



MY **KOVALTRY**  
CONVERSATION

MEET OUR  
SPEAKERS >

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Talk to your doctor about KOVALTRY.



# COMMUNIQUE

For Bleeding Disorders

JANUARY 2024

## Welcome

This year will be tumultuous in politics, which could impact health care decisions later on. Now is the time to register for our national organization's news briefs, advocacy updates and in-person events. The US has the greatest number of resources for those with hemophilia and other bleeding disorders. Are you registered to get information delivered to your inbox?

Check out [hemophilia.org](https://hemophilia.org), [hemophiliamed.org](https://hemophiliamed.org), and most of all your state or local bleeding disorder organization. Some health care decisions will impact you only at a state level, so be sure you know what's happening in your state.



History has shown that our community is one of the most powerful for advocacy, but times are changing. Our voices will grow fainter if we don't unite with one message to our politicians and payers, to request what we want and need for therapy and coverage.

Stay safe and hopeful,

Laurie

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## Events

### Learn more about Gene Therapy

A free webinar on Wednesday, **January 17**, will be about one-time treatment Roctavian gene therapy for eligible adults with severe hemophilia A. Learn about eligibility testing to see if

Roctavian is right for you; hear from a person with severe hemophilia A about their experience; get answers to your questions. [Register today here!](#)



### Have HOPE

Join community members and life-long advocates Kirstin Drye and Michelle Stielper on **January 18** at 11:30 am CST for a free webinar about the importance of everyone advocating for women and girls with bleeding disorders. Both Kirstin and Michelle have hemophilia B. [Register for this HOPE Session 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 with bleeding disorders; 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.](#)

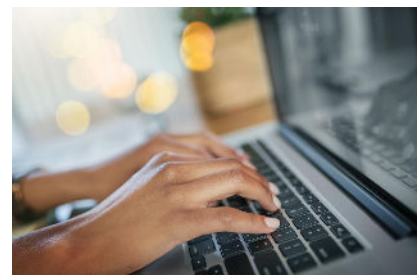


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## Resources

### Paid Surveys

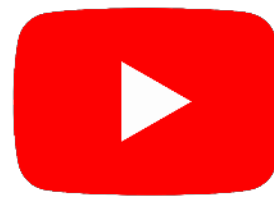
Have you registered yet for our paid surveys? Most offer \$150/hr or more for your participation, right in the comfort of your own home. Researchers want to know what you think about treatments, living with hemophilia and more. [To register click here.](#)



### Understanding Your Child: Ages and Stages

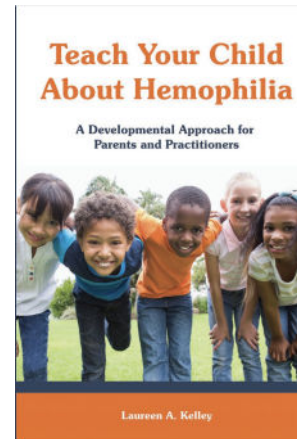
As your child grows and changes through

developmental stages, so do their needs and expectations. As parents, we are constantly seeking information on how to aid our children with their ever-changing growth process, knowing no two children are the same. HFA offers two videos for the various stages in your child's life. To learn about elementary school children needs, [view here](#).



### Teach Your Child About Hemophilia

You can also read our book which shares research from interviews with dozens of children, about how they understand different topics about hemophilia. What is hemophilia? How does factor work? Why do I have hemophilia? Children at different stages have different and very predictable answers! This will help you teach your child about his hemophilia. [Order here](#).

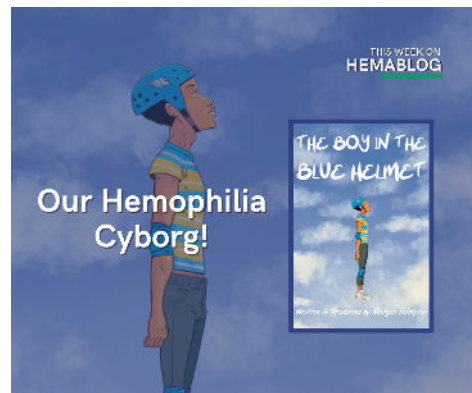


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## HemaBlog

### Our Own Cyborg!

Meet Morgan, an amazing young man with hemophilia who writes for DC Comics, for the very cool character Cyborg! In our Q&A, Morgan discusses his latest plans to publish a video about a boy in a blue helmet who has hemophilia. [Read more here](#).



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## Advocacy

### What's the State of States?

This quarter's State of the States reports on continuing concerns over the high rate of Medicaid/CHIP terminations as insurance companies relax coverage post-Covid. Coverage losses among children exceed adults, heightening concerns about erroneous terminations and the adverse impact on vulnerable populations. Separately, Colorado and New York take the lead in protecting consumers from medical debt. [Read more here](#).



## Medical

### **NovoSeven® RT 8 mg Vials Unavailable**

Due to supply constraints, Novo Nordisk will be unable to provide the 8 mg vial of NovoSeven from January until mid-2024. Importantly, the overall supply of NovoSeven is expected to remain stable as other vial sizes are available. NovoSeven is an excellent therapy for people with hemophilia A and inhibitors.

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## Science

### **Intranasal Delivery of Factor IX**

French researchers are exploring the possibility of treating hemophilia B patients with intranasal delivery (nose drops or sprays) of factor IX. In studies in mice, both standard and longer half-life recombinant factor IX were taken up after intranasal delivery and delivered to the bloodstream. This “proof-of-concept” study demonstrated that the nasal route might be a possible alternative to i.v. infusion. [Fieux M et al., J. Thromb. Haemost., online ahead of print 8/24/23] [Read here.](#)

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## World

### **Maximum Impact Program**

LA Kelley Communications is introducing a new program to provide funding for people in developing countries in need of surgery, durable medical equipment, prosthetics and basic necessities. Already we've help fund several joint replacements, prosthetic legs and motorized scooters. [Read more here.](#)



## In Case You Haven't Heard...

- Medicaid is a US government health insurance program financed by federal, state, and local funds to provide hospitalization and medical insurance for people of all ages who meet certain income limits.
- Medicare is a US government program of hospitalization insurance and voluntary medical insurance for people 65 and older, and for certain disabled people under 65.
- COBRA is a federal law that may allow you to pay out-of-pocket to keep you and your family on your employee health insurance for a limited time

(usually 18 months) after your employment ends.

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