

Carriers of Hemophilia

Clotting Factor Levels & Abnormal Bleeding

20–25% of carriers of hemophilia have a factor level in the range of mild hemophilia

Carriers of hemophilia and females who potentially could be carriers should have a factor VIII or IX level performed

The IHTC can discuss treatment with you for abnormal bleeding you experience and recommend preventative treatment for future procedures if needed

This information is important for carriers of hemophilia or females who could be carriers of hemophilia to know. In the last 5-10 years more has been learned about the occurrence of bleeding symptoms in women who are carriers of hemophilia A (factor VIII deficiency) or hemophilia B (factor IX deficiency). It has been known that there is a wide range of clotting factor VIII or IX levels in female carriers of hemophilia A and B. Recently, studies have revealed more about the frequency of bleeding symptoms experienced by carriers of hemophilia.

Carriers have been shown to have factor levels that may range from 5%–220%, with the normal range being from 50–150%. It is estimated that 20–25% (1/4–1/5) of female carriers of hemophilia A and B have a clotting factor level less than 40%; these women are low level carriers of hemophilia. Low level carriers are at-risk for abnormal bleeding, similar to men with mild hemophilia, with symptoms that may include:

- » abnormal bleeding after tooth extraction
- » abnormal bleeding after tonsillectomy and/or adenoidectomy
- » heavy menstrual bleeding
- » abnormal postpartum bleeding
- » bleeding complications after surgical or invasive medical procedures

These bleeding problems may lead to complications that require treatment. Therefore, knowing your factor VIII or IX level is important to know when preventative treatment is needed.

Females who are carriers of hemophilia rarely have spontaneous bleeding problems. Therefore, not having experienced abnormal bleeding in the past does not rule out the possibility that your factor level is insufficient to prevent bleeding, especially in stressful events such as childbirth, surgery, or trauma. It is recommended that all females who are carriers of hemophilia, or potentially could be a carrier of hemophilia, have a factor level performed to determine the risk of abnormal bleeding. This is done by obtaining a blood sample. We can assist you in having this testing completed.

If it is found that you have a low factor VIII or IX level, we will discuss preventative treatment recommendations prior to procedures, and treatments for abnormal bleeding. We keep a record of factor levels of females with a family history of hemophilia, and can provide this information and treatment recommendations if necessary in an emergent situation. If you have this testing performed by another physician, please call or forward a copy of your results to the IHTC so that we have it on file.

If you have questions, would like to arrange to have your factor level performed, or need assistance, please contact us at 317-871-0000 or toll-free 1-877-256-8837.

