

Hemophilia C/Factor XI Deficiency

What Your Results Mean

Testing results indicate that you are a carrier of factor XI deficiency, also known as hemophilia C. Factor XI carriers have an increased risk for mild bleeding. You and your partner or donor would both have to be carriers of factor XI deficiency for there to be an increased chance to have a child with symptoms; this is known as autosomal recessive inheritance. Carrier testing of your partner or donor is recommended in addition to consultation with a genetic counselor for a more detailed risk assessment.

We recommend that you share and discuss this information with all of your health care providers. Since this is an inherited gene change, this information may be helpful to share with family members as it may impact their family planning and their own personal clinical management.



Recommended Next Steps

Carrier testing of your partner or donor is available. If both you and your partner or donor are carriers for factor XI deficiency, each of your children has a 1 in 4 (25%) chance to have the condition. Consultation with a genetic counselor for a more detailed risk assessment is available.

Factor XI Deficiency/Hemophilia C Explained

What is Factor XI Deficiency/Hemophilia C?

Factor XI deficiency, also known as hemophilia C, is a mild inherited bleeding disorder. It is typically less severe than hemophilia types A and B because it rarely causes spontaneous bleeds; however, bleeding episodes may occur with trauma, certain types of surgery, and dental procedures. Individuals with factor XI deficiency are also prone to bruising and nosebleeds. Affected women often have heavy menstrual periods and can experience prolonged bleeding after childbirth.



Prognosis

Life expectancy is normal if proper precautions with surgeries are taken.

Treatment

A variety of treatment options are available to prevent bleeding, including fresh frozen plasma (preferably pathogen-inactivated), factor XI concentrates, and antifibrinolytics, to name a few. Additionally, individuals with factor XI deficiency will benefit from referral to federally funded hemophilia treatment centers.



Resources

National Hemophilia Foundation

<https://www.hemophilia.org/Bleeding-Disorders/Types-of-Bleeding-Disorders/Other-Factor-Deficiencies/Factor-XI>

Genetics Home Reference

<https://ghr.nlm.nih.gov/condition/factor-xi-deficiency>

National Society of Genetic Counselors

<https://www.nsgc.org/>