NATIONAL HEMOPHILIA PROGRAM COORDINATING CENTER

This family planning resource was created by the National Hemophilia Program Coordinating Center (NHPCC) Genetics Workgroup.

About the National Hemophilia Program Coordinating Center

The American Thrombosis and Hemostasis Network (ATHN) is a non-profit organization committed to improving care for individuals affected by bleeding and clotting disorders. In June 2012, the Maternal and Child Health Bureau of the Health Resources and Services Administration funded ATHN to establish the National Hemophilia Program Coordinating Center. The NHPCC serves as a bridge between the regional HTC networks, helping to create value on a national scale. The NHPCC partners with regional leadership, over 135 ATHN-affiliated HTCs, the National Hemophilia Foundation, Hemophilia Federation of America, and other patient advocacy groups, government partners, the 340B Drug Pricing Program, the genetics and newborn screening collaborative, payers, and thought leaders to guarantee a community-wide perspective. **To learn more about the NHPCC, visit athn.org/what-we-do/nhpcc/about.**

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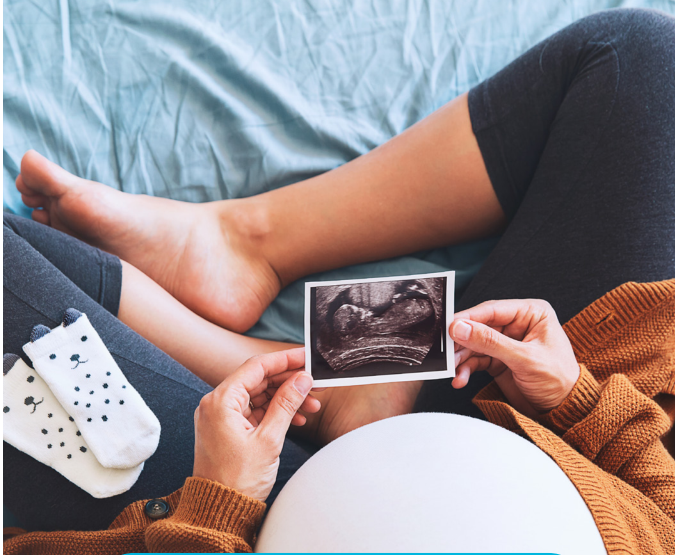

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Family Planning for Hemophilia Carriers

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If you have a genetic link to hemophilia, there are special options to consider and decisions to make when planning a family. Whether you are thinking about starting a family, already pregnant, or preparing for delivery, this family planning overview can help at each stage.

Pre-pregnancy planning

A woman who has one non-working copy of a hemophilia gene is considered a "carrier". A carrier may pass an affected gene on to her child. A carrier may or may not exhibit symptoms of hemophilia.

Before getting pregnant, it's important to find out if you are a carrier so you can make informed decisions and get clear and accurate information about concerns such as:

- ➜ Likelihood of transmitting hemophilia to your child
- ➜ How it may affect the child, whether male or female
- ➜ Options available for conception, prenatal testing, and fetal sex determination
- ➜ Treatment and care options available in case your child has hemophilia
- ➜ Managing pregnancy, labor, and delivery to reduce risks to both mother and child

Pregnancy and delivery planning

Most women who are hemophilia carriers are able to have normal pregnancies without any bleeding complications. However, it's still important to take some precautions. For example, it's important to monitor the levels of protein factor VIII, which should rise, and protein factor IX, which does not change significantly. Factor levels should be checked in the third trimester of pregnancy, when they are at their highest. If levels are low, precautions need to be taken to reduce the risk of excessive bleeding during labor and in the days after delivery.

Your hemophilia treatment center (HTC) health care team can work closely with you and your obstetrician to create a birth plan that will help improve the likelihood of a safe birth and post-partum recovery.

Be sure to talk with your health care provider about which prenatal testing and birth planning options are right for you and your baby.

Talk to your health care provider or a genetics counselor about hemophilia carrier testing, reproductive options, and other considerations before getting pregnant.