



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

JULY 2025

Welcome

It's hard to keep up with the whip-snapping policy changes in Washington DC that could very well impact your healthcare coverage. More than ever, you must read and research, starting with your own healthcare policy. Don't wait until Medicaid, Medicare and Marketplace changes hit you in November or early next year. Contact your HTC social worker, your specialty pharmacy rep, your insurance company and most of all, your state and national bleeding disorder groups. I've listed some resources below.

Get going! The future is coming fast, and it could be a bit dystopian, unless we act.

Stay safe and hopeful,

Laurie



Events

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](#).

And Then Drop In!

One-Drop is a conference dedicated to the smaller subsets of the ultra-rare or orphan bleeding disorders community. Since 2012, the Factor 7 Retreat (for individuals and families with factor VII deficiency), and later followed by the Glanzmann's Thrombasthenia Symposia, have both offered program experiences for those with rare bleeding disorders. This year's conference will be held November 14-16, in Tampa, Florida. [Register here](#).

Have HOPE

The 2025 HOPE Conference takes places 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](#).



Resources

HemoLife Podcast

This podcast, hosted by L.A. Aguayo, a man with hemophilia who is an elite body builder, encourages conversations among members of the community to inspire and motivate. In the podcast "Bloodlines and Breakthroughs: Two Brothers, One Mindset," two brothers come together to share their unique perspectives on growing up in a family affected by hemophilia, exploring how their different paths led them to similar life philosophies and purposes. [Listen here](#).



PBM Podcast

Listen to a podcast on the power of PBM—pharmacy benefit managers. First exposed in LA Kelley Communications' issue of PEN in 2005, this



podcast updates how PBM's power has strengthened, affecting choice of product and factor delivery provider. The podcast features Dr. Mattie Feldman. [Watch here.](#)

Know Your Patient Assistance Programs

There are a great range of programs that offer financial assistance and factor for qualified patients. Co-pay assistance, free factor, scholarships and hotlines for help, listed by manufacturer. [Read more here.](#)

Scientific

Prophy Treatment Research is Promising

Roche announced positive data from its Phase I/II NXTAGE trial of NXT007, a next-generation investigational therapy intended as a prophylactic treatment option for persons with hemophilia A. Their findings were presented at the International Society on Thrombosis and Haemostasis (ISTH) Congress in Washington, D.C. NXT007 is a bispecific antibody derived from Roche's Hemlibra that similarly mimics the action of factor VIII by bridging activated factor IXa and factor X, but has been engineered by Roche group member CHUGAI to optimize factor VIII mimetic activity and half-life, with the goal of enhancing potency while reducing required dosing frequency.

Advocacy

Beware Healthcare

The Coalition for Hemophilia B has summarized threats to healthcare from the current administration. What's at risk? Currently, more than 24 million Americans—including those with chronic and rare conditions—pay less for monthly insurance premiums. These benefits are set to expire for 2026, if Congress doesn't reauthorize them by September 30. This will mean huge increases in premiums for many families. Some people will be forced to drop coverage altogether—especially in states that didn't expand Medicaid. If nothing changes by November 1, when Open Enrollment starts, families will see higher prices and fewer affordable options. The Coalition urges families to contact their members of Congress at once, and tell them to renew the enhanced premium tax credits before Sept. 30 so families don't lose affordable health care. [Read more here.](#)



HemaBlog

A Tireless Giant, Now at Rest

Dr. Carol Kasper was both a giant and an angel to thousands in the bleeding disorder community, especially to those with von Willebrand disease. Dr. Kasper served as vice president, medical, of the World Federation of Hemophilia (WFH) in the 1990s, and according to the WFH, “she played a pivotal role during a transformative era—guiding strategy, expanding global programs, and deepening the organization’s commitment to care and access for all.” She was a respected hematologist and director of the hemophilia program at Orthopaedic Hospital, in Los Angeles. Dr. Kasper passed away at age 89.

[Read more about her legacy here.](#)



World

Donations Pour In

LA Kelley Communications’ Maximum Impact Program donated 2,083,600 IU of factor VIII and IX, 221 mg of inhibitor medicine, and 24 mg of Hemlibra in the second quarter of 2025, altogether worth a conservative estimate of \$5 million. All donated products are shipped free of charge to patients, hospitals and nonprofits in developing countries, with the majority going to the Philippines, Pakistan and Vietnam.



In Case You Haven't Heard...

- Takeda's Hemofil® M is discontinued and will no longer be manufactured; inventory is expected to last till mid-2026.
 - Blood-clotting products remain among the highest cost of all drugs.
 - You can download a chart showing all factor and other therapies at www.kelleycom.com
-



LA Kelley Communications, Inc.
21 Sawmill Way, Georgetown, MA 01833

You are receiving this email because you signed up for information from LA Kelley Communications, Inc. updates. If you no longer wish to receive these emails, you can [unsubscribe here](#).

[View as a Web Page](#)