

There are ways to help you

AFFORD YOUR HEMOPHILIA A MEDICINE.

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COMMUNIQUE

For Bleeding Disorders

FEBRUARY 2024

Welcome

February is our month of advocacy—when members of our community travel to Washington DC to speak with one voice to our government. Members visit their state legislators, and impress upon them the needs of the community, while sharing personal stories of hardships and challenges overcome. I went to one Washington Days, and it was a fabulous experience. I saw members of our community who I knew but had never seen “in action.” It was impressive! This is one of the most important things our community does, and it impacts us all. Try to attend some year. There are often scholarships to help you attend.



Speaking of scholarships, it's time! Apply for them starting now and get the financial help you need to make your vocational dreams come true.

Stay safe and hopeful,

Laurie

Events

Listening is Leadership

With organizational changes at Hemophilia Federation of America announced in January, you may have questions or concerns about their important programs and services, and the future of this organization. Submit your questions to be addressed during the session on March 14 at 7 p.m. EST to listening@hemophiliamed.org. [To register click here.](#)



Getting Together for the 76th Time!

Registration is now open for National Bleeding Disorder Foundation's 76th Annual Bleeding Disorders Conference (BDC), held on September 12-14 in Atlanta, Georgia. There will be educational sessions, valuable networking opportunities, and exciting exhibits at the Georgia World Congress Center. [Reserve your spot here.](#)



Meet at the Crossroads of America

Registration is now open for Hemophilia Federation of America's 2024 Symposium, April 11-13, 2024, in Indianapolis! It's one of the largest, family-friendly events for members of the bleeding disorders community. The three-day symposium offers: sessions on advocacy, pain management, addiction, parenting, and women and girls, and more; education for rares, milds, severes, and moderates in both English and Spanish; rap sessions for blood sisters, blood brothers, families, Sangre Latina, milds and spouses and partners; and an excited Final Night Event! [Register here.](#)



Resources

Be Social!

Our advocacy groups have many social media platforms. Try these for NBDF: TikTok:

[@natlbdfoundation](#); X (Twitter):
[@NBD_Foundation](#) and [@NBDFespanol](#);

LinkedIn:

[@NationalBleedingDisordersFoundation](#);

Facebook:

[@NationalBleedingDisordersFoundation](#);

Instagram: [@nbd_foundation](#)



Educational Cost Assistance

Getting a college degree or advanced training can be expensive. There are many scholarships available for students with a bleeding disorder and sometimes their family members. LA Kelley Communications had the first on-line listing of scholarships—we believe in education, training

and our future leaders. [Check here to see if you qualify for a scholarship.](#)



HemaBlog

Layoffs and Life Cycles

It's not the end of the world when bleeding disorder nonprofit organizations need to restructure to adapt to the changing environment. [Read why here.](#)



Advocacy

A Capitol Idea

NBDF's Washington Days happens March 6-8. It's an opportunity for people affected by inherited blood disorders to advocate for issues that are important to them. In 2021, Washington Days had more than 400 volunteer advocates from 45 states that met with legislators and staff to discuss federal funding for bleeding disorder programs and support policies that increase affordability of coverage and access to care. [Learn more and register here.](#)



Learn to Lead

Want to become a better advocate for your child, yourself or your community? [Check out the do's and don'ts at NBDF's website](#)

Medical

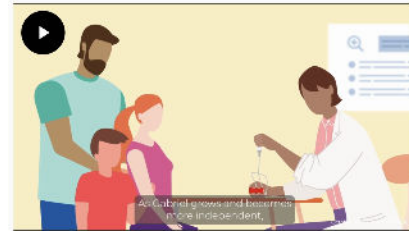
Rebinyn 3000 Shortage

Novo Nordisk launched the Rebinyn® 3000 IU vial size in May 2023. The demand for this vial size outpaced expectations. There is a temporary shortage of this vial size, which is expected to last a few months. Novo Nordisk can maintain its overall supply of 500 IU, 1000 IU, and 2000 IU vial sizes, which can be used in combination to achieve appropriate dosage for patients. For

questions about how to make up dosage size, please contact your healthcare provider. You can also reach out to your Novo Nordisk representative, or contact Novo Nordisk Customer Care at 800-727-6500.

Exploring Treatment Options

An animated video explains about how hemophilia is diagnosed, the typical course of the illness over a lifetime, options patients have for managing the condition and how patients can participate in treatment decisions. [View the video at the CSL website here.](#)



Science

First Gene Therapy Administered

In December 2023, an adult with hemophilia A became the first person in the United States of America to receive treatment with Roctavian™ — approved in June of last year — outside of clinical trials. The treatment was administered at the Center for Comprehensive Care and Diagnosis of Inherited Blood Disorders in California. Roctavian is a one-time gene therapy designed to address the underlying genetic cause of hemophilia A. It offers the potential for long-term relief and a significant reduction in the need for traditional clotting factor replacement therapies. Roctavian is sold by BioMarin Pharmaceutical, and is the first gene therapy approved by the US FDA for hemophilia A.



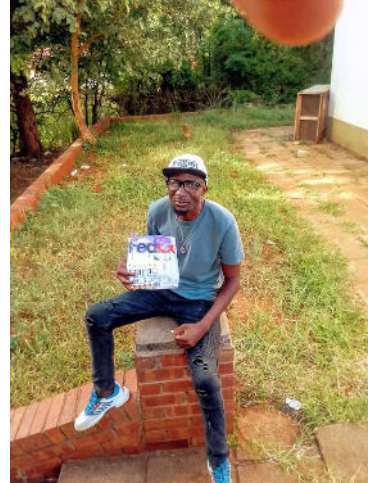
Third Gene Therapy Administered

Tampa General Hospital's cancer institute is the first healthcare center in Florida, and the third in the US, to administer the first and only hemophilia B gene therapy, Hemgenix, to a patient. The one-time infusion therapy delivers to liver cells a healthy copy of the gene encoding factor IX. The gene therapy is expected to restore the body's ability to make functional factor IX. After the treatment, clotting activity should normalize and lower or eliminate the need for factor IX replacement therapy.

World

Maximum Impact Program

In 2023, LA Kelley Communications' Maximum Impact Program shipped over 5.8 million units of factor, worth about \$10 million dollars; and 539 mg of NovoSeven, worth about \$1 million, to 24 countries.



In Case You Haven't Heard...

- Advocacy is the attempt by individuals or private interest groups to make known the opinions and desires of a specific group of people, in order to influence government decisions.
- Professional advocacy involves hiring an individual, group, or company to represent and lobby for a position or desired action. These advocates are paid. Grassroots advocacy requires individuals, volunteers, and nonprofit organizations to volunteer their own time and resources to petition or inform government officials about their point of view.
- The word “lobbyist” was coined to refer to people who waited in the lobby, or entrance hall, of the US House or Senate chambers to try to influence legislators going in to vote.

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