

Is it a **good option**
for me?



Watch the videos

HEMOPHILIA
FORWARD 

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COMMUNIQUE

For Bleeding Disorders

NOVEMBER 2023

Welcome

November is a special month. For those of us in the nonprofit world, it's an important month of giving. #GivingTuesday is November 28, and I hope you will consider some of the amazing and worthwhile hemophilia organizations that work tirelessly to improve hemophilia care and to ease the suffering of those who do not have access to care.

The world seems to be unstable and tense lately and the news is both depressing and shocking. Let's do what we can to help ease the suffering. See our list below of excellent and qualified nonprofits that rely on us—moms, dads, patients, family members, industry reps and medical staff—to give.

Stay safe and hopeful,

Laurie



Erratum

We regret that in our last issue, we mentioned Pfizer's product Marstacimab, in clinical trials, as being administered intravenously. It is administered subcutaneously. We apologize for this error.

Events

Does Factor Affect Your Bones?

Did you know that approximately 40% of

people with hemophilia A have reduced bone density (osteopenia) and 30% have osteoporosis? Join a free webinar called “Impact of Factor 8 on Bone Mineralization” followed by a Q&A to learn more about this important health concern. Wednesday, November 29, at 8:00 pm EST. To join [click here](#).



Resources

Season of Thanks

BCares Patient Assistance Program provides short-term, limited financial aid to hemophilia B community members who encounter unforeseen emergencies, including COVID-19 related hardships. Administered by the Coalition for Hemophilia B, with support from donors. To apply: contact@hemob.org

Survive and Thrive!

Attend a virtual workshop on mental health issues with expert coaches, to learn tools that can help you better cope. November 29, 7 pm EST. To attend: hemob.org/upcoming-events.



HemaBlog

Remembering Our Veterans

November 11 is Veteran’s Day, and it’s a time to remember those who have passed but dedicated their lives to improving hemophilia care. This month we remember one of the founders of von Willebrand Disease care: Renée Paper. [Read here](#).



Advocacy

Open Enrollment for Medicare

If you have Medicare, insurance for those 65 and older, now's the time to compare all your coverage options, and find one that best fits your needs and budget for 2024. You could save money, find better coverage, or both. If you have an account, add your prescriptions and local pharmacies to get better estimates of drug costs. Costs can vary widely. Also view the estimated Yearly Drug and Premium Cost when comparing coverage options. A plan with the lowest monthly premium may not always offer you the lowest total cost. For more info [click here](#).

Victory over Copay Accumulators

Hemophilia Federation of America and other patient advocacy groups claim victory for a September 29 court ruling over copay accumulator programs (CAAPs). CAAPs are policies used by health insurance plans that accept copay assistance from factor manufacturers, designed to save the patient money on drugs, but then do not apply the cost savings towards patient deductibles and out-of-pocket maximums. For more info [read here](#).



Medical

Women with Bleeding Disorders and Other Medical Concerns

Women who have von Willebrand disease or hemophilia are not at risk for other female medical problems, but two common disorders in women, polycystic ovary syndrome and endometriosis, can cause additional concerns and pain, and need proper diagnosis and treatment. An excellent article in HemAware covers this interesting and vital topic. [Read here](#).

Gene Therapy Preparedness

With the advent of gene therapy, patients will need to educate themselves more about eligibility, risks, compliance and costs. And they should educate themselves in conjunction with their hemophilia treatment center (HTC). HTC staff also need to be prepared to help patients make this important decision. A new National Bleeding Disorder Foundation (NBDF) MASAC document, #282, discusses what is needed for a team decision about gene therapy. The document stresses that multi-stakeholder preparation is required to develop clinical protocols for eligibility screening, administration, and follow-up of gene therapy, and to identify ways to remove barriers to access and achieve excellence in clinical delivery to maximize health outcomes. [Read here](#).



Science

New Inhibitor Drug Investigated

Centessa Pharmaceuticals will present “groundbreaking” findings at the upcoming ASH Annual Meeting on November 2. The company will present a 52-week analysis of continuous treatment data from the third year of its Phase 2a study on SerpinPC, a therapy for hemophilia B. The subcutaneous treatment is targeted for management of hemophilia B without inhibitors. For more info, [click here](#).



World

November is a Giving Month

November has become a month known for several holidays and events: Veterans Day, elections, Daylights Savings Time, Thanksgiving and Black Friday. There is also National Philanthropy Day and Giving Tuesday. The majority of charitable giving to nonprofits is done by individual people. This month, consider giving to these bleeding disorder charities: NBDF, HFA, Coalition for Hemophilia B, Save One Life, WFH, HOPE or your state or local hemophilia nonprofit. To give visit the organization websites: hemophilia.org, hemophiliamed.org, hemob.org, saveonelife.net, wfh.org, hopeforhemophilia.org.

GIVING TUESDAY

November's Child

Dennis is a ten-year-old who lives in the Philippines. He has hemophilia A, and his parents earn only between \$50-100 a month. Sponsorship would make a huge difference in his life. It's only \$35 a month. November is the month of giving—can you help? To sponsor, [click here](#).



In Case You Haven't Heard...

- More than 50% of people with moderate or severe hemophilia have experienced *hematuria*—blood in the urine.
- Used needles and other contaminated medical supplies that can penetrate the skin are often called “sharps.” Sharps containers are designed to contain such waste while minimizing the risk of a needle stick.
- Joint bleeds, called *hemarthrosis*, are the most common bleeds in people with hemophilia, and make up about 80% of all bleeds.

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