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LA KELLEY  
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# COMMUNIQUE

For Bleeding Disorders

SEPTEMBER 2023

## Welcome

School days, school daze! Enrolling your child with a bleeding disorder in school is emotionally hard—I recall those days well. In the late 1980s and early 1990s we had to learn on our feet: there was no information really available until my book was published. It includes an entire chapter about school. Now we have social media, and virtual meetings, and so many more resources! I hope you browse below and see all the offerings: events, books, downloadable info sheets—your child will do fine, and so will you! Read up!



Stay safe and hopeful,

Laurie

## Events

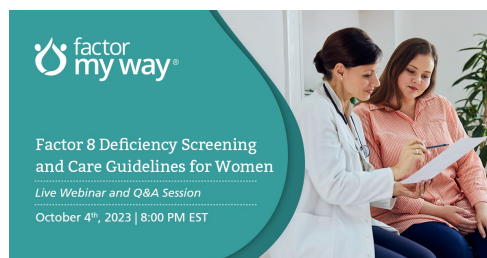
### Would You Please Go Away?

Enjoy the outdoors with a bleeding disorder, in this new series, called Pathfinders. Learn the essentials about backpacking, hiking and just enjoying nature. Attend a series of 60-minute virtual workshops, free, for the bleeding disorder community. Hosted by the renowned GutMonkey! The next one is October 11, 7 pm EST. To register [click here](#).



### Factor My Way: FVIII Guidelines for Women

Register for the upcoming Factor My Way® live educational webinar on Wednesday, October 4, at 8:00 pm EST. Topic will be “FVIII Deficiency Screening and Care Guidelines for Women.” [Register here](#).



### Men with Hemo B: Retreat!

A series of men’s retreats offering a unique three-day experience, during which men are given a safe space to share their journey with others and gain support. All men attending benefit from the enhanced

THE COALITION FOR  
HEMOPHILIA 

camaraderie and learn strategies for managing hemophilia B through all life stages.

October 19-22, Tennessee. To register [click here](#).

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## Resources

### Science Class: Hemophilia

Do a deep dive into the science behind hemophilia: how factor VIII functions, the different types of genetic mutations and the importance of understanding these nuances so you can make informed therapy choices. HFA offers “Master Class” for you! For more info [click here](#).



### Need Help?

“Healthy Living Items Assistance” helps people with bleeding disorders defray the cost of medically necessary items that are not covered by insurance, or even by out-of-pocket payment. This includes wheelchairs, crutches, splints, and even workout equipment to help you live a healthier life! [To apply click here](#).



### Give Your Child’s Teacher Tools!

Download a great two-page resource for your child’s school. “My Bleeding Disorder” provides teachers, coaches and school personnel with necessary information in one place, to alleviate their worries—and yours! [Download here](#).

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## HemaBlog

### Dignity Restored: Zaid of India

Zaid Raja is a young man from the impoverished state of Bihar, India. He has hemophilia A. Due to a pseudotumor—something you almost never see in the US—he had his leg amputated in December 2022. Hemophilia and poverty together create exponentially greater hardships. Rather than continue to be a burden to his family with hemophilia and now only one leg, we bought a great prosthetic leg. Look at Zaid now! Not just mobility restored, but dignity restored. [To see video, go here](#).



## Advocacy

### Payers Living in Alternative Universe?

“Alternative funding programs” are the latest payer-side scheme to save money at the expense of patient access to care. These programs, encouraged to

employers, promise to lower health plan spending on specialty drugs—like factor—by dropping the brand or class of drug from the employer’s formulary. What happens next? [Read more here.](#)

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## Medical

### 340B Programs: Time for Reform

An article in the *Times of San Diego* by renowned HTC hematologist Dr. Diane Nugent urges reform of the 340B Program. The 340B Program allows covered entities like hospitals and HTCs providing charity care or nonprofit healthcare providers serving the most vulnerable citizens to buy medications at a significantly discounted price, sell them, and use profits to fund the centers. But many for-profit hospitals take advantage of the steeply discounted drug prices offered through the program, to then overcharge patients and payers, and make significant profits. Is it time for a reform? [To read more click here.](#)

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## World

### Wheels for the World Rolls Out Again!

After the passing of Barry Haarde, first known person with hemophilia to cycle across America (six times!), it was doubtful the international charity Save One Life could find anyone to fill his clip-in shoes. Enter Doug Mildram, a fan of Barry’s and the hemophilia community, who is cycling right now across the United States to raise money for the cause. Save One Life was founded by LA Kelley Communications’ president Laurie Kelley. It supports over 1,200 children and young adults with direct sponsorships; it also supports summer camps, offers scholarships and microenterprise grants, and supplies millions worth of factor annually. [Donate here.](#)



### September’s Child

Joseph is a 10-year-old boy who lives in Uganda. He has severe hemophilia A. His father is a peasant farmer and only earns about \$50 a month, and he has two siblings and a young aunt. His birthday is February 27—what a great gift to have someone sponsor him! It’s only \$35 a month. To sponsor him [click here.](#)



## Just in Case You Haven't Heard...

- The National Hemophilia Foundation has rebranded; its new name is The National Bleeding Disorders Foundation.
  - The World Federation of Hemophilia (WFH) was established in 1963 by Frank Schnabel, a Californian businessman with severe hemophilia A, who moved to Montreal, Canada for more affordable care.
  - The oldest hemophilia foundation in the world is in Argentina, founded in 1944 by the director of the Hemotherapy Service of the National Academy of Medicine.
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