

There are ways to help you

AFFORD YOUR HEMOPHILIA A MEDICINE.

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LA KELLEY
communications, inc.

COMMUNIQUE

For Bleeding Disorders

JULY 2024

Welcome

The heat is on! The country seems to be sweltering under unseasonably hot weather. People often ask me about shipping factor in such heat. I usually say it's typically fine to ship without ice packs, as long as you don't leave it in a hot mailbox or car. Read the product insert (PI), which will state that all factor is effective if kept at room temperature—and there will be a range of temperatures.

When at home, keep it in the fridge, if you like. You're less likely to forget you have it. So many have discovered that after their children leave home for college or for good, a bunch of factor is discovered in the closets!

Stay safe and hopeful—and cool!

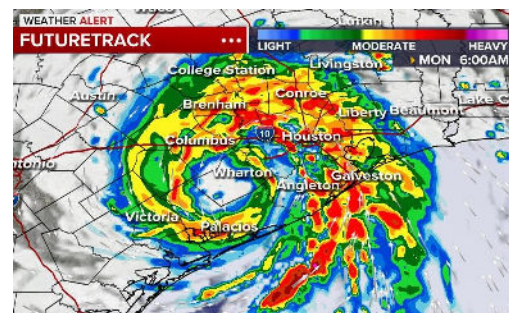
Laurie



Events

Beryl Counts as an Event

The Lone Star Chapter alerted all its members to the potential devastation of Hurricane Beryl via its [Facebook page](#): "Today you should be finalizing hurricane plans—be sure you have batteries/flashlights, water, food, and have secured outdoor items. Be sure you have



adequate factor and supplies in a go-bag in case you need to evacuate if you haven't already. Have important phone numbers handy, including your Hemophilia Treatment Center, and remember the Chapter will be here for you after the storm!" If you are in the Houston greater area, please follow their Facebook page, and join as a member. Learn how to protect yourself when disaster strikes!

National Bleeding Disorder Meeting

September 12-14. Georgia World Congress Center, Atlanta. NBDF is hosting its 76th Annual Bleeding Disorders Conference (BDC). Join your community for three incredible days of educational sessions, valuable networking opportunities, and exciting exhibits. [Learn more here.](#)



Resources

Are You Aware?

Get the latest from NBDF with the new Spring-Summer issue of *HemAware*! It's free and easy to download, and provides important news and feature articles about the bleeding disorders community. [Download here.](#)



Where is Your HTC?

Do you need an HTC? A new HTC? Do you need to find one when you travel across the US? [Check out the listing here](#), to see where to find the closest HTC.

Career Decisions and Money

New treatments, remote work options, and employment opportunities in a challenging economy, work and career decisions require preparation. This on-line session provided by HFA will cover what to consider about job options when you have a bleeding disorder, when to disclose your bleeding disorder, how to communicate need for accommodations, and what rights you have as a job applicant and as an employee. [Learn more here.](#)



You Belong! Chat

Join HFA's Bleeding Disorders Monthly Gathering for Adults; Uniting Blood Brotherhood and Blood Sisterhood, a Zoom chat for blood sisters and blood brothers (ages 18+). There will be a discussion of shared experiences blood brothers and blood sisters have and their unique needs.



There will also be time devoted to breakout into individual discussions to debrief and answer questions of whether to continue to meet jointly or separately (or a combo of both each month) going forward.

[Join here.](#)

HemaBlog

What Kind of Leadership Matters Most When?

The US is going through a leadership crisis—what kind of leadership matters most at this time and why? At the same time, our bleeding disorder community has gone through a leadership change.

[Read about what kind of leadership matters most at certain times.](#)



Advocacy

Planting the Seeds of Leadership

NBDF's National Youth Leadership Institute (NYLI) provides 18-24 year olds in the bleeding disorders community with leadership opportunities to encourage personal growth, effect change, and positively influence others. This is a two-year program designed to assist young people from the bleeding disorders community in becoming well-trained, recognized leaders. In addition, NYLI provides an amazing opportunity for youth to learn and share experiences of living with a bleeding disorder. NBDF achieves these outcomes by providing young adults with training, support, and opportunities to provide education to the bleeding disorders community. [Learn more here.](#)



Eliminating Medical Debt from Credit Reports

The Consumer Financial Protection Bureau (CFPB) proposed new regulations last month that would ban information on medical debt from being reported on all consumer credit reports nationwide. At least 20% of Americans had more than \$88 billion in medical debt on their credit reports, which affects their ability to own a home, buy a car, or secure loans to start a business. [Learn more here.](#)



Medical

Defining Gene Therapy for Patients

Gene therapy is a welcome treatment for patients, which has been anticipated for decades. But how do parents and patients discuss this with their HTC staff, when they don't know the language of science associated with gene therapy? A bleeding disorder gene therapy lexicon is currently being



developed by various industry stakeholders, which is highly needed for dissemination of the complexities of gene therapy to patients, caregivers, and healthcare providers. [Read MASAC Document 285.](#)

NovoSeven and NovoEight Potential Shortage

A product concern with NovoSeven[®] RT and Novoeight[®] might cause a shortage for some patients. Please note this is not a product recall. A manufacturing issue has led to a temporary shortage of the NovoSeven RT 1 mg and 2 mg vials and some strengths of Novoeight. Please contact your HTC if you have concerns about your treatment regimen and availability. You can also contact Novo Care customer support at 844-668-6732. [Read Novo Nordisk's full letter here.](#)

World

Maximum Impact: Factor Donations Q2

We're dedicated to helping those with bleeding disorders overseas get the surgeries and help they need. LA Kelley Communications received over 1.19 million IU of factor in the second quarter of 2024. And all of it has been shipped to several countries and individual patients. Thanks to all who donate!



France Gets Gene Therapy

Hemgenix, the first approved hemophilia B gene therapy, was administered to two patients in France, marking the first time the treatment has been given in Europe. Hemgenix had already been approved in the US and in Canada, and most recently in Switzerland, for patients age 18 and older with severe or moderate hemophilia B. [Read more here.](#)

In Case You Haven't Heard...

- UK patients will get CSL Behring's FIX gene therapy Hemgenix for free.
 - Hemgenix costs a US patient about \$3.3 million for the one-time treatment.
 - The UK has a nationalized health care system; the US has a primarily commercialized health care system.
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