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About Your Child's Hemophilia

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What is hemophilia?

Hemophilia (heem-o-FILL-ee-ah), is a type of bleeding disorder. When you bleed, your blood forms a clot to help the bleeding stop. When you have hemophilia, your blood doesn't clot properly.[1,2]

People with hemophilia have less clotting factor than people who don't have the disease. Clotting factors are proteins your body needs to help stop bleeding. The key clotting factors responsible for normal clotting are factor VIII (8) and factor IX (9).[1,2]

People with hemophilia have low amounts of either factor VIII or XI. Hemophilia can be mild, moderate, or severe depending on the amount of clotting factor in the blood.[1]

The two most common types of hemophilia are:[1]

- **Hemophilia A**—missing or low levels of clotting factor VIII
- **Hemophilia B**—missing or low levels of clotting factor IX

Hemophilia A is about 3 to 4 times as common as hemophilia B.[1]

About 400 babies are born with hemophilia A each year. It's estimated there are up to **33,000 males** in the United States living with the disorder.[3]

What causes hemophilia and why is it more common in boys than girls?

Hemophilia is usually passed down from parent to child. This means most people are born with it. Hemophilia is caused by a mutation (change) in the gene that makes clotting factor VIII or clotting factor IX. When this occurs, the blood doesn't clot properly. The genes for these factors are located on the X chromosome. Chromosomes are structures inside of your body's cells that contain genes.[2]

Males get an X chromosome from their mother and a Y chromosome from their father (XY). Females get two X chromosomes, one from their mother and one from their father (XX).[2]

Because males have only one X chromosome, if they inherit an X chromosome from their mother with a gene mutation for factor VIII or factor XI, they will have hemophilia. Since females have two X chromosomes, this gives them some protection from hemophilia. Girls can have severe hemophilia if both parents pass down a copy of the faulty gene, but this is rare.[2]

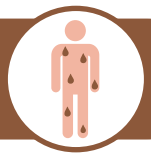
Females that inherit one X chromosome with a gene mutation for hemophilia will be carriers of the disorder. Carriers can pass hemophilia on to their children. Some girls and women who are carriers can have bleeding symptoms, but they are usually mild.[2]

How Hemophilia is Inherited[2]

Overall, if the mother is a carrier and the father doesn't have hemophilia there's: • A 50% chance their daughters will be carriers • A 50% chance their sons will have hemophilia	Overall, if the mother isn't a carrier and the father has hemophilia, there's: • A 100% chance their daughters will be carriers • A 0% chance their sons will have hemophilia

About one-third of babies born with hemophilia don't have a family history of the disease.[4]

What are the signs and symptoms of hemophilia?



Common signs of hemophilia may include:[1,5]

- Bleeding that's hard to stop after the newborn's umbilical cord falls off
- Too much bleeding that doesn't stop with pressure after a cut, dental procedure, or surgery
- Frequent and hard to stop nosebleeds
- Blood in urine or stool
- Pain and swelling from bleeding into joints – such as the elbows, knees, and ankles
- Large bruises and bruising often
- Bleeding under the skin, causing tiny purple, red, or brown spots

Bleeding can be serious or life-threatening if it goes on for too long or if it occurs in the brain, throat, joints, abdomen, or organs.[6]

How is Hemophilia Diagnosed?

In the United States, most people are diagnosed at a very young age.[1] Most parents with a family history of hemophilia will ask that their baby be tested soon after birth.[4] If the doctor thinks your baby is showing signs of hemophilia, they will:[4]

- Ask about any personal and family history of bleeding disorders
- Do an exam to check for signs of bleeding
- Do screening tests to see if the blood is clotting properly

Blood factor tests are required to diagnose hemophilia. This type of test will show the type of hemophilia your child has and how serious it is. This is important as it will help determine the best treatment plan for your child.[4]

Hemophilia treatment centers (HTCs)

The best place for patients with hemophilia and other bleeding disorders to be diagnosed and treated is at a comprehensive hemophilia treatment center (HTC). The doctors, nurses, and other healthcare providers at HTCs are specialists in caring for people with bleeding disorders. HTCs provide a range of services for patients and their families within one treatment facility. They can also serve as a resource for your child's regular doctor or dentist. An HTC can help ensure your child receives the expert care, education, and support they need to be healthy and prevent serious problems.[7,8]

Tips to Help Support and Protect Your Child

- Learn all you can about hemophilia and your child's treatment plan so you can make informed decisions about their care[9]
- Learn how to examine your child and recognize signs of bleeding early[6]
- Help your child understand their condition. Ensure they can explain it to someone if needed[9]
- Know how to keep your child safe and protect them from injuries[6]
- Get support and connect with others in the bleeding disorders community. Attend educational events for people with hemophilia[6,9]
- Talk with your child's teachers, coaches and other caregivers about when to contact you and when to call 9-1-1[6]
- Ask your child's doctor or pharmacist about medicines that may not be safe. Some medicines can increase the chance of bleeding[6]
- Have your child wear a medical identifier, such as a necklace or bracelet[6]

Get more information and support at stepsforliving.hemophilia.org

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