

There are ways to help you

AFFORD YOUR HEMOPHILIA A MEDICINE.

**LEARN
MORE >**



COMMUNIQUE

For Bleeding Disorders

MAY 2023

Welcome

New products, gene therapy... the United States is awash in factor. Indeed, we are the engine that drives the hemophilia world. With so many changes, patients and families are looking to donate the factor they no longer need or want. Do you know where to donate it? Read below to find out!

Stay safe and hopeful,

Laurie



Opportunity

Register for Our Paid Surveys

LA Kelley Communications has partnered with MedPanel, Inc., a full service market recruitment agency specializing in chronic diseases and disorders to conduct paid surveys, interviews and focus groups to learn what bleeding disorder patients experience. If you haven't already, register now to take advantage of our paid surveys, ongoing. Email: laurie@kelleycom.com



Events

Hemophilia B on the Road!

The Coalition for Hemophilia B is taking its meetings to you! Learn about new treatments and connect

with other families. In June, meetings take place in Boston, Indianapolis, Birmingham, Salt Lake City and Rochester. [Sign up here.](#)

2023 MEETINGS ON THE ROAD!
FUN - ENGAGING - INTERACTIVE - NEW SPEAKERS

THE COLLABORATION OF HEMOPHILIA

DATES & LOCATIONS

- JUNE 3: INDIANAPOLIS, IN & BIRMINGHAM, AL
- JUNE 10: BOSTON, MA
- JUNE 24: ROCHESTER, NY & SALT LAKE CITY, UT
- SEPTEMBER 16: AUSTIN, TX
- SEPTEMBER 23: CLEVELAND, OH & CONCORD, CA
- OCTOBER 7: PHILADELPHIA, PA
- OCTOBER 14: NEW ORLEANS, LA
- NOVEMBER 4: PHOENIX, AZ, MIAMI, FL & MILWAUKEE, WI

TOGETHER WITH NEIGHBORING STATES!

THE MEETINGS ARE FREE, BUT YOU MUST REGISTER NOW!
HEMO.ORG/UPCOMING-EVENTS/

- GAS AND TOLLS REIMBURSED | CHILDCARE | KID/TEEN TRIP
- APPLY FOR A HOTEL NIGHT IF MORE THAN 3 HOUR DRIVE

Questions? Email Erica at contact@hemob.org or call 212.520.6272

Gain Momentum in Atlanta!

Momentum brings together adult male members of the inhibitor community ages 18+ for a weekend of education and community building. Topics include: vocational and career planning, ACA/health insurance changes, techniques for continued venous access health, pain management-traditional and complimentary strategies. July 28-30, Westin Atlanta Airport.

[Register here.](#)



Programs

Self-Infusion: Independence, Flexibility, and Control

Attend a complimentary live webinar to learn about self-infusion: reasons why, the benefits and how to. June 22, 8 pm EST. Sponsored by Octapharma.

[Register here.](#)



Resources

Kevin Child Scholarships: Apply Now!

NHF offers the Kevin Child scholarship, which awards \$1,000 to a U.S. student with hemophilia A or B who aspires to attend college or vocational school, to a matriculating college/univ/vocational student, or to an eligible individual in pursuit of a post-secondary degree. Deadline: June 1! [Apply here.](#)



Is donating plasma safe when you have hemophilia?

Plasma fully regenerates in the body within 48 hours. When you have a bleeding disorder, you will need to donate in a special Source Plasma Licensed facility. [Read more about this fascinating topic here.](#)



HemaBlog

Waste Not!

What to do with factor you no longer need? Perhaps you switched brands, or received too much factor and cannot use it; wrong dosage size? Doesn't work? You can donate it. In two months, we already received 2 million IU from families, HTC's and pharmacies. Contact us first, to see if yours qualifies for a donation. [Read here](#) to learn how we find homes for this factor in developing countries.



Advocacy

NHF: 75 Years of Advocacy

National Hemophilia Foundation is celebrating its 75th anniversary this year. This article examines its amazing history of advocating for the bleeding disorder community. Building strength chapter by chapter, advocating for HTC funding, compensation for HIV infections, skilled nursing facilities and more. [Read more here.](#)

Medicaid and CHIP Eligibility Reviews

It's important that you respond promptly if you received notice about your eligibility for Medicaid and CHIP. *States may initiate coverage terminations with some starting as early as April 1, for people who don't respond or who are no longer eligible for coverage.* Act today! [For more info visit here.](#)

Medical

Clinical Trial Needs More Women

The PREDICT clinical trial examines better ways to treat people with hemophilia A, and needs female participants. The study examines how well a new scoring approach works to select a treatment plan for the prevention of bleeding in people with hemophilia A who switch their treatment from standard half-life products to Jivi®. Different types of information will be used to calculate the risk score like bleeding history, certain biological factors, or physical activity of the participant. All participants will receive Jivi for six months. [For more info click here.](#)

The Low Cost of Being Female with a Bleeding Disorder?

Female hemophilia A patients and carriers have more frequent bleeds than males, yet a smaller proportion receive factor to prevent or stop them, a U.S. study finds. The medical and pharmacy costs for women with hemophilia A or carriers were up to about 14 times lower than men, perhaps meaning they are undertreated. Study results were reported in “Real-world analysis of patients with hemophilia A and hemophilia A carriers in the United States: Demographics, clinical characteristics and costs,” in *Haemophilia*. [Read here.](#)



World

May's Child

Muni Samy is seven years old and lives in Maduri, India. His birthday is September 29. He has severe hemophilia A. His parents only earn about \$50 a month! For only \$35 a month, you can change his life! [To sponsor him click here.](#)



Just in Case You Haven't Heard...

- In medical terms, how frequently a person bleeds is referred to as their bleeding phenotype.
- Unlike factor IX levels, factor VIII levels vary and are affected by some hormones: factor VIII levels rise in pregnant women, when a person is scared or stressed, or after vigorous exercise.
- Hemophilia B is also called Christmas disease, named after Stephen

Christmas, a 10-year-old boy from England who in 1952 was the first person to be diagnosed with hemophilia B.

LA Kelley Communications, Inc.

kelleycom.com

