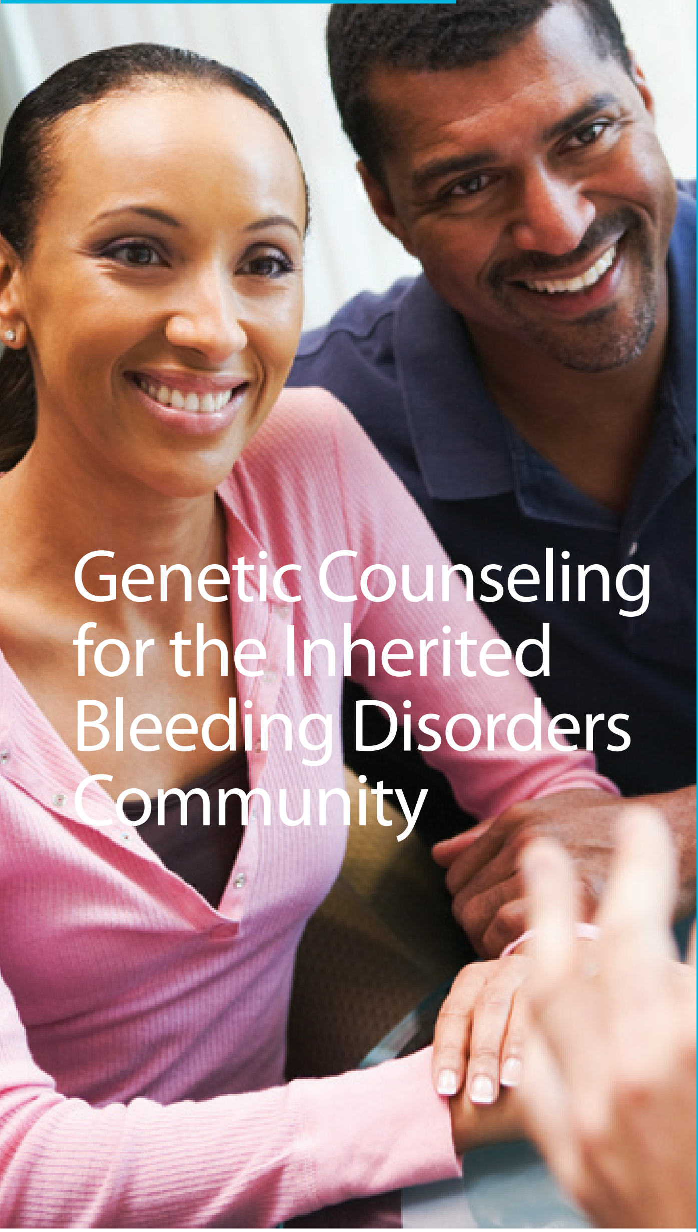
NATIONAL HEMOPHILIA PROGRAM
COORDINATING CENTER



Genetic Counseling for the Inherited Bleeding Disorders Community

athn™
american thrombosis
& hemostasis network

Securing Data. Advancing Knowledge. Transforming Care.

Genetic counseling is a way of helping you understand a genetic disorder, like an inherited bleeding disorder.

Genetic counselors are health care providers with specialized training in medical genetics and counseling. They can help make difficult information about genetics easy for you to understand. They can provide information and support to family members and individuals who have or may have a chance of having an inherited bleeding disorder. They can also talk to your other health care providers to help them understand the genetics of your inherited bleeding disorder. They are part of a health care team.

Genetic counseling may be helpful if you:

→ have an inherited bleeding disorder;

→ are being evaluated for an inherited bleeding disorder;

→ are considering genetic testing for an inherited bleeding disorder;

→ are thinking about having children and want to know if they would have a chance of inheriting a bleeding disorder;

→ have a family member with an inherited bleeding disorder;

→ want to know if other family members have a chance of having an inherited bleeding disorder;

→ want help understanding the results of your genetic testing; and

→ want help talking with your family members about inherited bleeding disorders.

A genetic counselor can:

- describe what genetic testing can and cannot tell you and your family members;
- help you collect a detailed family history, with focus on family members who may have an inherited bleeding disorder or bleeding symptoms;
- provide you with information about how inherited bleeding disorders run in families;
- explain the chances of you or your family members having (or being a carrier for) an inherited bleeding disorder;
- talk about how genetic testing may change or impact your care;
- inform you about available genetic resources and genetic research studies;
- walk you through and arrange genetic testing for you, if desired;
- review results of your genetic testing with you, or your family members, at your request;
- provide support and written information to help you tell other family members about your diagnosis; and
- answer any questions you might have about prenatal or preconception testing options.

Find a Counselor near you.

Go to the National Society of Genetic Counselors website to find a genetic counselor near you at www.nsgc.org.

For more information about genetic counseling or to speak with a genetic counselor, talk to a healthcare provider at your Hemophilia Treatment Center clinic or doctor's office.

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, patient advocacy groups, government partners, payers, and thought leaders to guarantee a community-wide perspective. **To learn more about the NHPCC, visit athn.org.**

This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number #UC8MC24079, the National Hemophilia Program Coordinating Center, for $800,000. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government. Brochure developed by the Genetics Work Group of the National Hemophilia Program Coordinating Center (NHPCC)

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