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"ALTUVIIIO® is the right balance for our family."

—Ashley, mom of ALTUVIIIO patient Harrison

Ashley is a promotional speaker compensated by Sanofi.

[See their story](#)



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COMMUNIQUE

For Bleeding Disorders

AUGUST 2025

Welcome

While the current administration continues to cut healthcare services, our bleeding disorder community seems to provide even more. Whether you need medical advice, parenting tips, an in-person meeting, a conference call or news about new products, this community is there for you! Read below to see the many offerings.

Stay safe and hopeful,

Laurie



Events

Choosing HOPE

The 2025 HOPE Conference takes place from November 6-8 in Orlando, Florida. This annual educational event offers people who have bleeding disorders a place to learn, grow and connect. [Learn more here.](#)



Mental Health Mondays!

Join the Coalition for Hemophilia B every week for an ongoing series that features practical tools and

calming moments to help you take care of your mind, body, and soul. Whether you're looking for motivation, stress relief, or a safe space to reset, these weekly sessions will help you begin your week right, with compassion, clarity, and community. Join live or watch on replay exclusively in the B Education Hub. Every Monday from 1-2:00 pm EST. [Learn more here.](#)



Gen IX Leadership Project

The Generation IX Leadership Project is a call to action for young adults who have hemophilia B and want to put their skills to the test in an immersive leadership program. All selected applicants will receive a travel scholarship that includes airfare or mileage, lodging, and meals provided as part of the official event agenda. November 7-9. [Apply here.](#)



Inhibitor Families Unite!

Plan to attend InhibitCon West, October 3-5, in Portland, Oregon. InhibitCon is a CHES Foundation program with three distinct tracks designed for the inhibitor community: Caregiver, Adult Men, teens and kids. The adult track will keep CHES' long standing "Momentum" inhibitor program intact. This weekend program is packed with education and support. Open to individuals under 18 with an adult caregiver and two additional immediate family members (such as another parent and sibling active in care), and adults ages 18 and over with a caregiver, significant other or spouse. [Register here.](#)



Resources

ABCs and IEPs

Students with bleeding disorders may qualify for an Individualized Education Program (IEP). With an IEP, and depending on students' needs, a school district may be required to provide these services: specialized instruction, accommodations and

modifications to the curriculum, adaptive equipment or assistive technology devices, a classroom aide, assistance with health-related needs, school transportation, or other related services. [Learn more here.](#)



By and For Females

By Females for Females (BFFF) is open to any female or those who identify as a female who are 19 years or older. BFFF welcomes the experience, knowledge and shared space that this group is fostering from females of all ages! [Sign up for BFFF news and events here.](#)



How to Educate the Educators?

You can best explain your child's bleeding disorder to his or her teachers with this great, customized guide from Hemophilia Resources of America. [Download it in time for the start of school!](#)



Gene Therapy Rap Sessions

If you're considering gene therapy or have already received it, the Coalition for Hemophilia B invites you to join a private group discussion with a member of the hemophilia B community. They will share firsthand experiences and answer questions. Dinner vouchers will be provided. For men with hemophilia B over 18. The next one is August 26. [Sign up here.](#)

Scientific

First Participant Dosed in BeCoMe-9 Trial of BE-101

Beigene Biopharma announced that a first participant was dosed in the BeCoMe-9 Trial of BE-101 for hemophilia B. BE-101 is a first-in-class, engineered to insert the human factor IX (FIX) gene into primary human B cells for the treatment of hemophilia B. BE-101 aims to offer a transformative new therapeutic option by delivering long-lasting FIX levels, with the flexibility to be titratable and re-dosable, and without the need for preconditioning. [Click here for more information.](#)

Advocacy

The Not-So-Affordable Care Act?

Americans may see monthly premiums jump an average of 75% next year according to the Kaiser Family Foundation. Rises are due to the end of COVID-era subsidies, which began under the Biden administration, which helped the ACA more than double the amount of enrollments, to a record 24 million people according to NPR.org.



Medical

Alhemo Approved for Patients 12 and Older

The U.S. Food and Drug Administration (FDA) has approved Alhemo (concizumab-mtci) injection (60 mg, 150 mg, or 300 mg) as a once-daily prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and adolescents (12 years and older) with hemophilia A or B (HA/HB) without inhibitors. It is not known if Alhemo® is safe and effective in people receiving ongoing immune tolerance induction (ITI) or in children younger than 12 years of age. This new indication builds on the December 2024 approval of Alhemo® for HA/HB patients with inhibitors. [Click here for more information.](#)

HemaBlog

Words of Wisdom

When times are tough, when TV news is devastating, when social media has us distracted and angry.... it's good to hear comforting, uplifting words. Especially when these words come from someone who knows something about pain, suffering and hope, like Matt Barkdull. [Read more here.](#)



World

Maximum Impact: Operation for Peter

Peter H., a hemophilia A patient who lives in Uganda, says his “dream has come true today.” Our program pledged financial support for a prosthetic knee replacement. “I lost what to say for the moment after seeing your email because this is beyond my expectations from someone I have



never met. I have seen tears coming out of eyes which I can't control because of the joy I have in my heart. I had lost hope asking myself where will I get such a huge sum of money for my operations? This is a miracle God has done for me through you. May God bless you and Madam Agnes [president of the Haemophilia Foundation of Uganda] for bringing joy in my life.”

In Case You Haven't Heard...

- Iron deficiency is an under-diagnosed, under-appreciated concern for many women and girls with bleeding disorders.
 - Recent research has shown that saliva contains tiny particles that promote clotting.
 - Both hemophilia A and B are associated with reduced bone mineral density (BMD).
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