

What Should I Tell My Family?

Now that you know you are a carrier of hemophilia, you should consider talking to family members

How do I get started?

Genetic counselors at the Indiana Hemophilia and Thrombosis Center (IHTC) will:

- » Review your family history to help identify any family member who could be a carrier
 - Generally sisters, mothers and daughters first, then consider aunts and female cousins
- » Determine individuals that need to be tested for hemophilia

How can I get help with this?

Discussing your family history of hemophilia can be difficult. We are here to help in any way we can. If you want to discuss who to talk to, what to say, or ways to approach family members, please contact one of the IHTC genetic counselors. Let your family members know that the IHTC is always available should they have any questions or concerns. You are always welcome to refer family members to us if they need assistance you cannot provide.

Important facts to review with your family members

- » The type of hemophilia in your family: factor VIII deficiency, also called hemophilia A, and factor IX deficiency, also called hemophilia B or Christmas disease
- » Testing is available to determine whether they are a carrier
 - If a woman is not a carrier, her child will likely not have hemophilia
 - If a woman is a carrier, there is a 25% chance of having a child with hemophilia with each pregnancy
 - Each son has a 50% chance of having hemophilia
 - Each daughter has a 50% chance of being a carrier
- » If a woman is a carrier, she should:
 - Have her factor level checked, because carriers may have an increased risk of abnormal bleeding, especially with dental, surgical, or invasive medical procedures if their factor level is low
 - If pregnant, contact the IHTC to:
 - Help determine if there is a risk for bleeding during delivery
 - Ask that recommendations for delivery be sent to your obstetrician
 - Send cord blood testing - if the baby is a boy (need special kit and instructions which will be provided)
- » If your family has a history of mild hemophilia, male family members of any age may not know they have hemophilia and need to be tested
- » There are multiple reproductive options available to carriers. These options can be discussed with a genetic counselor at the IHTC