

**ALPROLIX**  
[Coagulation Factor IX  
(Recombinant), Fc Fusion Protein]

**DOING THINGS YOUR WAY  
STARTS RIGHT HERE,  
RIGHT NOW.**

**LET'S GO**

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**LA KELLEY**  
communications, inc.

# COMMUNIQUE

For Bleeding Disorders

APRIL 2023

## Welcome

April is the month when we celebrate World Hemophilia Day, April 17, birthday of the founder of the WFH, Frank Schnabel, an American who emigrated to Canada for better healthcare coverage. Bleeding disorder patients worldwide will be celebrating in a variety of ways, while here in the US, lighting up major architectural sites in red has become the standard. How will you celebrate the day?

Stay safe and hopeful,

Laurie



## Events

### Celebrate World Day!

World Hemophilia Day is April 17, the birthdate 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](#).



### Hemophilia in Puerto Rico

April is National Minority Health Month. The president of the Puerto Rico Hemophilia Association shares what it's like to have hemophilia in Puerto Rico. [Watch here](#).



## Programs

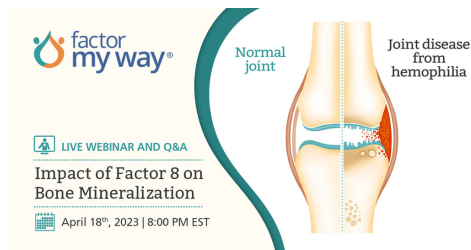
### Keep the Beats!

Join fellow musicians ages 13 and older with bleeding disorders in Nashville this summer for a special jam session! July 4-8. [Apply here now](#).



### Factor VII and Bone Mineralization

Attend a complimentary live webinar to learn about how factor VIII affects your bones, followed by a live Q&A session with an expert. **April 18.** [Register here.](#)



### Inhibitor Camp!

If your child has hemophilia and an inhibitor, women with bleeding disorders, or an 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.](#)



## Resources

### Scholarships: Last Call!

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



### Best Way to Record Bleeds?

Get tips on how to document your bleeding episodes more effectively. It’s important to record information for your treatment center and for you! [For more info click here.](#)



### Elite Athletes Get a Movie!

The bleeding disorder community has many great athletes, thanks to the high level of care available in the US. Get ready to meet these individuals in August, when the movie “Elite Athletes with Hemophilia” debuts in August at NHF’s Bleeding

Disorder Conference!



### And Meet These Success Stories!

Five members of the hemophilia community share their career experiences in a series produced by Believe Limited, the team behind the movie *Bombardier Blood* and the hemophilia web series *Stop The Bleeding*. [Watch here](#)

HemeWork™

About HemeWork

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## HemaBlog

### Island of Dreams

Laurie visited a patient she has known for 22 years on Mayreau Island, part of St. Vincent and the Grenadines. Imagine having hemophilia, no direct medical care, access to a clinic only by boat, and no access to factor except through donations? And yet Kishroy Forde is doing great, with our help. [Read here.](#)



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## Advocacy

### Where's My Financial Aid?

Many patients in the bleeding disorder community rely on patient copay assistance programs from manufacturers of factor to help defray the out-of-pocket costs of their factor. A disturbing trend has been health insurance companies pocketing the financial assistance meant for patients' copays. Read how these accumulator adjuster programs might affect you, and what HFA is doing to combat this trend. [More info here.](#)

### Gift of GIFs

McCann Health New Jersey launched a successful GIF campaign, to fight the stigma that exists on social media about hemophilia. The campaign provides a series of GIFs with input from hemophilia community chapters and caregivers, to stop the spread of misinformation and stereotypes around hemophilia that persist on social media, allowing the community to control the narrative about how hemophilia is portrayed online. [For more info click here.](#)



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## Medical

### New role for wilate

Octapharma USA has applied to the U.S. FDA to expand indication of *wilate* to

include routine prophylaxis to children and adults with any type of von Willebrand disease (VWD). Currently, *wilate* is indicated in children and adults with VWD for on-demand treatment, as well as for routine prophylaxis to reduce the frequency of bleeding episodes and on-demand treatment and control of bleeding episodes in adolescents and adults with hemophilia A. [Click here for more info.](#)

### More Good News for Gene Therapy

Pfizer announced positive findings from its pivotal Phase 3BENEGENE-2 study evaluating fidanacogene elaparvovec, an investigational gene therapy for adult males with moderately severe to severe hemophilia B. Fidanacogene elaparvovec is a vector containing a bio-engineered adeno-associated virus (AAV) capsid and a high-activity human coagulation factor IX gene. [Click here for more info.](#)

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## World

### April's Child

Salmanfarias lives in Kunnamkulam, India. He is 12, and his birthday is October 10. He has severe hemophilia A. Life is very difficult for patients in India. For only \$35 a month, you can change his life! [Click here to sponsor him.](#)



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## 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.
- The worldwide therapeutic plasma proteins market reached over **\$29 billion** in 2021, up 7.3% annually from 2018.
- Prophylaxis with **Hemlibra** appears to be efficacious and has a favorable safety profile in people with non-severe hemophilia A without factor VIII inhibitors.
- **Altuviio**<sup>TM</sup> is a once-weekly, first-in-class, high-sustained factor VIII replacement therapy indicated for prophylaxis and on-demand treatment.

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