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For Bleeding Disorders

Welcome

Now more than ever, you need to stay on top of the news in bleeding disorders. With the advent of gene therapy, you might think all our problems are solved. But not so. There's great news, including more gene therapy products in the pipeline, and even more standard factor therapies coming in with increased benefits.

Where to go for all this info? *The Communiqué* (now in its 17th year!) is one place to start. But you must take action: click through, read, discover, go to meetings, talk to people, listen to podcasts, register with your state and national bleeding disorder organizations. Health care coverage is never a guarantee in the US; policies are changing constantly. The good news is that new products are coming that will increase our choices of therapies, and we have probably the best advocacy group in history to help you help yourself.



Stay safe and hopeful,

Laurie

Events

Plan Soon to Attend SeaWorld and HFA!

Come see Hemophilia Federation of America! Join friends, family and experts in the bleeding disorder community in person at SeaWorld, Florida, April 13-15, 2023. For more info, [go here](#).



What's Happening NOW?

The 2023 Spring National Outreach for von Willebrand will be in person April 21- 23 in Phoenix Arizona. While registration has closed, you can still sign up for the wait list. For more info, [go here](#).

The time is...



Programs

Podcast: Interview with Dr. Stephen Pipe on Hemgenix

Recognized hemophilia expert Dr. Steven Pipe discusses the first gene therapy approved for hemophilia B, HEMGENIX, on Bloodstream. As the lead investigator of the HEMGENIX trial, Dr. Pipe details what patients need to know about HEMGENIX and what questions to consider when speaking with their hematologist. A must listen episode! [Go here.](#)



Factor My Way Webinars

Some excellent webinars on hemophilia and VWD are taking place this year. These live webinars include a Q&A with the guest expert. The next one is **February 28** so hurry! Sponsored by Octapharma. [Register here.](#)



Resources

Sing a Long!

My First Factor Song is an adorable sing-along song to the tune of the French song “Alouette.” It’s about what to do when you get an infusion. Lyrics by hemophilia parent Carri Nease. [Download it for free here.](#)



HemaBlog

Bulletproof Your Target Joint

You can help prevent bleeds and future joint damage by following Dr. Michael Zolonitsky’s excellent advice. Mike is a person with hemophilia, and a physical therapist. [For more info, go here.](#)



Advocacy

DC is the Place to Be!

Washington Days is in-person this March. This important event allows our community to share advocacy needs with elected officials. Registration for this event is closed, but you can follow results of our community advocacy on NHF’s and HFA’s website, as well as on your state’s bleeding disorder website.



What the Health?

The bleeding disorder community is always monitoring policy changes that may affect reimbursement and healthcare coverage. A podcast and its transcription posted by Kaiser Health Foundation analyses the State of the Union address for changes in health care policy. [For more info, go here.](#)

Medical

FDA Proposes Blood Donation Policy

The US FDA announced proposed changes to national blood and plasma donation policies. If approved, the policy would eliminate time-based donation deferrals for men who have sex with men. Revised donor history questionnaires would ask all donors, regardless of gender, about risks, designed to reduce the risk of transfusion of blood-borne viruses. [For more info, go here.](#)

World

February's Child

Each month we will feature a child in need of sponsorship. Padmesh lives in India, has severe hemophilia A, loves science and hopes to own his own farm someday. If you or someone you know would like to help this future farmer, [visit here](#).



Donating Factor

Project SHARE (operated by Save One Life) donates factor to patients in developing countries. Donations are used to save lives and limbs threatened by uncontrolled bleeding. In 2022, SHARE shipped over 7 million IU of factor to 28 developing countries. For more info, email share@saveonelife.net

Just in Case You Haven't Heard...

- “The inhibitor” and “inhibitors” are often used interchangeably. Inhibitors are antibodies that the body produces to infused factor; a person can also be said to have an inhibitor to factor VIII or IX.
 - Report negative side effects of prescription drugs to the FDA by visiting www.fda.gov/medwatch or calling 1-800-FDA-1088.
 - Tennessee posts the names and photos of people arrested for alleged Medicaid fraud on a government website and social media. Some people even wind up on a “most wanted” list.
 - The first gene therapy for adults with hemophilia B —Hemgenix (*etranacogene dezaparvovec*)— is commercially available.
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