My 6-year-old son has severe hemophilia B that was discovered after he had surgery in 2010. I was told by the nurse that I am probably a carrier. My son receives prophylaxis twice each week. Because I am focusing on my son, I forget about myself.

– 30-year-old woman who hasn’t been diagnosed

When I saw my hematologist, I thought, ‘Gosh, I feel appreciated. I have somebody that cares now’.

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Just because my factor is at a certain level doesn’t mean I don’t bleed.

– 46-year-old woman with hemophilia

Men aren’t the only ones with hemophilia.

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This guide was created with the help of women with hemophilia B. You’ll see that women with hemophilia B don’t always have the same symptoms as men.

Facts about women who are hemophilia B carriers:

- 57% have heavy periods vs 9-14% of the general population
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Women with low factor IX levels can have the same problems as men with hemophilia B:

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And they face challenges men don’t:

- Heavy menstrual bleeding
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These issues can only be managed when a hemophilia B diagnosis is made and the right treatment is prescribed.

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Use this checklist to make sure you’re ready to talk about a possible hemophilia B diagnosis and treatment options.

Tell your complete story

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- Deaths from bleeding issues
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☐ Write down how bleeding problems impacted your life

- Relationship problems
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Hemophilia B in women

Women and girls can have hemophilia B since the 1950s, medical literature has shown that hemophilia B carriers have bleeding problems. In fact, about one third of carriers have factor levels below normal, and many clearly have problems with bleeding. These women have hemophilia based on their bleeding, genetics, and factor levels.

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Bleeding symptoms may occur regardless of factor IX levels

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 = ≥40%, Mild = >5% to <40%, Moderate = ≥1% to ≤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.

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. 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

- 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

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Tell your clear, complete story

- Bring a bleeding log and pain log that tracks your joint or muscle bleeds and pains, such as shin splints. If you prefer a mobile app, one can be found at www.sisterhoodapp.com
- Share your family history of any and all bleeding problems. Don’t assume that “women in our family are just bleeders.” You may still have hemophilia if you don’t have a family history.
- Tell how your bleeding problem has impacted your life, including your family, relationships, career, education, and other areas.
- Make a list of all medications you are taking (including herbal medications).

Tips for the talk

- Advocate for yourself. Be confident and prepared.
- Work with your doctor or nurse as a team to make the best treatment decision for you.
- Be open to the conversation. Don’t go in defensively, and be willing to listen.
- If you’re considering a trial of medical treatment, discuss with your healthcare team which is a good fit for your lifestyle and activity level.
- Know what hemophilia-related terms mean.
- Bring someone supportive with you.

Be ready for the conversation

It’s important to get all your facts together before you talk with your hematologist. Below are some areas you’ll want to think about and prepare.

Use the resources, checklist, and logs on the next few pages to make sure you’re ready to talk with your hematologist.
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The more concrete evidence that you bring in to your visits and talk to your doctor about, the more they’re going to say, ‘Okay, this is really happening with her.’

– Medical professional

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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.

“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
Aptevo BioTherapeutics LLC, Berwyn, PA 19312

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References:

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Your Period Log

Date of last period: _____ / _____ / ______
Date of first day of period: _____ / _____ / _______

Use copies of this sheet for additional periods.

FOR EACH DAY, RECORD HOW MANY PADS OR TAMpons YOU USED THAT MATCH EACH ILLUSTRATION.

Day 1 Day 2 Day 3 Day 4 Day 5 Day 6 Day 7 Day 8 Day 9 Day 10

Clots the size of a grape or larger (yes or no)
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  - Missed school

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Have you or any family members experienced any of these problems?

- Heavy or long-lasting menstrual periods (number of days, number of pads or tampons used, etc.)
- Joint pain or joint swelling
- Nosebleeds
- Bleeding problems with dental work or surgery
- Heavy or long-lasting menstrual bleeding
- Excessive bleeding after giving birth
- Anemia
- Large clots the size of a grape or larger
- Blending during pregnancy
- Excessive bleeding after giving birth
- Anemia/iron deficiency
- Chronic muscle pains
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- Prolonged bleeding after dental work or surgery
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- Chronic pain
- Muscle bleeds
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Women and girls can have hemophilia B

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### Your Bleeding and Pain Log

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Pain Severity Now</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>2/2/2016</td>
<td>Knee joint</td>
<td>Hurts Little More</td>
<td>Ice and acetaminophen</td>
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</tbody>
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- **Factor IX** (also called anti-hemophilic factor, or AHF)

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