

Why Esperoct®?

Find out now



esperoct®
antihemophilic factor (recombinant),
glycopegylated-exei



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LA KELLEY
communications, inc.

COMMUNIQUE

For Bleeding Disorders

NOVEMBER 2024

Welcome

Almost twenty years ago we warned the bleeding disorder community about startling changes that were coming regarding insurance costs and coverage in our PEN 2005 article “The Coming Storm.” PBM dominance, increasing out-of-pocket costs and restricted choice... it all came true. Now we face more challenges: the benefits we achieved with the Affordable Care Act (ACA)—“Obamacare”—may be threatened as the incoming administration seeks to cut government benefits and support businesses. And bleeding disorders are a business.



Now is the time to read: articles, books, newsletters. Now is the time to contact your HTC social worker, your local bleeding disorder organization, your peers, to learn what they think, anticipate, and even fear. What could be at risk? How will it affect you? While I have no specific predictions, I will say change is coming. Be prepared.

Stay safe and hopeful,

Laurie

Events

Woman’s Education & Empowerment Program

The Coalition for Hemophilia B’s Women’s Education and Empowerment Program provides vital support and resources to

women with hemophilia B, mothers of children with hemophilia B, and their spouses, fostering empowerment and education for all. It's a unique two-day online experience, during which women have a safe space to share their experiences and get support. December 6- 8, 2024. [Apply here.](#)



DEADLINE TO REGISTER: NOVEMBER 15

VIRTUAL WOMEN'S EDUCATION & EMPOWERMENT PROGRAM

CHIT CHAT & CHOCOLATE

ALL NEW SPEAKERS!

POCKETBOOK BINGO

DECEMBER 6-8, 2024
HEMOB.ORG/UPCOMING-EVENTS

THE COALITION FOR HEMOPHILIA B **sanofi**

Family Meetings on the Road

Join hemophilia B community members for the Coalition for Hemophilia B's 2025 Family Meetings on the Road. These events will take place nationwide and may be held close to you. These are free for all hemo B families and patients who attend. Gas and toll expenses will be reimbursed, and meals will be provided. There are field trips for tweens and teens in every city, as well as a childcare playroom for babies, toddlers, and young children. The first one in the new year is February 1, 2025, in Birmingham, Alabama. [For more info click here.](#)



SIGN UP TODAY!

MEETINGS ON THE ROAD

WE ARE TRAVELING NEAR & FAR TO COME SEE YOU!

DISTANCE WILL NEVER BE AN OBSTACLE FOR US TO SEE OUR MEMBERS!

B EMPOWERED

FEBRUARY 1: BIRMINGHAM, AL
REGISTER BY JAN 20: HEMOB.ORG/MEETINGS-ON-THE-ROAD

WE HAVE EXCITING NEW PROGRAMS FOR OUR FAMILY MEETINGS ON THE ROAD

Partnership with Purpose
CSL Behring **THE COALITION FOR HEMOPHILIA B**
Biotherapies for Life™

Resources

B Informed!

For thirty years, the Coalition for Hemophilia B has improved the quality of life for people with hemophilia B and their families through education, empowerment, advocacy, and outreach. Their programs bring patients with hemophilia B together from all over the US, connecting with a common bond and empowering them to gain support, lifetime friends, and the knowledge needed to make important life decisions and to act as advocates on their behalf. [Download its semiannual newsletter](#) to stay informed.



THE COALITION FOR HEMOPHILIA B

HEMOPHILIA B NEWS

NATIONAL NONPROFIT ORGANIZATION SUMMER 2024

BEATS MUSIC PROGRAM

MEN'S EDUCATION & EMPOWERMENT PROGRAM

Community Strong!

THE BEATS GO ON

MEN'S EDUCATION & EMPOWERMENT

THERESA'S BATTLE, PERSEVERANCE & WORDS OF WISDOM

PRODUCT LANDSCAPE

DAD

HemaBlog

Angelo's Story

Responding to our blog about autobiographies, Angelo, a young man from the Philippines, felt compelled to share his story. Factor VIII deficiency, inhibitors, poverty and no access to factor for treatment in a country that does not provide government assistance—these are only some of the challenges Angelo has faced. [Read who has helped him on his journey.](#)



Advocacy

New Video Series: Voices for Policy Change

Voices for Policy Change is a video series created by the National Bleeding Disorders Foundation (NBDF) designed to educate, empower, and mobilize the community and individuals on important legislative issues related to bleeding disorders advocacy, providing a one-stop destination for learning and action. View dozens of videos from community members, advocates and HTC providers on advocacy initiatives such as copay accumulators, HTCs, and advocacy tips. [View here.](#)

Step by Step Advocacy Playbook

The Bleeding Disorders Substance Use & Mental Health Access Coalition (BD SUMHAC) launched its State Advocacy Program to identify a state champion for the bleeding disorders community within state governments, to assess the regulatory landscape and to develop next steps for advocacy within that state. This resource provides in-depth insights into the advocacy efforts within five selected states, along with a step-by-step guide and specific recommendations for future state advocacy work in other states. The guide will help advocates effectively engage with state agencies, overcome regulatory barriers, and achieve their advocacy goals. [Read more here.](#)



Medical

FDA Approves Hympavzi™

The US FDA has approved Pfizer's Hympavzi (marstacimab-hncq) for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and pediatric patients ages twelve and older with hemophilia A or B without inhibitors. Hympavzi is the first once-weekly subcutaneous prophylactic treatment for eligible people with hemophilia B, and the first to be administered via a pre-filled pen or syringe for eligible people living with hemophilia A or B.

[Read more here.](#)

Get the Facts on SevenFact

Inhibitors are a grave complication of hemophilia. Sevenfact® is a bypassing agent used to treat bleeding in FVIII and IX patients with inhibitors. An article published in *Haemophilia* ("Real-world effectiveness of eptacog beta in patients with haemophilia and inhibitors: A multi-institutional case series") found Sevenfact safe and effective at stopping bleeds, according to real-world data from a study in the U.S. Sevenfact is made using genetically engineered rabbits, that have a gene that provides instructions for making human factor seven (FVII) in their mammary glands. The clotting protein is secreted into their milk, and then converted to activated FVIIa. Despite its name, Sevenfact is not indicated for use in congenital FVII deficiency. [For more info read here.](#)



World

Maximum Impact: New Knee in Nepal

LA Kelley Communications is dedicated to helping those with bleeding disorders in developing countries get the direct help they need to improve the quality of their lives. In addition to providing free factor, we also fund surgeries and prosthetics when possible. This month we are funding knee replacement surgery for Monsoon, a young man with hemophilia A in Nepal. We wish him good luck!



In Case You Haven't Heard...

- Rep. Ritchie Torres (D-NY) and Rep. Roger Williams (R-TX) joined the cosponsor list for the HELP Copays Act (HR 830), bringing the total number of House cosponsors to 141.
- NBDF's Washington Days will be held March 5-7, 2025 in Washington DC.

- The US Department of the Treasury reports that fifty million Americans have been covered through the Affordable Care Act health insurance marketplaces since 2014.

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