



CELEBRATING 10 YEARS OF
TRUST WITH ALPROLIX®

[Learn more here >](#)

ALPROLIX®
[Coagulation Factor IX
(Recombinant), Fc Fusion Protein]

MAT-US-2401648-v1.0-03/2024

LA KELLEY
communications, inc.

COMMUNIQUE

For Bleeding Disorders

MAY 2024

Welcome

Our first quarter saw astounding factor donations—400,000 IU of factor VIII and IX, all shipped out free of charge to patients in developing countries. The Philippines and Vietnam were our biggest recipients of aid.

I call this program **Maximum Impact**, because that's what it offers: a program with no overhead, no employees and no fundraising ... making the biggest impact on patients' lives. See below what else we offer through this program!



Stay safe and hopeful,

Laurie

Events

Inhibitor Conference

August 2-4. Houston Airport Marriott.
"InhibitCon" is a new Comprehensive Hemophilia Education Services (CHES) program with three distinct tracks

designed for the inhibitor community: Caregiver, Adult Men and Tweens/Teens. The adult track will incorporate CHES's long standing Momentum inhibitor program. This weekend program is packed full of education and support! InhibitCon is open to children (12-17) and their adult caregiver, and adults ages 18+ with an active inhibitor. Topics include treatment products, health insurance changes, mental health support, techniques for continued venous access health, pain management and more.

[Register here.](#)

InhibitCon™
CHES FOUNDATION

National Bleeding Disorder Meeting

September 12-14. Georgia World Congress Center, Atlanta. NBDF is hosting its 76th Annual Bleeding Disorders Conference (BDC). Join your community for three incredible days of educational sessions, valuable networking opportunities, and exciting exhibits. [Learn more here.](#)



Inhibitor Camp Registration Open

Register for “After the Shock”!. See if your child age 0-18 with hemophilia and an active inhibitor are qualified to attend this fabulous family camp from June 21-24. Funding provided for those selected to attend. [Learn more here.](#)



Resources

Be Social!

Our advocacy groups have many social media platforms. Try these for the Coalition for Hemophilia B:

YouTube: https://www.youtube.com/channel/UCw23ySDhKaLRM_Ic6zETJaw

X (Twitter): <https://twitter.com/CoalitionHemoB>

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

Facebook: <https://www.facebook.com/HemophiliaB>

Instagram: <https://www.instagram.com/coalitionforhemophiliab/>



VWD Emergency Care Manual in Spanish

Emergency Care for Patients with von Willebrand Disease is a treatment manual now available in Spanish. *Cuidado de Emergencia a Pacientes* is for emergency department staff who are not familiar in the treatment and management of von Willebrand disease (VWD). [Click here to order.](#)

Hemophilia Fast Facts

NBDF's announces the availability of a Hemophilia Fact Sheet. This two-page

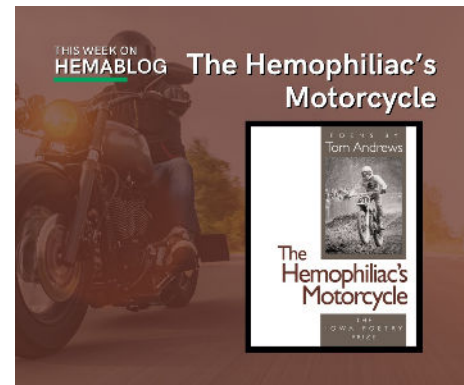
PDF document was created to fill the need for a current, accessible resource containing basic information about hemophilia. It can be used as an introductory resource for individuals and family members new to hemophilia or to help educate personnel at schools or in childcare settings. The document can also be used to aid outreach efforts by chapters in local communities.

[Download a copy here.](#)

HemaBlog

Poetry and Hemophilia

April was National Poetry Month: read our two blogs to learn about famous poets in the hemophilia community. [Read here.](#)



Advocacy

Privacy Please!

Patient privacy continues to be a huge concern worldwide, especially in the healthcare field, and especially online. The states of Washington, Nevada, and Connecticut have passed strict patient privacy laws recently, that go into effect in June for small businesses. Patients cannot passively receive ads and notifications from third parties, without the express permission of the patient. These new laws also address the collection, sharing, and selling of consumer health data. Due to these new laws, all patients on the LA Kelley Communications mailing list from these states have been removed. [Review Washington State's privacy bill as an example here.](#)



Extended Time for Coverage from CMS

HFA reports that the Centers for Medicare and Medicaid Services (CMS) has formally extended the special enrollment period (SEP) created during the COVID-19 “unwinding”, allowing people who lose Medicaid/CHIP coverage 60 days to transition to coverage through the Affordable Care Act Marketplace. This was set to expire on July 31 but CMS has agreed to postpone the expiration until November 30. This is due to states helping to promote continuity of coverage, minimizing wrongful terminations, and other state-specific situations. [Read more here.](#)

Medical

Does Your HTC Administer Gene Therapy?

Not every HTC administers gene therapy. CSL Behring has updated their website so that patients can locate HTC's that have its gene therapy treatment, Hemgenix, available. This tracker is updated on a weekly basis as the company continues to train more and more sites. [Go here.](#)



Ixinity for All

Medexus Pharmaceuticals has received FDA approval for their hemophilia B treatment, Ixinity®, for children under 12. This approval, based on positive Phase 3/4 study results, allows the use of Ixinity® for prophylaxis and management of bleeding episodes in pediatric patients, offering hope for improved quality of life for affected children. [Read about it here.](#)

Science

More Gene Therapy Trials from New Players

ReciBioPharm and GeneVentiv Therapeutics are developing GENV-HEM, a gene therapy for hemophilia patients, including those with inhibitors. ReciBioPharm will help GeneVentiv take GENV-HEM from preclinical development to Phase 1/2 clinical testing. A one-time infusion, GENV-HEM is designed to deliver a gene coding for activated clotting factor V, through an adeno-associated virus 8 (AAV8), which has been modified to not cause disease in humans. In preclinical studies, GENV-HEM safely and effectively prevented bleeding in hemophilia animal models, regardless of the presence of inhibitors. In November 2021, GENV-HEM was granted orphan drug designation by the US FDA for hemophilia A and B, with or without inhibitors. [Read more here.](#)

And from Familiar Players: Pfizer

Pfizer Inc. announced that its gene therapy Beqvez (fidanacogene elaparvovec-dzkt) has been approved by the US FDA for treating adults with moderate to severe hemophilia B who undergo regular prophylaxis and are facing a current life-threatening bleed. The company indicated that the FDA's decision was influenced by data from the BENEGENE-2 trial, a Phase 3 study that investigated the efficacy and safety of Beqvez in adult males between 18 and 65 years old with moderately severe to severe hemophilia B. [Read more here.](#)

World

Maximum Impact: Surgeries

We're dedicated to helping those with bleeding disorders overseas get the surgeries they need. In March, LA Kelley Communications funded surgery for Amitava Chatterjee from Durgarpur, India. He had been suffering with pain in his abdomen since June 2023, and despite regular infusions of factor, donated by his local hemophilia chapter, still suffered. In January 2024, the pain was intense, and tests revealed a pseudotumor in the lower abdomen. It was a life and death situation; surgery, which he could not afford, was \$5,000—a fortune in India. With our help and the expertise at Christian Medical Center Vellore, India, Amitava had his surgery and is recovering well now!



World Hemophilia Day

April 17 is World Hemophilia Day and is celebrated around the world, to increase awareness of treatment inequities, especially in countries where treatment is difficult to obtain. On April 18, World Hemophilia Day was observed in the Kurdistan region at the GIN Blood Centre in Duhok, Iraq. Many children with blood diseases enjoyed fun activities and were handed gifts and toys. [See more photos here.](#)



Iran Makes Factor

An Iranian company has succeeded in producing “Coageight” for hemophilia patients in Iran, which suffers from shortages of factor products. Coageight is considered a second source of production. Ahmad Qavidel, an advisor to the managing-director of Iran’s hemophilia center, reported that the Iranian Food and Drug Organization has promised to import 10% to 15% of hemophilia patients’ needs.



In Case You Haven't Heard...

- National Bleeding Disorders Foundation’s website is change from Hemophilia.org to Bleeding.org
- You can attend virtual programs for inhibitor patients [here](#).
- Download a fact sheet about gene therapy [here](#).



LA Kelley Communications, Inc. | PO Box 846, Georgetown, MA 01833

[Unsubscribe amanda@kelleycom.com](#)

[Update Profile](#) | [Constant Contact Data Notice](#)

Sent by laurie@kelleycom.com powered by



Try email marketing for free today!