

Understanding Hemophilia B

Hemophilia B is a bleeding disorder that reduces the ability of blood to clot.



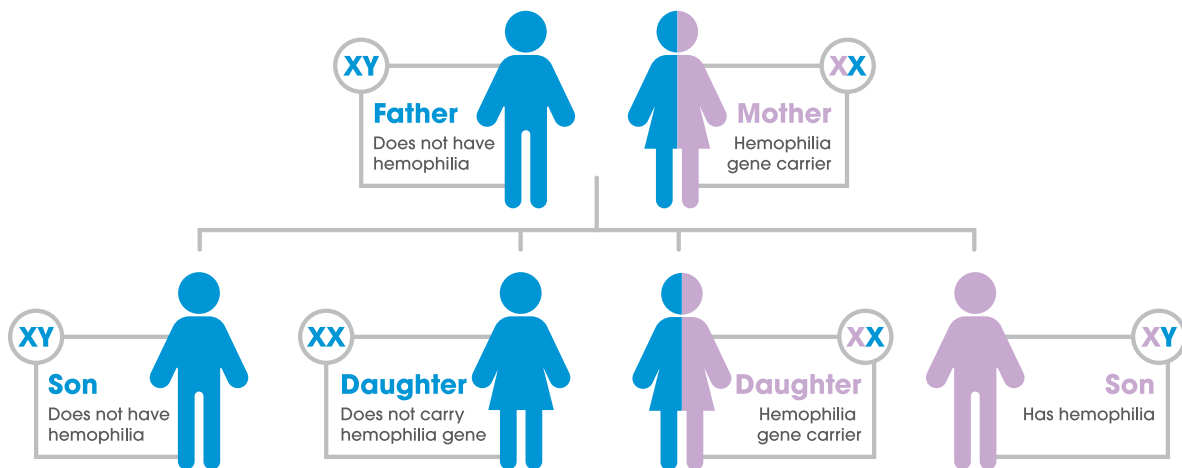
Affecting about 24% of the hemophilia population, hemophilia B causes people to bleed for longer than those without hemophilia. This happens because they are missing or have defective factor IX (FIX or Factor 9)—an important clotting protein in the blood.

Hemophilia B is as unique as you are

While hemophilia A and hemophilia B have similarities, there are important differences between the two that might impact how your hemophilia B is managed. Every person is unique, and individual bleed rates, joint bleed prevention, and personal goals should be considered as part of treatment management discussions with your doctor.

Hemophilia inheritance

Hemophilia B is most common in males and often inherited. It is caused by a mutation to a gene located on the X chromosome. This mutation causes the body to produce less or faulty factor IX. About 30% of hemophilia B cases are caused by a spontaneous gene mutation, meaning there is no family history.



Males

Since males have one X and one Y chromosome (XY), they will have hemophilia if they inherit an X chromosome carrying the hemophilia gene. Males inherit their X chromosome from their mother, so hemophilia is always passed down from a mother to a son.

Females

Since females have two X chromosomes (XX), they can inherit an unaffected gene on at least one of their X chromosomes. Women with a mutated gene are considered carriers and can pass it down to their children.

Hemophilia and severity

People with hemophilia B have less than 50% of FIX in the blood compared to someone without the condition. Depending on factor level, or severity, people with hemophilia can experience bleeds differently. Doctors will classify severity as mild, moderate, or severe.

Mild

5% to <40% FIX in the blood**
Bleeding can occur from injury or surgery
Spontaneous bleeding is **rare**

Affects ~25%
of hemophilia B population

Moderate

1% to 5% FIX in the blood**
Bleeding can occur from injury or surgery
Spontaneous bleeding is **possible**

Affects ~35%
of hemophilia B population

Severe

<1% FIX in the blood**
Bleeding likely from injury or surgery
Spontaneous bleeding is **frequent**—often into joints and muscles

Affects ~31%
of hemophilia B population

*Severity classifications may be different for women with hemophilia

**Factor levels may not reflect bleeding patterns

Hemophilia B is less common than hemophilia A and impacts 15%-24% of all people with hemophilia.

Muscle and joint bleeds

For people with hemophilia, bleeds can happen in muscles or joints, commonly elbows, knees, or ankles.

20%

Nearly 20% of bleeds occur in muscles

80%

Nearly 80% of bleeds occur in joints

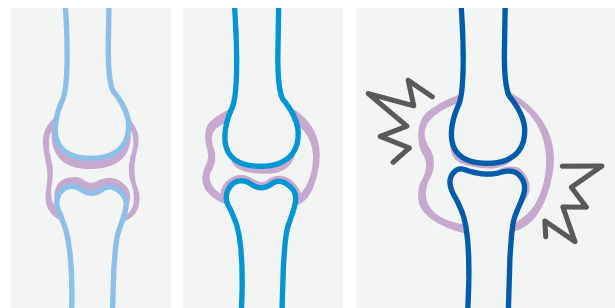
3+

Target joints are joints with 3+ bleeds within a 3-to-6-month period



Frequent joint bleeds can lead to arthritis in people with hemophilia.

Prevention and care of joint bleeds play an important role in avoiding arthritis.



Progressive joint damage

Hemophilia B treatment

Hemophilia B can be treated through factor replacement therapy, infusions of clotting factor to replace what is missing in the blood. Treatment can be for bleed prevention or bleed management:



Bleed prevention:

Regular infusions of factor, or prophylactic treatment, to prevent bleeds before they happen.



Bleed management:

On-demand infusions to resolve a bleed when it occurs. On-demand treatment is especially important for managing bleeds during surgery.

Detecting and managing a bleed

Recognizing the signs and symptoms of a bleed is an important part of managing hemophilia B. People with hemophilia should talk to a doctor before medical or dental procedures and if any of these symptoms are present:



Swelling, pain, or tightness in the joints, particularly the knees, elbows, or ankles



Bleeding after having shots, which could lead to muscle bleeds



Heavy menstrual periods



Bruising on the skin



Blood in the urine or stool



Being diagnosed as iron deficient or anemic



Bleeding in the mouth and gums that's difficult to stop



Frequent and hard-to-stop nosebleeds

Remember: When experiencing a bleed, use the RICE method to help manage it:

Rest

the affected area to avoid further injury



Ice

the affected area to help reduce pain



Compress

the affected area to help limit bleeding



Elevate

the affected area to help reduce swelling



Always talk to a doctor about any bleeding episodes.

Ask your doctor

Ask your doctor about hemophilia B

Here are a few suggestions to help start the conversation.

1. How severe is my hemophilia B?
2. What types of activities are safe for me?
3. If I experience a prolonged or spontaneous bleed, what should I do?
4. What can I do to help prevent joint bleeds?

Notes



For additional resources on navigating life with a bleeding disorder, reach out to your Sanofi CoRe Manager.