Hemophilia Carriers & Pregnancy

Indiana Hemophilia & Thrombosis Center

If you are pregnant or planning a pregnancy and your family has a history of hemophilia, there are some important facts you should know:

- **Knowing your chance to have a child with hemophilia is important medical information for you, your child and your physician.**
- **There is testing available to better define your chance of having a child with hemophilia.**
- **If desired there may be prenatal testing available for your baby or testing prior to conception.**

Hemophilia A (factor VIII deficiency) and hemophilia B (factor IX deficiency) are bleeding disorders caused by an abnormality in one of the clotting factors. Both types of hemophilia are inherited as X-linked recessive conditions. They are called "X-linked" because the genes for factor VIII and IX are located on the X chromosome. Chromosomes are in each of our cells and contain all of our genetic information. Chromosomes are very similar between males and females, except females have two X chromosomes while males have an X and a Y. Thus, females normally have two copies of clotting factor VIII and IX genes and males have only one copy. When there is an alteration or change in the factor VIII or factor IX gene, a male will have hemophilia. A female with an alteration will be a carrier of hemophilia.

Testing is available to find out whether or not a female who has hemophilia in her family is a carrier. Genetic testing is the most accurate method of carrier testing, and involves obtaining a blood sample to look at a woman's factor VIII genes for the specific gene alteration causing hemophilia in the family. Testing for carrier status with factor levels does not rule out carrier status. If you were tested by factor levels, you may have received inaccurate information. Finding out if you are a carrier gives you important medical information for yourself and your children. ***Carrier testing may help you make family planning decisions, allows for prenatal diagnosis if desired, and may indicate precautions for yourself and your child when your child is born.*** Therefore, if you are currently pregnant or planning to have children, it is important to find out more about your risks and the availability of testing.

The following are steps you should take to learn more about carrier testing:

1. Talk with your physician and arrange to meet with a genetic counselor to discuss carrier testing and your options.
2. Contact the Indiana Hemophilia and Thrombosis Center (IHTC) at (317)338-7200 or toll-free at 1-877-256-8837 for more information and to speak to the IHTC genetic counselor.
3. Talk with your family to find out what type of hemophilia (factor VIII or factor IX) is present, the severity (mild, moderate, or severe) and whether anyone has had genetic testing done.
4. If you are found to be a carrier for hemophilia or if there is a chance you are a carrier, difficult delivery (suction apparatus; high forceps) should be avoided and a male baby should be tested for hemophilia at birth through cord blood testing. Cord blood testing instructions and kits are available through the IHTC. Circumcision should be delayed until his results are known.

Indiana Hemophilia & Thrombosis Center, Inc.
8402 Harcourt Road, Suite 500 Indianapolis, IN 46260 Phone: 317-871-0000 | Toll Free: 1-877-256-8837 | www.ihtc.org