

AI in Patient Education on Five Commercial AI-Based Platforms

4/20/26 Another group of U.S. and Italian researchers examined the AI tools commonly used by patients to explore questions online. Twelve male patients were given ten questions about hemophilia to pose to five commercial AI platforms. The questions covered recent therapeutic advances and future perspectives on hemophilia. The subjects then rated their satisfaction with the responses on a 50-point scale across 10 criteria. Note that the patient ratings weren't based on the accuracy of the AI response, but rather on the patient's satisfaction with it.

The five platforms and their average ratings were: Chat GPT, 39.6 (out of 50); Perplexity, 39.3; Copilot, 33.8; Gemini, 39.5; and DeepSeek, 37.2. All five platforms received moderate-to-high scores according to the authors. They conclude, "The findings suggest that AI tools can already contribute meaningfully to medical education for PWH [people with hemophilia], especially in regions with limited access to specialized hemophilia treatment centers or clinical expertise." However, they also add the standard cautions that AI can get things wrong and even make up answers: "these resources must be used under professional supervision to prevent misunderstandings or the dissemination of incorrect medical information." [WFH abstract MP-269]

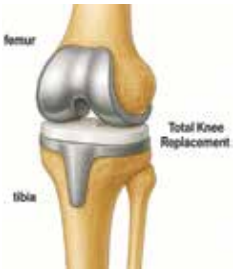
Recovery Time after Joint Bleeding

2/4/26 A group from The Netherlands looked at the time it takes to recover from a joint bleed. They point out that recovery time varies from patient to patient and from bleed to bleed. The study examined several

parameters to determine their effects on recovery time. The parameters included 1) trough level, 2) joint status, 3) cause of the bleed, 4) joint location, 5) limitation in range of motion (ROM), 6) effusion (fluid build-up) on ultrasound, 7) time between start of symptoms and start of treatment, 8) treatment days and 9) Hemlibra treatment for the hemophilia A patients.

They reviewed 64 bleeds in 44 patients (87.9% with hemophilia A; 50% with severe hemophilia). The median time to recovery was 32.5 days, but with a wide range of 8 – 174 days. ROM was the most significant predictor for recovery. Joints without limitation in ROM recovered 2.3 times faster than joints with a limitation in ROM (>15 degrees limitation). The only other parameter that showed a significant difference (at a 95% confidence level) was joint location (upper or lower extremity), although the trough level was almost significant. Pain level was not included as a variable but could be in future studies. The small number of hemophilia B patients is a limitation, since factor IX may be involved in healing. [Aertssen G et al., EAHAD abstract PO324 and Aertssen G et al., Haemophilia, online ahead of print 2/28/26]

A Series of Studies on Total Knee Replacement (TKA)



Quoting from the article below by Koc et al. (Koc and co-authors), "Haemophilic arthropathy [joint damage] develops as a consequence of recurrent intra-articular [inside the joint] bleeding, leading to chronic synovitis [inflammation], cartilage destruction and joint degeneration particularly in the knees. Total knee arthroplasty [total knee replacement] (TKA) is the gold-standard treatment…as it can dramatically improve knee function and reduce intra-articular bleeding. TKA is associated with high patient satisfaction rates, significant knee function improvement, and pain relief." [Definitions in brackets mine.]

However, they go on to say, "…many studies have reported higher complication rates and lower implant survivorship in people with haemophilia (PwH) than in people without haemophilia." Several recent articles have explored the complication and prosthesis survival issues in more detail.

Importance of Rehabilitation

11/13/25 A group of Chinese researchers reported on a 10-year study of rehabilitation (rehab) after TKA. In 50 patients, they found that knee joint function improves after rehab, and in fact, they recommend a pre-rehab (physical therapy) before surgery to further improve outcomes. They found that the range of motion (ROM) before surgery is a strong predictor of ROM after surgery. Therefore, if you can improve the ROM with physical therapy before surgery, the patient will tend to have better ROM after surgery.

It is also important to begin rehab as soon as possible after surgery, as there is a window beyond which improved results are less readily achieved. Many of their patients tended to want to delay rehab because of pain and/or anxiety, but that led to poorer outcomes. Thus, the authors also recommend psychological counseling to prepare the patients for a quick switch to rehab after surgery. The pre-rehab also helps reluctant patients get used to the idea of rehab. They also found that better ROM before surgery tends to lead to less pain after surgery and that patients not adhering to their prophylaxis regimen after surgery leads to increased pain. [Jin Z et al., BMC Musculoskeletal Disorders, online ahead of print 11/13/25]

TKA in Patients with Severely Stiff Knees

11/28/25 A group from Iran looked at outcomes of TKA in patients with severely stiff knees (ROM ≤40°). They report, "[Previous] studies report complication rates of 28.7% in hemophilic patients versus significantly lower rates in non-hemophilic populations, with specific risks including excessive blood loss, infection, and prolonged rehabilitation requirements. TKA surgery becomes even more technically demanding when performed in severely stiff knees."

In 24 patients (31 knees) followed for an average of 7.2 years (range 3.2 – 14.8 years), they found an average improvement in ROM from 42.8° to 81.3° and an improvement in flexion contracture (FC, the angle of the knee when the leg is fully straightened) from 16.2° to 5.8°. The ten-year implant survival rate was 93.4%. The group included four patients with inhibitors. They showed similarly good results but required more intensive bleed monitoring and treatment, as well as longer hospital stays.

As above, they found that rehabilitation compliance was crucial: "The critical role of rehabilitation compliance cannot be overstated. Our finding that patients with excellent compliance (77.4% of knees) achieved significantly better [ROM] outcomes (86.3° vs. 68.7°) emphasizes the importance of structured postoperative care and patient education in optimizing functional results." [Mortazavi SMJ et al., Haemophilia, online ahead of print 11/28/25]

Residual Flexion Contracture

11/28/25 A group from the same Iranian research center also examined improvements in residual

flexion contracture after TKA. FC, the angle of the knee when the leg is fully straightened, is much more common in hemophilic joints (65% of cases) than in joint damage from osteoarthritis (OA) in the general population (30-50% of cases). This results from chronic joint inflammation, the accumulation of fibrous tissue around the joint, and muscular imbalances that arise from adapting to joint damage. The higher prevalence in hemophilia patients is also attributed to a younger age at the onset of joint issues.

FC was once seen as something that could only remain the same or get worse, but this study shows that with proper care (including rehabilitation) and surgical technique, hemophilia patients undergoing TKA can actually improve. In 65 hemophilia patients with FC undergoing TKA at their treatment center, they found that an average contracture of 27.6° pre-surgery improved to 14.3° immediately post-surgery. Moreover, their average contracture improved to 6.9° after three months, to 4.4° at 6 months, 2.2° at 12 months and finally 2.1° at 56 months. Note that the patients all underwent an intensive physical therapy regimen, including twice-weekly supervised sessions, for the first three months after surgery.

Their detailed analysis suggests that patients with FC greater than 15° immediately after surgery and/or those whose age is over 40 have the highest risk of a final FC over 5°. However, for the whole group, a final FC of 5° or less was achieved by 90.8% of the patients after 12 months and by 92.3% at the 56-month study completion. The authors conclude, "In haemophilic patients with excellent rehabilitation compliance, surgeons can be confident that mild residual contracture is likely to improve over time." [Mortazavi SMJ et al., Haemophilia, online ahead of print 11/28/25]

Implant Loosening after TKA

10/25/25 A group from Turkey looked at implant loosening after TKA. During surgery, the long stems of the implants are inserted into the marrow canals of the tibia (shin bone) and femur (thigh bone) and fixed in place with "bone cement." Those stems can loosen over time, often due to bone remodeling. Bone is a living material that responds to stress, growing thicker in areas of high stress (high load) and thinner in areas of low stress. This is called remodeling. Since the stress distribution may change from the joint-damaged situation before TKA to the implant-stabilized situation afterward, in some cases, the bone tends to grow away from the implant, resulting in implant loosening.

This is called aseptic loosening, because it does not result from infection, which can sometimes result in loosening. Aseptic loosening is the main cause of complications for hemophilia patients after TKA and contributes significantly to revision. "Revision" is another surgery to replace all or part of an implant that has failed, due to loosening or other causes. In patients without hemophilia, the tibial component, the part in the shin bone, is more often the part that loosens. However, this study shows that in hemophilia, the femoral component is more often the one to loosen.

In the study, a group of 53 hemophilia patients was compared to a matched control group of 58 TKA patients without hemophilia. X-rays were taken at three and six months after surgery and then annually up to five years. X-rays show loosening by detecting space developing between the implant and the bone. Femoral component loosening was observed in 22.6% of hemophilia patients but only 5.2% of controls, a statistically significant difference. Tibial component loosening was about the same in both groups, with rates of 11.3% in the hemophilia group and 8.6% in the control group, not a statistically significant difference.

The average time to loosening of the femoral component was 27.6 months in the hemophilia group compared with 31.3 months in the controls. The average time to loosening of the tibial component was 20.4 months in the hemophilia group compared with 9.6 months in the controls. Note that the average age of the hemophilia group was 35.7 years at surgery compared with 60.5 years for the control group. Hemophilia patients tend to require TKA at much younger ages than do non-hemophilia patients who receive TKA for osteoarthritis. These results suggest that TKA patients with hemophilia might benefit from improved implant designs. [Koc B et al., Haemophilia, online ahead of print 10/25/25]

Implant Survival after TKA in Patients with Hemophilia 2/4/26 A group from the Netherlands explored implant survival rates in hemophilia patients after TKA or total hip replacement (THA). In 139 TKA patients with hemophilia, they found a 15-year implant survival rate of 92.2% and a 25-year survival rate of 90.9%. That is, 92.2% of the implants were still functioning adequately 15 years after surgery, and 90.9% 25 years after surgery. The survival rates for THA were 91.1% at 15 years and 79% at 25 years. They also found that TKA patients with an inhibitor at the time of surgery had a 32.3 times higher risk of implant failure than non-inhibitor patients. [Aertssen G et al., EAHAD abstract PT03]

Hemophilia in Women - The Cost of Denying Treatment to Women with Bleeding Disorders

4/24/26 An interesting article was recently published in the Indianapolis Business Journal concerning the cost of ignoring bleeding disorders in women. The bottom line is that every 1,000 individuals denied treatment for bleeding disorders costs the state about $2.4 million in direct medical costs. Beyond that, there are many other indirect costs, such as poorer workplace productivity,

absenteeism at both work and school and additional pregnancy-related complications. The author points out that there is "a clear opportunity to incorporate bleeding disorder screening and access to specialty care into existing policy frameworks." In other words, Indiana and other states are wasting money by ignoring women (and others) with bleeding disorders. [Ahuja S, Indianapolis Business Journal, 4/24/26]

It's a Myth that Factor IX Levels Don't Increase During Pregnancy

3/3/26 The idea that factor IX levels do not increase in carriers of hemophilia B during pregnancy, which is even stated in some international treatment guidelines, is apparently incorrect. We know that factor VIII and von Willebrand factor levels increase during pregnancy in both hemophilia A carriers and non-affected women, and that factor IX levels increase in non-hemophilic women during pregnancy. What then is special about hemophilia B carriers? A group of Irish researchers decided to explore this question.

Of course, our hemophilia B carriers are very special, but not in this way. This study shows that their factor IX levels do indeed increase during pregnancy. It turns out that the idea that factor IX levels in carriers don't increase is based on ten older studies including 30 carriers, many of which were single-patient case reports. Others had very low factor IX levels to begin with, which makes it harder to observe any increase.

Data in the Irish bleeding disorder database uncovered 49 carriers over 87 pregnancies, who had both baseline (pre-pregnancy) and antepartum (during pregnancy, prior to labor) factor levels. Analysis of that data shows that factor IX levels do in fact increase. Overall, they saw an increase from an average level of 54% of normal before pregnancy to 89% during pregnancy. Importantly, in women with mild hemophilia B, the average levels increased from 27% to 51%. Thus, factor IX levels do increase during pregnancy, which "highlights the importance of evaluating FIX levels to guide hemostatic management of delivery." This is just one more case of jumping to the wrong conclusion because of insufficient data. [Kelly C et al., J Thromb Haemost, online ahead of print 3/3/26]

Not Everyone Ignores Women with Hemophilia!
3/3/26 The article summarized above contains a statement that should inspire U.S. providers to better serve women with hemophilia. In describing the source of their data, they write:

In Ireland, due in part to a founder effect, we have an increased prevalence of HB (1 in 12,500 for males vs 1 in 30,000 males internationally). Our national bleeding disorder database has always registered hemophilia carriers, assigning a dual diagnosis of hemophilia to females with FVIII/FIX levels <0.40 IU/mL to ensure national visibility of all hemophilia carriers. Every patient contact, laboratory test, and hemostatic challenge is recorded in a national hemophilia Electronic Patient Record. All hemophilia carriers can avail of combined obstetric/hemophilia antenatal care at hemophilia comprehensive care centers (CCCs) at no cost. These factors cumulatively offer unique longitudinal insights into our national cohort of hemophilia carriers. [Kelly C et al., J Thromb Haemost, online ahead of print 3/3/26]

One of the primary reasons this is possible is that Ireland has a national healthcare system, which makes it easier to track everyone. We have partially done this in the U.S., for instance, with the CDC's Community Counts program. However, funding for that program was ended, and the whole blood disorders division was eliminated in April 2025. [NBDF article "Take Action: Protect Bleeding Disorder Programs", 4/8/25] We should do better.

Bleeding in Women Does Not Correlate with Factor Levels – More Evidence

3/6/26 One of the tragedies caused by deciding 200 years ago that women can't have hemophilia is that there hasn't been much research on bleeding in women. Most of what we know about bleeding and clotting was worked out in men and then assumed to apply equally to women. That turns out to have been a very poor assumption (as was the idea that women don't get hemophilia). One of the big mysteries is why bleeding in hemophilic women and carriers doesn't seem to depend in the same way on factor levels.

This fact was demonstrated dramatically by a new study from the Netherlands. Because of high postpartum hemorrhage (PPH, bleeding after giving birth) rates in hemophilia carriers, the Dutch government revised their guidelines to increase the desired factor level in the third trimester from 50% of normal to 80%, and the level during birth from 100% to 150%. This was expected to reduce the incidence of PPH in carriers.

Except that it didn't! In 170 deliveries after the change, severe PPH still occurred in 12.4% of deliveries, not statistically different from the rate before the change. The authors conclude, "More research is needed on optimal clotting factor levels during delivery to prevent severe PPH." In fact, we could use more research on bleeding/clotting in women in general to get a better idea of even what research questions to ask. [de Vaan A et al., J Thromb Haemost, online ahead of print 3/6/26]

Hemophilia Landscape
Emerging Therapies

By David Clark, Ph.D.

Spring 2026 With the recent approval of several new products for hemophilia B, including rebalancing agents and gene therapy, product development is now in a lull. Much of the current research focuses on how these new therapies perform in the real world. Hemophilia B products can 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 the order of the organizations that develop the products.

Some of the items below were presented at the European Association for Haemophilia and Allied Disorders (EAHAD) Congress, February 3 – 6, 2026, in Dublin, Ireland. Copies of the abstracts (summaries) for the presentations are available for free at https://onlinelibrary.wiley.com/toc/13652516/32/S1. Some other items below were presented at the World Federation of Hemophilia (WFH) World Congress, April 19 – 22, 2026, in Kuala Lumpur, Malaysia. Copies of the presentation abstracts are available free of charge at https://onlinelibrary.wiley.com/toc/13652516/32/S2.

IMPROVED FACTOR PRODUCTS

These are improved versions of the factor products that most people with hemophilia B currently use, including products for inhibitor treatment.

Sobi Reports Final Results for Alprolix® in Children

2/4/26 Sanofi markets Alprolix, an extended half-life recombinant factor IX product, which was developed in conjunction with Sobi, a Swedish organization. At EAHAD, Sobi reported on the final Phase III study results for Alprolix in children. The 24-month study included 151 subjects with hemophilia B, of whom 73 were pediatric. The pediatric (all male) subjects were divided into age groups: < 6 years (13 severe); 6 to < 12 years (27 severe; 11 moderate); and 12 to < 18 years (11 severe; 3 moderate). (Note - the numbers don't add up because some patients' data were not available.) All patients had at least 34 months of Alprolix treatment.

All annualized bleeding rates (ABRs) were low, with median values of 0.3, 0.8, and 0.0, respectively, from the youngest group to the oldest. Median infusion frequencies were similar, at about 1 infusion per week. There were no cases of inhibitor development or serious adverse events. [Glosli H et al., EAHAD abstract PO064]

Staidson Reports on Bemiltenase Alfa for Inhibitor Treatment

2/4/26 Staidson (Beijing) Biopharmaceuticals is developing bemiltenase alfa (BA), a factor X activator, for the treatment of patients with hemophilia A or B and inhibitors. BA is purified from the venom of the Russel's viper snake. Many snake venoms contain coagulation activators, so the snake's victim clots itself to death from thrombosis. Russel's viper venom (RVV) is a common laboratory reagent used in clotting assays.

In a person without hemophilia, a complex of factor VIII and factor IX activates factor X to continue the clotting process. In a hemophilia patient deficient in either factor VIII or IX, factor X activation is either slow or doesn't happen at all. That's why many of the symptoms of hemophilia A (factor VIII deficiency) and hemophilia B (factor IX deficiency) are similar. You need both factor VIII and factor IX together to activate factor X. If either is missing, you don't clot well.

They recently reported the results of their Phase Ib/IIa and IIb clinical studies, which demonstrated that BA is safe and effective in treating bleeding in both A and B inhibitor patients. [Liu W et al., Blood Advances, online ahead of print 2/4/26]

TiumBio Reports on TU7710 for Inhibitor Treatment

2/4/26 TiumBio, a South Korean company, is developing TU7710, an extended half-life recombinant activated factor VII (rFVIIa) product for the treatment of hemophilia A and B patients with inhibitors. Two rFVIIa products are currently available for inhibitor treatment, but both have relatively short half-lives, which require the products to be infused more than once a day to treat a serious bleed. TU7710 links rFVIIa to recombinant transferrin to give it a significantly longer half-life in circulation.

They recently reported the results of their Phase I study in healthy male volunteers without hemophilia. It is common practice in Phase I studies to include subjects without the disorder of interest, since Phase I is primarily intended to ensure that the product is not harmful. However, many hemophilia clinical studies include patients in their Phase I studies to collect additional data. The subjects were all pre-treated with warfarin to reduce their clotting factor levels, simulating hemophilia.

The results show that TU7710 has a half-life about seven times longer than that of currently available products and can effectively normalize clotting times in warfarin-treated patients. The product demonstrated dose-dependent behavior, meaning that as the dose increases, the product's effect increases. Dose-dependency is an important parameter for a pharmaceutical. The product was well-tolerated at all dose levels. [Kim B et al., J Thromb Haemost, online ahead of print 2/4/26]

REBALANCING AGENTS

Rebalancing agents tweak the clotting system to restore balance so that the blood clots when it should and doesn't when it shouldn't. The clotting cascade is a complex system of clotting factors that promote clotting, as well as anticoagulants that inhibit and control it. In a person without a bleeding disorder, the clotting and anticoagulant activities are in balance, so the system produces clots as needed but doesn't clot when it shouldn't. In hemophilia, with the loss of some clotting factor activity, the system is unbalanced; there is an excessive level of anticoagulant activity, preventing the blood from clotting. Rebalancing agents primarily reduce or inhibit an anticoagulant's activity in the system. Most of these agents help restore clotting in people with hemophilia A or B, with or without inhibitors, and are likely to find applications in other bleeding disorders.

Pfizer Submits sBLA for HYMPAVZI® for Children and Inhibitor Patients

2/6/26 Pfizer markets HYMPAVZI (marstacimab) as a rebalancing agent for treatment of patients with hemophilia A or B without inhibitors who are 12 years of age or older. HYMPAVZI is a weekly, subcutaneous, monoclonal antibody product that inhibits tissue factor pathway inhibitor (TFPI), an anticoagulant. They have now submitted a supplemental Biologics License Application (sBLA) to extend their indication to all hemophilia A and B patients aged 6 years and older, with or without inhibitors. FDA has granted Priority Review for the sBLA and expects to make a decision in the second quarter of 2026. If the application is approved, HYMPAVZI would be the only rebalancing agent indicated for children ages 6 to 12. [Pfizer press release 2/6/26]

Does HYMPAVZI® (and the other rebalancing agents) Represent a Genuine Advance in Treatment?

3/9/26 Johnny Mahlangu, a hemophilia treater in South Africa who participated in the clinical studies for both HYMPAVZI and Alhemo, wrote a recent editorial raising the question "Does marstacimab represent a genuine advance in personalized hemophilia management, or merely an incremental addition to an already crowded therapeutic space?" Although the editorial focuses on HYMPAVZI (marstacimab), many of its points also apply to both Qfitlia and Alhemo, the other two recently approved rebalancing agents.

First, these products will be game-changing for most hemophilia B patients with inhibitors. Their primary treatments for bleeds have been bypassing agents (BPAs), which work somewhat but are burdened by the need for intravenous infusion, sometimes several times a day, because of BPAs' short half-lives. Although protocols for prophylactic use of BPAs have been developed, they can be problematic for some patients, and the products are expensive. Most B inhibitor patients are treated on-demand, which we know is inferior to prophylactic treatment. Inhibitor patients with hemophilia A have been able to receive Hemlibra for several years, but for Bs, this is the first alternative.

All hemophilia B patients, with or without inhibitors, can benefit from the subcutaneous (subQ) injection used for rebalancing agents.

One big question that remains is whether the efficacy of the rebalancing agents in preventing bleeds is comparable to that of clotting factor. Mahlangu points out that this is a "critical limitation" of the rebalancing agent clinical studies. Pfizer did compare HYMPAVZI against factor in 83 subjects (21.1% were Bs) who were studied on their routine prophylaxis regimen for six months before switching to HYMPAVZI. That group saw a decline from an ABR of 7.90 on factor prophylaxis to 5.09 on HYMPAVZI, a statistically significant change. However, Mahlangu questions whether that is a clinically significant change, and points out that only about 30 – 35% of subjects experienced zero bleeds, the desired outcome for clotting factor treatment.

In terms of product safety, there are two main concerns: thrombosis and immunogenicity. Although no thrombotic events were observed during the clinical studies with HYMPAVZI, a couple have occurred since the product was licensed. One was in a patient who was unaware that he had Factor V Leiden, which makes him more susceptible to thrombosis. The other patient died of a heart attack that hasn't been confirmed as due to HYMPAVZI.

About 5% of the population (including people with hemophilia) has Factor V Leiden, and a number of others have other conditions that make them prone to thrombosis. Yet this concern is not addressed in the Prescribing Information. The FDA approvals assume that the rebalancing agents are good for all patients with hemophilia, regardless of severity, even though they have only been tested on severe or moderately severe patients. There are no instructions for treating patients who are prone to thrombosis, only a warning that thromboembolic events are possible. Physicians are left without much guidance.

The question about immunogenicity is, will the immune system see HYMPAVZI and other rebalancing agents as foreign agents and produce antibodies against them? These antibodies are called anti-drug antibodies (ADAs). In hemophilia, ADAs against infused factor VIII or IX are called inhibitors because they interfere with the action of the clotting factors. In the clinical studies, about 20% of subjects developed ADAs against marstacimab, the active ingredient in HYMPAVZI, but those ADAs did not appear to affect its efficacy. Mahlangu wonders whether those ADAs might pose a problem over the long term and whether specific patient groups might be more susceptible.

Unlike medicines for many major diseases, which are sometimes tested on thousands of subjects, clinical studies for hemophilia usually include only a hundred or so subjects. Therefore, we don't have as much information about the products. Under those circumstances, the patients who receive the products soon after licensure are, in a sense, still part of the experiment, still part of the study. That requires caution and careful observation of those patients.

The rebalancing agents have great potential. The dosages for most of them are confined to a handful of approved levels – a one-size-fits-most approach. Mahlangu would like to see them adapted for more personalized use. Ideally, a physician could measure a patient's individual clotting potential and then prescribe a more precise dose. We're not there yet, but maybe we're on our way. [Mahlangu J, Expert Review of Clinical Pharmacology, online ahead of print 3/9/26]

Lower Doses for Some Patients with Sanofi's Qfitlia™

2/4/26 Sanofi markets Qfitlia (fitusiran) as a rebalancing agent for treatment of patients with hemophilia A or B, with or without inhibitors. Qfitlia is a monthly subcutaneous injection that reduces antithrombin (AT) production, an anticoagulant. To avoid thrombosis (unwanted clotting) while maintaining low bleeding rates, they determined that AT levels should be kept at 15–35% of normal. However, even at the lowest dose level of 20 mg every two months, about 12% of patients still had low AT levels < 15% and had to discontinue treatment.

To provide treatment with Qfitlia for those patients, Sanofi worked with the FDA to approve a lower dose of 10 mg every two months. That dose level was determined by computer simulation using data from the 283 subjects in the clinical studies. The results suggest that fewer than 1% of patients would now be excluded from receiving Qfitlia due to low AT levels. [Young G et al., EAHAD abstract PO043]

CELL AND GENE THERAPY (CGT)

Gene therapy is the process of inserting new, functional factor IX genes into the body to allow it to produce its own factor IX. Cell therapy is the transplantation of whole cells that have been modified with a new gene to perform a specific function, such as producing factor IX.

Belief BioMed Reports Five-Year Results for BBM-H901

4/20/26 Belief BioMed, a Chinese company, has developed BBM-H901 (dalnacogene ponparvovec), a gene therapy for hemophilia B. BBM-H901 uses a proprietary AAV vector (AAV843) to deliver the Padua factor IX gene variant to the liver. It was approved by China in April 2025 as the first gene therapy to be approved by a Chinese company. It costs $350,000 in China. China is committed to producing lower-cost medicines to serve its population, and the $3,500,000 cost of HEMGENIX is completely unaffordable in China.

At WFH, they presented five-year follow-up results from their initial clinical studies. Ten patients were initially dosed between 2019 and 2021, giving a median follow-up duration of 235.5 weeks, with three patients completing 5 years (260 weeks). The patients received a 5 x 1012 vg/kg dose (HEMGENIX dose is four times higher at 2 x 1013 vg/kg; vg/kg is the abbreviation for "vector genomes per kilogram of body weight." It's basically the number of copies of the new gene infused per kg.) All BBM-H901 patients are given corticosteroids (prednisone) prior to the gene therapy infusion to help

prevent liver inflammation.

One subject experienced a decline in factor IX level to less than 5% after 130 weeks and resumed treatment with factor. The other nine discontinued factor treatment completely. Those nine had an average factor IX level of 40.95% that remained stable over time. The average ABR was minuscule, with only one of the nine patients having one bleed in the five-year period. In the subsequent Phase III study, the 26 subjects had an average ABR of 0.6 one year after treatment. [Phase III results from Belief BioMed press release 3/19/26]

Belief BioMed is apparently planning to bring BBM-H901 to the U.S. and Europe, but the timing has not been announced. They have received Breakthrough Therapy Designation, Orphan Drug Designation, and Rare Pediatric Disease Designation from the FDA, as well as Advanced Therapy Medicinal Product Classification from the EU. They are also developing a gene therapy for hemophilia A. [Xue F et al., WFH abstract FP-014]

BioMarin Announces Discontinuation of its Hemophilia A Gene Therapy, Roctavian®

2/24/26 BioMarin developed Roctavian, the only gene therapy for hemophilia A. They have now discontinued the product due to poor sales. The only gene therapy for any type of hemophilia is now CSL Behring's HEMGENIX for hemophilia B. Roctavian suffered from the same slow uptake of their product that has plagued HEMGENIX. However, in addition to the logistic and cost issues similar to those facing HEMGENIX, Roctavian was also up against two other issues.

First, the durability of factor VIII expression, the amount of time the transformed liver cells keeps producing factor VIII, is estimated to be only 8 – 12 years. The durability of most other gene therapies, including HEMGENIX, appears to be much longer. Second, there are more easy-to-use alternative treatments for hemophilia A, including Hemlibra, a monthly subcutaneous injection, and ALTUVIIIO, an ultra-extended half-life product. [BioMarin press release 2/24/26]

Long-Term Durability of HEMGENIX® Gene Therapy

2/4/26 A paper at EAHAD reported on the long-term durability of HEMGENIX. Durability is the duration after treatment during which the body continues to produce clinically meaningful amounts of factor IX. A summary of the results from the Phase III licensure study after five years (the end of the study) shows that factor IX levels have remained fairly constant, ranging from 39.0 % of normal after treatment to 36.1% after five years. The average ABRs for all bleeds ranged from 3.61 during the lead-in period before receiving HEMGENIX to 0.68 after 1 year, 0.52 at two years, 0.56 at three years, 0.19 at four years, and 0.34 at five years. There were no long-term liver problems and no signs of cancer. [Leebeck FWG et al., EAHAD abstract OR11]

St. Jude/UCL Report Nine-Year Results for Gene Therapy Enriched in Full Vector Capsids

2/4/26 St. Jude Children's Research Hospital (St. Jude) and University College London (UCL) published one of the first successful studies of hemophilia B gene therapy in 2011. Last year, 2025, they provided a 13-year follow-up showing stable factor IX expression and no long-term toxicity, although four of six patients in their high-dose subgroup initially experienced temporary liver inflammation after treatment. That is a common occurrence with many gene therapies, including HEMGENIX, and is usually treated with a course of corticosteroids.

Manufacturing AAV gene therapy vectors is difficult, and the final preparation typically contains many empty viral capsids that lack genes. The capsid is the shell of the virus, without the viral genes. Capsids are filled with the gene of interest, in this case a factor IX gene, to form the vector that introduces the new gene into the body. The capsid-filling process is fairly inefficient, leaving many empty shells. Those empty capsids can't transmit the new gene, but the immune system doesn't know that. It sees those empty capsids as just more viruses that could harm the body and reacts against them.

The St. Jude/UCL researchers wondered whether the large number of empty capsids was contributing to liver inflammation. Their original preparation contained about 10 times as many empty capsids as full ones. They added another purification step to the manufacturing process, which reduced the empty/full

capsid ratio from 10:1 to 3:1 and administered it to four patients to determine whether the lower total number of vectors would reduce liver inflammation.
It didn't. The four new subjects still saw liver inflammation and lower, less stable factor IX levels. That leaves them with a number of possibilities.

There might still have been too many empty capsids, or the additional purification step could have affected the product's performance. The four new patients still saw benefit from the therapy, though. They all saw increases in factor IX levels, and their median ABR dropped from 11.6 to 3.2. [EAHAD abstract PO041]

Gene Therapy in Hemophilia Patients Infected with HIV

4/25/26 Many older people with hemophilia were infected with the Human Immunodeficiency Virus (HIV, the virus that causes AIDS) from contaminated plasma-derived products in the 1970s and 1980s. A research group from Germany surveyed all of the results available for HIV-infected hemophilia patients who participated in clinical studies for hemophilia gene therapy products. There were only a few HIV-positive patients in the trials, partly because companies don't want subjects with conditions that might complicate the results.

There has been a total of 11 HIV-positive patients in hemophilia gene therapy studies. Early studies for the hemophilia A therapy Roctavian included three HIV-positive patients. Two patients did fine, but the third developed a severe adverse reaction related to liver toxicity. All three developed liver inflammation, which was treated with corticosteroids. Further investigation suggested that the problem was with the older version of antiretroviral therapy (ART, which keeps the HIV virus in check) the third patient was taking, which by itself gives a high risk of liver toxicity. When that patient was switched to a newer ART, the severe adverse reactions disappeared. After this experience, BioMarin, the product developer, limited study enrollment to non-HIV patients only.

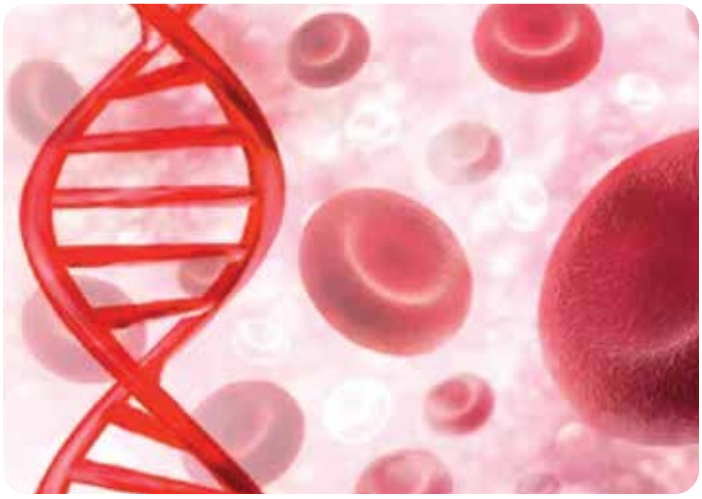
The studies for giroctocogene fitelparvovec, a hemophilia A gene therapy that was discontinued during development, included three HIV subjects. All three responded well to gene therapy and only one developed liver inflammation, which was successfully treated with corticosteroids. Liver inflammation after gene therapy is a normal reaction in some patients, whether HIV-positive or -negative. The studies for HEMGENIX, the hemophilia B gene therapy, included five patients with HIV. All responded well to the therapy, and only one developed liver inflammation.

The issues for gene therapy in HIV-positive patients seem to come down to the condition of the patient's liver and the type of ART they are taking. Many HIV-positive patients have liver damage and other conditions, and that must be taken into consideration when deciding to receive gene therapy. Older versions of ART can put a lot of stress on the liver, and that can be a problem for gene therapy, which itself puts stress on the liver. The authors suggest that patients on older ART treatments switch, if possible, to newer versions that are more liver-friendly before receiving gene therapy. Except for the use of older ARTs, there seems to be little risk for HIV-positive patients with gene therapy. [Rockstroh JK et al., Haemophilia, online ahead of print 4/25/26]

Risk of Hepatitis B Reactivation after Gene Therapy

2/4/26 Many older hemophilia patients who used plasma-derived products are infected with hepatitis B virus (HBV). Even if their infection is not active, they can still have the virus in their liver, but it is normally kept in check by the immune system. However, it is known that in about 5% of patients given corticosteroids for immune suppression at doses over 40 mg/day, their HBV infection can be reactivated. This can be an issue in hemophilia patients receiving gene therapy who develop liver inflammation and are treated with corticosteroids.

Recognizing this, a group of researchers in Italy examined patients at their hemophilia center to determine how many might be at risk after gene therapy. Their patients were 85% hemophilia A with a median age of 44 years, and about 21% had a current or prior HBV infection. The researchers calculated that about 16% of their patients eligible for gene therapy could be at risk of hepatitis B reactivation. That number may vary across other patient groups and locations, but it underscores the need for physicians to consider this issue when prescribing corticosteroids after gene therapy or for other reasons. [La Mura et al., EAHAD abstract PO049]



women & girls with hemophilia

articles to support, educate, and empower

Turning Uncertainty into Action: Erica's Hemophilia Story

By Allyson Kamps

"This is our life now, and I don't want it any other way."

Erica often jokes that she lives on a "funny farm." With two kids, two dogs, two goats, two chickens, and a handful of other animals, it's not far from the truth. Her home in rural Pennsylvania hums with activity and the rhythm of daily life. But when her son Liam was born, that familiar pace shifted, prompting a journey in search of answers that would transform her understanding of medicine, motherhood, and community.

Liam was born via scheduled C-section on October 19, 2021. During his newborn screening, the medical team noticed he wouldn't stop bleeding from a heel prick. After a circumcision, the bleeding became unmanageable. He was airlifted to a larger hospital, where Erica later learned he had coded from critical blood loss. Liam spent seven days in the NICU as clinicians worked to stabilize him. Those early hours left Erica desperate for answers.

With no history of bleeding disorders in her family, Erica immersed herself in research, reading medical literature, joining patient groups, and seeking every available resource. Although clinicians initially diagnosed Liam with moderate hemophilia, Erica's instincts told her to keep searching. Her efforts led her to a Hemophilia Treatment Center (HTC) in Hershey, where Liam was retested and classified as having severe hemophilia and started immediately on prophylactic factor therapy.

Erica also learned something unexpected about herself. After Liam's NICU stay, her factor level was tested; she recalls, "My levels came back as 38%." Doctors informed her she was not just a carrier but had hemophilia, too. In hindsight, Erica realized the bruises and aches she'd attributed to athletics, and the heavy menstrual cycles she thought were normal, were actually symptoms. Later testing at the HTC revealed her levels were even lower, making her a patient there as well.

These discrepancies revealed a gap in local care: the hospital's labs didn't measure the very low factor levels that indicate severe hemophilia, so a child with a factor level below 1% could be misclassified as having moderate



hemophilia. “How many other hospitals in this country do this?” she wondered. “How many others are being misdiagnosed?”

Getting treatment for Liam took persistence. For nearly a year, the family made a two-hour round trip to Hershey every week for his infusions because their local hospital couldn’t reliably care for an infant with hemophilia. Eventually, a home care nurse began coming to their home to administer the infusions, bringing immense relief.

Frustration with early missteps turned into action: Erica joined online support groups and attended the Hemophilia B Symposium. “At the symposium, I remember going back to the hotel room one night and telling my husband, ‘This is our life now, and I don’t want it any other way.’” Her volunteer work gave her a platform to help other families avoid the confusion and isolation she had faced.

Erica’s advocacy eventually led her to a new career. She joined a specialty pharmacy serving the bleeding disorders community. Her new role lets her help families in concrete ways, including navigating insurance, accessing treatment, and connecting parents with the HTC and nursing support. “Now I can support families not only emotionally but also practically. If someone has a question about hemophilia and wants to talk to me, I’m available,” she says.

That same determination shaped Liam’s care outside the hospital. Through her research, Erica found a medical daycare in Danville staffed by nurses and medical assistants. Liam was the first child with hemophilia in their care, and the staff welcomed guidance from Erica and her HTC nurse during a collaborative session on hemophilia management. Thanks to this teamwork, Liam fully participates in activities such as field trips and the nine-day Bloomsburg Fair, supported by a team that understands his needs. Even with Erica’s research and advocacy, it’s the combined efforts of her husband, their family, the HTC, and the daycare that keep Liam safe. Their nine-year-old daughter, Zayleigh, will soon be tested to determine whether she carries the gene. For now, the family’s support network continues to grow.

Erica’s advocacy now takes practical, everyday forms: answering questions from new moms in online support groups, visiting the HTC, and helping families connect with nurses and resources. “If I hadn’t done my own research and found an HTC two hours away, I’m not sure what would have happened to my son,” she says. That experience fuels her commitment to ensuring other families receive guidance and access to care. For Erica, her “funny farm” is now part of a larger network where her experiences help guide other families on their hemophilia journey.

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MEDEXUS PHARMA

Adulting Unlocked: Supporting Young Adults Living with Hemophilia B

By Kelly Ireland

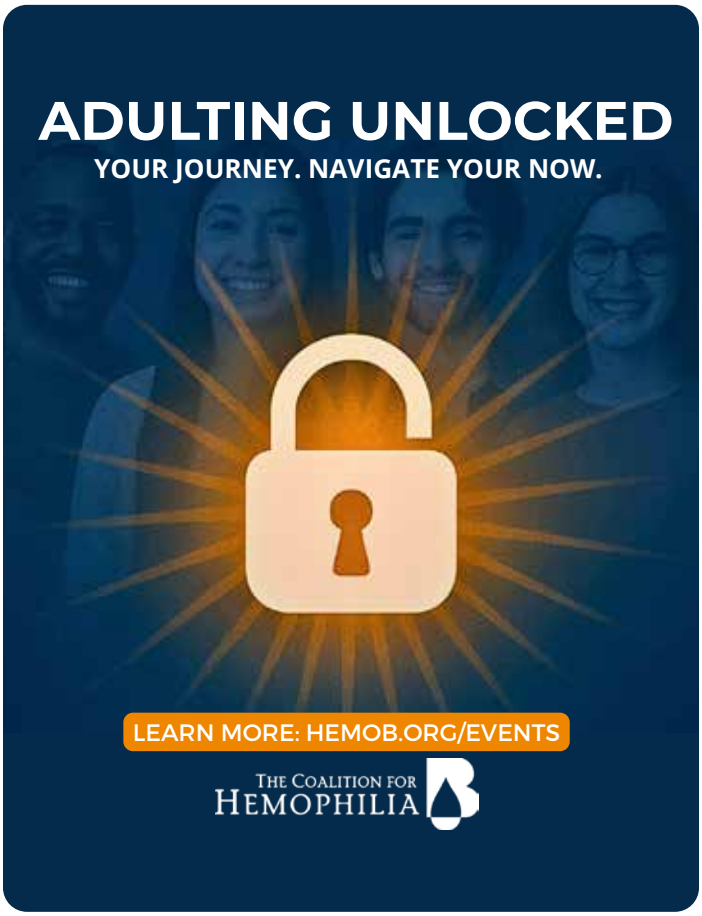
The Coalition for Hemophilia B is excited to launch Adulting Unlocked, a new program that supports young adults ages 18–35 as they navigate real life, real challenges, and real growth while living with Hemophilia B. (And yes, older adults are absolutely welcome, too!)

Let's be honest, life doesn't move in a straight line. There are twists, setbacks, surprises, wins, awkward moments, career questions, relationship challenges, financial stress, and times when you are simply trying to figure things out, step by step. Adulting Unlocked was created to provide a supportive space where young adults can connect, learn practical life skills, ask honest questions, and build confidence for the road ahead.

Our first session featured special guest speaker Dr. April Willis, leading an engaging conversation on navigating today's workplace, building confidence, communicating effectively, and learning to advocate professionally for yourself. Participants explored ways to set goals, find mentors, and recognize that the experiences gained from living with a chronic condition can become strengths in leadership, resilience, and personal growth.

The second series featured financial wellness expert Shari Carlson of Unity Wealth Strategies, who presented "Managing Your Money in Tough Times." Her session offered practical, real-world advice on budgeting, managing debt, planning, understanding insurance, and reducing financial stress while balancing everyday life with healthcare needs.

Our May program featured Carlisa Johnson, MPH, who led a thoughtful, empowering discussion on "How to Get Your Life Together Without Burnout." The session offered practical tools for daily life, strategies for healthy boundary-setting, stress-management techniques, and simple breathing exercises that can be integrated into everyday life. Participants left with helpful tips, relatable insights, and reminders that success and self-care can coexist.



Adulting Unlocked is more than just another educational program. It is a space for connection, encouragement, growth, laughter, honest conversation, and learning to navigate adulthood together. Whether participants are figuring out careers, relationships, independence, healthcare decisions, or simply trying to balance life, the program is designed to meet young adults where they are.

We are excited about what lies ahead and look forward to welcoming even more young adults to future sessions as we continue building a supportive community focused on empowerment, confidence, and living fully.

YETI: BUILDING INDEPENDENCE AND LEADERSHIP

By Matt Marlatt

The Pacific Northwest Bleeding Disorders Youth Effectively Transitioning to Independence (YETI) program supports teens and young adults ages 16–20 as they prepare to take greater responsibility for their health and future. Created by Pacific Northwest Bleeding Disorders in partnership with GutMonkey, YETI builds confidence, leadership, self-advocacy, and practical skills for adult medical care, higher education, and the workforce.

This year's train-the-trainer conference was held February 19–22 at Camp Collins, a scenic retreat along the Sandy River near Portland. The weekend began with GutMonkey's 90s Disco Night, an energetic activity designed to help participants connect, express themselves, and build community.

Friday focused on transitioning to adult care, self-management, and informed decision-making. Teens and adults also joined a facilitated discussion on communication and self-advocacy, gaining practical strategies for speaking with healthcare providers, educators, and employers. A Project Runway-style challenge ended the day with creativity, teamwork, and laughter.

Saturday prepared participants for the realities of adulthood, including navigating insurance, college, the workplace, and accommodations. Leadership sessions encouraged youth to see leadership as everyday action, such as speaking up, supporting peers, and contributing to the bleeding disorders community. A Chopped-style team challenge reinforced collaboration, problem-solving, and communication.

The evening concluded with YETI bracelet branding. More than a keepsake, the bracelet symbolizes connection, growth, independence, and a commitment to supporting others.

On Sunday, participants reflected on the weekend and planned ways to bring YETI's momentum back to their local chapters. They left Camp Collins with stronger skills, deeper connections, greater confidence, and a renewed sense of purpose.

YETI is more than a weekend conference. It is the beginning of a journey toward independence, leadership, and lifelong engagement in the bleeding disorders community.

Meetings on the Road

By Matt Marlatt

Chicago

The Coalition for Hemophilia B launched this year's *Meetings on the Road* series with events in Chicago, Illinois, on March 14th, and Dallas, Texas, on May 16th.

Both events began the evening before with a welcome dinner, providing a relaxed and inviting atmosphere where returning families could reconnect with old friends and first-time attendees were warmly welcomed into the community. These informal gatherings set the stage for a weekend centered on education, support, and meaningful connections.

The day opened with an energizing "Shake, Rattle & Roll" session led by Robert Friedman, who had participants up, moving, laughing, and ready for a full day of learning and engagement. The interactive session was an ideal way to start the morning, setting a positive and enthusiastic tone for the day ahead.

The morning continued with interactive rap sessions facilitated by Fel Echandi and me, offering families a welcoming environment to share experiences, exchange perspectives, and build meaningful relationships. Through open and honest conversations, participants discussed both the challenges and triumphs of living with hemophilia B, finding encouragement, practical advice, and reassurance from others who truly understand their journey. These heartfelt discussions remain among the most meaningful aspects of Meetings on the Road, strengthening the sense of community that defines the Coalition.

Throughout the day, attendees participated in engaging educational sessions on gene therapy, proactive health management, joint health, and practical stress-reduction strategies to incorporate into everyday life at home, at work, or while traveling. Participants left with valuable knowledge, new resources, and practical tools to help them make informed decisions about their health and well-being.

Following lunch, participants enjoyed uplifting movement sessions that brought energy and fun to the afternoon. In

Chicago & Dallas Highlights!

Dallas

Chicago, the Breathe and Move-Ment dance troupe led a joyful, interactive experience that encouraged everyone to get moving, while in Dallas, attendees were captivated by a flamenco performance by Sarah Moran. Between sessions, families continued conversations over meals, explored the exhibit hall, and connected with industry partners and community organizations.

While adults attended educational sessions, teens and tweens enjoyed age-appropriate activities that fostered friendships and reinforced the importance of community. In Chicago, they participated in an educational field trip to the Lincoln Park Zoo, while participants in Dallas spent the afternoon at Pinstack, enjoying bowling, arcade games, and other interactive attractions in a fun and welcoming environment.

Each meeting concluded with an inspiring presentation of "Our History, Our Story," delivered by Lisa Hensley, PhD, MSPH, in Chicago, and by Dr. Dave Clark in Dallas. Their presentations reflected the remarkable progress made within the bleeding disorders community while honoring the resilience, advocacy, and perseverance of those who have helped shape its history. Attendees left inspired by how far the community has come and hopeful for the future.

The Meetings on the Road continue to exemplify the strength, resilience, and compassion of the hemophilia B community by bringing families together to learn, connect, and support one another. Beyond the educational sessions, these gatherings also offer a sense of belonging and the chance to build lasting friendships with others who share similar experiences.

We extend our heartfelt gratitude to everyone who joined us and to our generous sponsor, CSL Behring, whose continued partnership makes these meaningful events possible. We look forward to welcoming even more families at future Meetings on the Road!

CSL

Navigating Gene Therapy Together

By Bobby Wiseman

The Coalition for Hemophilia B's Gene Therapy Peer-to-Peer Support Program provides a private, supportive, monthly virtual space exclusively for men aged 18 and older who are either currently on gene therapy or considering it.

More than an informational session, these conversations center on connection, honesty, reflection, and shared lived experience. As gene therapy continues to evolve for individuals living with Hemophilia B, participants are exploring questions that extend far beyond clinical outcomes. Discussions often focus on identity, mental wellness, relationships, uncertainty, expectations, financial considerations, and what long-term success truly means in everyday life.

The program recognizes that gene therapy is not simply a medical decision. For many, it is deeply personal, emotional, and ongoing. Through open dialogue and peer support, participants can learn from one another, ask difficult questions in a judgment-free environment, and feel less isolated during the decision-making process.

By bringing together individuals across different life stages and experiences, the program fosters meaningful connections and real-world insight that cannot be found in clinical data alone. The Coalition for Hemophilia B remains committed to creating safe, participant-driven spaces that bridge the gap between science and lived experience while supporting informed, empowered decision-making for the future of care.

Thank you to our sponsor, CSL Behring, for making this possible.

CHB on the Road to the HFA Symposium

By Matt Marlatt

The Coalition for Hemophilia B was honored to attend the 2026 Hemophilia Federation of America (HFA) Symposium, April 16–19, 2026, in New Orleans, LA.

The event brought together individuals and families affected by bleeding disorders, healthcare professionals, advocates, and industry partners from across the country.

The symposium featured educational sessions led by expert speakers on gene therapy, advocacy initiatives, women's health, mental health, and quality of life. Attendees participated in networking opportunities and meaningful discussions designed to foster connection, education, and shared learning. In addition to the educational programming, the symposium included an exhibit hall, family-focused activities, and special events that provided valuable resources and support for the bleeding disorders community.

We extend our sincere thanks to HFA for providing the Coalition with the opportunity to connect with new members and strengthen existing relationships.

Building Wellness and Connection Through the Living Well Lab

By Kelly Ireland

The B Hub Living Well Lab was created to support mental, physical, and emotional well-being across the hemophilia B community, offering participants practical tools, trusted guidance, and meaningful connections.

Over thirteen weeks, community members gathered for a unique learning experience designed to help build sustainable habits, strengthen resilience, and remind participants that they do not have to navigate life alone.

Through a thoughtful series of live and recorded sessions, participants explored a wide range of wellness topics, led by respected professionals and familiar community leaders. Rick Starks guided participants through Tai Chi and Qigong practices to cultivate inner peace and physical strength. Vanessa Harris shared practical nutrition strategies, healthy eating habits, and simple cooking skills to support everyday well-being.

Douglas Stringham encouraged participants to build momentum through accessible movement and physical activity. Karen Boyd, LMSW, and David Rushlow, LMSW, facilitated Mental Health Rap Sessions, creating space for honest conversation, reflection, and emotional support. Tina Sacchi introduced holistic resilience tools and guided imagery meditation to help participants strengthen their ability to navigate stress and change.

Beyond the lessons, this became an important space for encouragement, shared experiences, and connection. Participants were invited to celebrate small wins, ask questions, and support one another.

Although the live sessions have concluded, the Living Well Lab remains available through B Hub, so community members can access the full course at their own pace. Whether you are looking for practical wellness tools, meaningful connections, or simply a place to begin, the Living Well Lab is here for you whenever the time feels right.

Learning About HYMPAVZI®

By Marta Thomas

The Coalition for Hemophilia B recently hosted a virtual educational session on HYMPAVZI (marstacimab), Pfizer's treatment for individuals with hemophilia A or B.

The session offered community members a chance to learn more about the therapy in a welcoming environment that encouraged questions and discussion.

The presentation was led by Brad Schoenfeld from Pfizer's Hemophilia Advocacy and Community Engagement team. Brad explained that HYMPAVZI is a subcutaneous treatment for individuals ages 12 and older with or without inhibitors. Unlike traditional intravenous therapies, HYMPAVZI is delivered via an injection under the skin, which may offer an alternative for those who have difficulty with vein access.

Participants also learned about the prefilled pen used to administer the treatment and engaged in helpful discussions about treatment use, coexisting conditions, and women with bleeding symptoms.

The session reflected the Coalition for Hemophilia B's continued commitment to providing educational opportunities that support informed decision-making and foster connection within the bleeding disorders community.

Thank you to Pfizer for sponsoring this educational session and for their continued partnership.

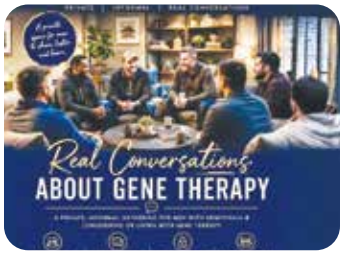
Join Us!
Upcoming Events

For more information and to register, please visit **hemob.org/events**

The Weekly Reset

Every Sunday
12–1:00 pm EST, Virtual
Sponsored by CVS Specialty

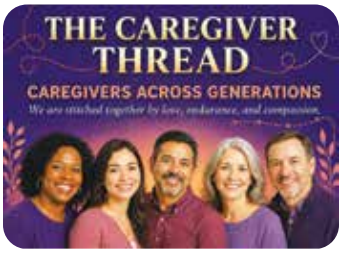
Join Renk Koçtürk in the B-Hub every Sunday for our new ongoing series, featuring practical tools and calming moments designed to help you take care of your mind, body, and soul.



Gene Therapy Support Network

Aug 4, Sept 8, Oct 13,
Nov 10, and Dec 8, 2026
8–9 pm EST, Virtual
Sponsored by CSL

Have had, or are considering gene therapy? Join our private group discussion to share firsthand experiences and have questions answered. Ages 18+. Dinner vouchers provided.



Caregivers Thread

Aug 6, Sept 14,
and Nov 13, 2026
8–9:30 pm EST, Virtual

Introducing The Caregiver Thread, a space for caregivers across generations. Whether you're a parent, partner, or family member, this is a place to connect, share, and feel supported by others who truly understand. What you do matters, and you're not alone.

Innovation Lab

July 29, and
Aug 5, 19, 26, and Sept 2, 2026
8–8:30 pm EST, Virtual
Sponsored by Pfizer

The pace of innovation in hemophilia B has never been greater. From extended half-life therapies and rebalancing agents to gene therapy and emerging treatments there are more options to navigate than ever before! With Dr. David Clark.

Strength in Connection

Sept 22, 2026
8–9 pm EST, Virtual

For ages 50+. Come ready for amazing fun, great trivia, meaningful conversation, and a chance to explore what true strength really means. We'll connect, laugh, learn, and celebrate the power of community. Food vouchers and raffle!

Living B, The Men's Collective

Aug 31, Sept 28,
and Nov 5, 2026
8–9:30 pm EST, Virtual

A space built for men living with hemophilia B and fathers of children with hemophilia B. A supportive conversation where men can share experiences, ask questions, learn from one another, and build meaningful connections.

Meetings on the Road

Sept 12, 2026|Albuquerque, NM
Sept 26, 2026|Salt Lake City, UT
Oct 10, 2026|Portland, OR
Nov 7, 2026|Redondo Beach, CA
Sponsored by CSL

Educational, supportive, and free for all attending community members. Meals will be provided and gas and toll expenses will be reimbursed.

Voices of Her Bloodline

Sept 10, Oct 9, and Nov 16, 2026
8–9:30 pm EST, Virtual

For women living with hemophilia and those still on the journey to diagnosis.

Foro Latino

Sept 24, and Oct 19, 2026
8–9:30 pm EST, Virtual
Sponsored by CSL

Esta serie está diseñada para la comunidad latina de hemofilia B, proporcionando un espacio dedicado a conectar, aprender y discutir temas clave que más te importan.

Women's Education & Empowerment Retreat

Sept 17–20, 2026
Orlando, FL
Sponsored by Pfizer

The Hemophilia B Women's Education & Empowerment Program is an outstanding success for women with hemophilia B, mothers of children with hemophilia B, and partners of affected men. Attendees will benefit from the connections and learn strategies for managing hemophilia B through all life stages. This unique three-day experience offers women a safe space to share their journey and gain support.

Eternal Spirit Award Gala

Oct 14, 2026
New York City

We are excited to hold our 2026 Eternal Spirit Award Gala in New York City!
Airfare and hotel accommodations will be provided for up to three attendees per family. Please apply to attend by September 1st.

Men's Education & Empowerment Retreat

Oct 22–25, 2026
Orlando, FL
Sponsored by Pfizer and Sanofi

The Hemophilia B Men's Education & Empowerment Program is a unique three-day experience where men with hemophilia B, fathers of children with hemophilia B, and partners of women living with hemophilia B are given a safe space to share their journey with others and gain support.
It's a space to connect, laugh, learn, and talk openly with other guys navigating similar experiences in a supportive, judgment-free environment.

Gingerbread House Decorating & Trivia

Dec 5, 2026
4–5:30 pm EST, Virtual
Sponsored by Medexus

Grab your family, bring your creativity, and join us for an afternoon of decorating delicious gingerbread houses, sharing laughter, and enjoying festive games with friends from across our community. Whether you're a frosting artist or a candy-stacking champion, there's fun for everyone!

In Remembrance

Aug 11, 1952 – May 31, 2026
Chillicothe, Ohio

Thomas Edward Allie

We are profoundly saddened by the passing of Tom Allie.

For more than 30 years, we at The Coalition for Hemophilia B have had the privilege of knowing Tom, one of the kindest, most caring, and dedicated individuals we have ever met. He was a steadfast advocate for our community, always ready to lend a hand and offer support.

Tom had an extraordinary ability to make everyone feel valued and welcome. His generosity and compassion touched countless lives, leaving a lasting impact on our community and all who were fortunate enough to know him.

Though he will be deeply missed, Tom's legacy of kindness, service, and friendship will continue to inspire us all. We extend our heartfelt condolences to Tom's wife, Carol, his children, grandchildren, great-grandchildren, extended family, and many friends. May he rest in peace.

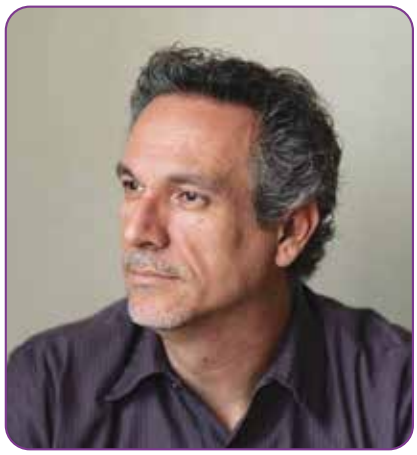
Matthew Todd Compton

We are deeply saddened to share news of Matthew Compton's passing.

Matthew was a well-known and beloved member of the bleeding disorders community. His kindness, friendship, and warm presence touched the lives of so many. His loss is profoundly felt throughout our community. He will be remembered not only as a dedicated member of our community but also as a loving husband, father, son, and friend.

The Coalition for Hemophilia B extends our heartfelt condolences to Matthew's family, friends, and all who had the privilege of knowing him. We hold his loved ones in our thoughts and prayers and hope they find comfort in the countless lives he touched and the cherished memories he leaves behind.

Matthew's impact on our community will never be forgotten. He will be deeply missed by all who knew him. Please keep Matthew's family and loved ones in your thoughts and prayers.



Feb 16, 1971 – June 13, 2026
Queen Creek, Arizona

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

We know that life can present unexpected challenges. Families may face difficult times such as reduced work hours, job loss, unemployment, hospitalization of a loved one, or even unexpected natural disasters. Our Patient Assistance Program was created to support patients and caregivers during these times of need. This program provides emergency funding to help ease the burden of sudden financial hardship.

- The program does not cover medical bills.
- Assistance is intended for urgent, short-term needs that directly affect patients and their families.

We are here to stand beside you when life feels overwhelming, offering help and hope in the moments when it matters most.

The Coalition for Hemophilia B is a national nonprofit serving the hemophilia B community for more than 35 years.

LEARN MORE: https://www.hemob.org/financial-assistance
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For information, contact us at 212-520-8272, contact@hemob.org

Ryan's Next Chapter

By Allyson Kamps

We last featured Ryan in our Winter 2022 article, *"Teen of Many Talents: Ryan."*

A few years ago, sixteen-year-old Ryan, now nineteen, described living with hemophilia B while discovering his passions. His pursuits included chess, woodworking, playing the guitar, and riding motorcycles. When asked what has changed most since then, Ryan laughs before replying, "Everything." In just a few short years, hobbies have given way to emergency calls and a life dedicated to serving his community.

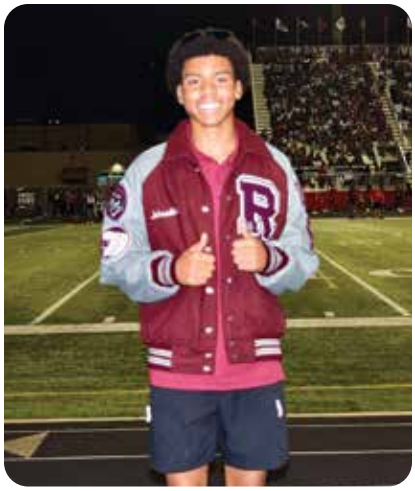
Originally inspired by his father, Ryan now follows in his footsteps by working at his local fire station. He takes pride in being a familiar face in his community and having the opportunity to "help people and actually make a difference." For Ryan, the reward comes from giving back. "It feels good being able to give back to the communities that have given to me," he says. "It's just a good feeling overall." Balancing hemophilia with the responsibilities of his job can sometimes be challenging. Ryan says treatment can "definitely be hard to keep up with," though he has learned to adapt to long shifts and an unpredictable schedule. He also enjoys community events where children can explore the trucks, try on gear, and learn about the department.

His free time is largely consumed by training, truck checks, and calls. While many hobbies have fallen to the wayside, he still makes music a priority. In slow moments at the station, Ryan and his buddies grab a guitar and have jam sessions. "It's a good way to just kind of escape from reality for a second, and let your mind kind of reset," he says. After difficult calls, he and his coworkers sometimes spend hours driving and processing what happened. Even when a call leaves him wondering whether the job is worth it, they always return because "we've got a job to do."

Ryan's commitment to serving others extends beyond Michigan. As a longtime Coalition participant, he values the relationships he has built within the bleeding disorders community, describing them as "very special." He appreciates hearing from members who remember a time before today's treatment options while encouraging children who are still learning to manage their own care. Watching them gain confidence in self-infusion and bleed management has become one of the most rewarding parts of staying involved. Reflecting on his own experiences, Ryan offers encouragement to teens and young adults with hemophilia. "It may challenge your life, but it opens doors for a lot that you never knew existed. It opens the door to people who are always going to be advocates, and it opens the door for a lot of good friendships that'll last a while."

Ryan's life has changed dramatically since his last interview. Although many of his early hobbies have taken a back seat to work, his passion for serving others has remained a central theme in his life. Whether in his hometown or through the Coalition community, Ryan continues to give back to the communities that have given so much to him.

Unstoppable Ambition: Johnathon's Journey



By Allyson Kamps

Johnathon's journey reflects a rare combination of intellect and determination in the face of significant challenges. At 16, he lives with hemophilia B with inhibitors, yet he has continued to grow academically and personally, never allowing circumstance to define his trajectory or limit his ambitions.

From an early age, Johnathon displayed a love of learning and a keen intellect. He skipped pre-K and third grade, too. Entering high school at age eleven meant taking extra precautions to ensure his safety among older peers, which required a level of maturity far beyond his years. He also navigated frequent school absences with profound tenacity. Bleeding episodes, weekly factor infusions at the hospital, and when in school, the cumbersome task of maneuvering a wheelchair down crowded hallways weren't enough to deter him.

These challenges alone would be daunting for any young person, yet Johnathon excelled academically, finishing in the top 25 of his class and scoring a 1510 on the SAT, all while working toward his associate's degree in general studies and steadily advancing his education alongside his high school coursework. The encouragement and support from his four brothers provide a strong foundation at home.

Two years ago, Johnathon discovered his passion for music. While in the hospital, he picked up the drums and guitar, turning what could have been idle time into creative expression. Johnathon soon added the piano and xylophone to his repertoire and is now in four bands, where he continues to refine his technical skill and artistic expression. With eagerness and talent as evident as his, the decision to pursue music seems only natural. After graduation, Johnathon plans to study music at the University of North Texas.

Even as his musical pursuits expanded, Johnathon has balanced them with the demands of managing a bleeding disorder and a rigorous academic workload. Rather than separating these parts of his life, he integrates them into a steady daily routine that requires discipline and adaptability. He approaches every responsibility consistently, maintaining his commitment to both academics and music, even when his health requires unexpected adjustments. This steady dedication reflects a quiet work ethic that shapes his daily life.

Johnathon's journey is defined by academic excellence, strength of character, and an enduring passion for growth. As he looks to the future, he will continue to meet new challenges with the same determination and sense of purpose that have defined his path, drawing on his talents and experiences to make a meaningful, lasting impact.

B inspired!

Stories and artwork from teens in the Hemophilia B Community

Spring 2026

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Meet Johnathon!

Meet Ryan (...again)!

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 mattm@hemob.org for your next steps!