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ADVATE[®] is right for you

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ADVATE
[Antihemophilic Factor (Recombinant)]

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LA KELLEY
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COMMUNIQUE

For Bleeding Disorders

MARCH 2023

Welcome

March is Bleeding Disorder Awareness Month! This has been observed each March since 2016, after being officially designated by the U.S. Department of Health and Human Services. BDAM helps to increase public awareness of inherited bleeding disorders.

Originally, March was known “Hemophilia Awareness Month” when designated by President Ronald Reagan in March 1986. How did we get this designation? It’s thanks to the persistent and dedicated lobbying efforts of many people in our community, to whom we are grateful!



Stay safe and hopeful,

Laurie

Events

One Last Reminder!

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



And Plenty of Time to Register Here

The 75th Annual Bleeding Disorders Conference (BDC) of the National Hemophilia Foundation (NHF) will take place from August 17 to 19, 2023 at the Gaylord National Resort & Convention Center in National Harbor, Maryland.

[Register here](#).



Celebrate World Day!

World Hemophilia Day is April 17, the birth date of founder and American Frank Schnabel. Contact your local hemophilia organization to learn how you can participate in person. For online activities and events, [visit here](#).



Programs

Podcast: Gene Therapy

Listen to a series of podcasts explaining gene therapy in hemophilia. With gene therapy now a reality, these podcasts can teach you more about therapy options in your future. [Subscribe here.](#)



Factor My Way Webinar

Attend the “Iron Deficiency and Bleeding Disorders” complimentary webinar, covering the essential role of iron in health, and the relationship between heavy bleeding, iron deficiency and anemia. It’s followed by a live Q&A session hosted by Octapharma resident hematologist Dr. Claudio Sandoval. **April 6.** [Register here.](#)



Inhibitor Camp!

If your child has hemophilia and an inhibitor, or if you are a woman with a bleeding disorder, or ultrarare factor or platelet deficiency disorder, register for camp! “After the Shock: Inhibitor Camp” will take place June 23-26, 2023 for children *and* their families; funding available. [Register here.](#)



Cannabis: 10 Things to Know

Join a webinar on April 26 at 2 pm to learn how cannabis may help with hemophilia pain. [Register here.](#)



Resources

Scholarship Season!

This is the time to apply for college scholarships for September. LA Kelley Communications had the first ever online listing of scholarships and it’s one of our most-visited pages. [Apply for as many as you can here.](#)



HemaBlog

Pandora’s Box of Myths

During Bleeding Disorder Awareness Month, it’s a good time to help clear up misconceptions of hemophilia. What are some myths associated with hemophilia—and what’s the truth? [Read here.](#)



Advocacy

Your Voice Counts

Your voice is at the center of NHF's Community Voice Registry (CVR). This community-powered registry will help researchers understand what it really means to live with a bleeding disorder and how current treatments, therapies, and policies affect the community. CVR will collect information from people with bleeding disorders, their parents, siblings, partners, and caregivers consistently over several years through surveys. To register [click here](#).



Medical

Welcome Altuviiiio!

The newest hemophilia therapy is here: Altuviiiio™ (previously called efanesoctocog alfa), a once-weekly therapy, is a first-in-class, high-sustained factor VIII replacement therapy indicated for prophylaxis and on-demand treatment to control bleeds. It can also be used for surgery in adults and children with hemophilia A. Altuviiiio claims to be the first and only hemophilia A treatment that delivers over 40% factor levels for most of the week. To learn more [click here](#).



World

March's Child

Each month we will feature a child in need of sponsorship. Reichel lives in the Dominican Republic, in the Caribbean. He's only 8, and has moderate hemophilia A. His birthday is October 16. For only \$35 a month, you can change his life! [Sponsor him](#).



Donating Factor

We're accepting factor donations of factor! As Laurie begins to travel overseas to visit patients in need, she can bring your donated unused and unwanted factor and ancillaries. Please email before sending: laurie@kelleycom.com.



Just in Case You Haven't Heard...

- Use #BleedingDisordersAwarenessMonth on social media to connect with the community and to participate in on-line events this month.
- It's NHF's 75th Anniversary Year; NHF was founded by a father of a child with hemophilia.
- Hemophilia A occurs in approximately 1 in 4,065 male births while hemophilia B occurs in about 1 in 20,000 male births.
- Down syndrome occurs in 1 of every 700 births, and spina bifida occurs in 1 to 2 of every 1,000 births.

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