

Bleeding symptoms may occur regardless of factor IX levels⁶

The numbers don't tell the whole story

Some men with severe hemophilia B bleed like those with moderate hemophilia B, and some with mild hemophilia B bleed more severely. *It's no different for women.*^{3,6}

Joint and muscle damage can happen at any hemophilia B severity level⁷

A study of the range of motion in the joints of girls and women with different levels of hemophilia B severity* showed:

- Reduced range of motion across all factor IX level severities and age groups—even pre-teens⁷
- Girls with low factor IX levels may have joint bleeds without symptoms before adolescence⁷

Early diagnosis and the right treatment can help or prevent bleeding problems and improve quality of life.⁸

“Despite being at a 25 [factor] level I bleed significantly more than my son, and his level is 1. He had his first spontaneous bleed at 12, and I have them all the time.”
- 46-year-old woman diagnosed at age 36

Women and girls with hemophilia B—even those with factor IX levels above 40%—may have a greater tendency to bleed.⁷

*Hemophilia severity classifications by factor levels: Normal = $\geq 40\%$, Mild = $>5\%$ to $<40\%$, Moderate = $\geq 1\%$ to $\leq 5\%$, Severe = $<1\%$ ⁷

Get help—start with a hematologist who understands bleeding disorders

Talk with a hematologist who treats people with bleeding disorders if you think you have hemophilia B. You may need to get a referral from your primary doctor first.

If you don't have a hematologist, the first place to start is at a hemophilia treatment center (HTC). **Search for an HTC at www.cdc.gov/ncbddd/hemophilia/HTC.html.**

Search clinics specifically devoted to the care of women and girls with bleeding disorders here: **<http://www.fwgbd.org/wgbd-learning-action-network-lan/current-lan-members>**

“I encourage women to keep pushing for second and third opinions if you feel something is wrong. Hemophilia is so unique to every individual.”
- 28-year-old woman diagnosed at age 26

Ask about a hemophilia B diagnosis

Men are typically diagnosed at birth, while women are usually diagnosed with hemophilia after age 18. Some doctors still think that women and girls with hemophilia B don't have an increased risk of bleeding.^{7,9}

Make sure you're tested for hemophilia B

You may have been tested for a more common bleeding problem called von Willebrand disease (vWD). People with vWD may also have hemophilia B. So, **if you're at risk of being a hemophilia B carrier, it's important that your hematologist tests your factor IX level to check for hemophilia B** even if you're tested for vWD.³ You should also ask to be tested for any other bleeding disorders. Work with your hematologist to understand all test results.

Know when your period points to a bleeding disorder^{2,5,8}

- Your period lasts 8 days or longer
- You often or always bleed through your pad or tampon within 1 hour
- Large clots the size of a grape or larger
- Anemia
- Need for blood transfusions





“I talked to my doctor, and they were all really open about me being a woman with hemophilia. I’m really appreciative of that, and they were all very helpful in trying to get me what I needed.”

– 23-year-old woman diagnosed with hemophilia B at birth

Help with hemophilia is here

There are so many people in the hemophilia community waiting to help you. Don’t hesitate to reach out for the help you deserve.

A nurse, doctor, or physical therapist at your closest HTC

Search HTCs at www.cdc.gov/ncbddd/hemophilia/HTC.html

The Coalition for Hemophilia B

hemob.org 212-520-8272

Hemophilia Federation of America

hemophiliafed.org 800-230-9797

National Hemophilia Foundation

hemophilia.org 800-424-2634

Foundation for Women & Girls With Blood Disorders

fwgbd.org

Centers for Disease Control and Prevention (CDC)

www.cdc.gov/ncbddd/hemophilia/women.html

Your local hemophilia organization

Search at www.hemophilia.org/Community-Resources/Chapter-Directory

You may already know someone who could help you, such as a nurse at a specialty pharmacy or someone close to you in the hemophilia community.

Insurance reimbursement assistance

Helpful insurance tips:

- **Call your local HTC** and ask them to help you with insurance issues, including referrals.
- **Most hemophilia products offer co-pay assistance.** Check the product website for help with your out-of-pocket costs.
- **If a billing problem comes up**, arrange a phone call with you, the insurance company, and your doctor’s office.