The Foundation Fighting Blindness recommends genetic counseling for patients and families before and after genetic testing. Genetic counseling includes discussions about (i) personal and family health, (ii) potential benefits of genetic testing to the patient and family, (iii) types of information genetic testing can and cannot provide, and (iv) health and lifestyle implications based on the outcome of the genetic testing.

Genetic counseling is typically provided by professionals specially trained in the field (e.g., physicians, geneticists, genetic counselors).

**Note about genetic testing outcomes:** It is important that patients understand that even though genetic testing is available, not all genetic mutations will be identified.

**Why is genetic counseling important?**

*It guides information gathering:* Genetic testing cannot be performed without an accurate body of background information about the patient’s medical condition and family medical history. This involves gathering and coordinating a body of data including the construction of a pedigree (a family tree). It helps with decision-making, tailors the genetic testing, and improves the likelihood of finding a genetic mutation.

*It guides patients and families as facts are imparted:* Genetic counseling guides patients and families through the jumble of information about the limitations and benefits of genetic testing and in the interpretation of test results. It is also designed to help patients and families manage the stress and emotional aspects of the process.

**Why seek the services of a trained genetic counselor?**

Genetic counselors are specially trained in genetics, all aspects of genetic testing, and psychological counseling. They hold graduate degrees and are typically a member of a health care team. Their focus is to guide the patient and family through the complex process and to be an informed conduit of information between the doctors, patients, laboratories, and often even the insurance companies. Although rare, some ophthalmologists and primary care physicians have experience in genetic counseling. Geneticists, who may also provide genetic counseling services, are usually research scientists.
What happens during genetic counseling?

A genetic counselor would typically work with a patient and family over an extended period of time. Following is the common course of action for a genetic counselor:

- Gather information about family history and medical history.
- Discuss the diagnosis affecting the patient or family.
- Explain typical inheritance patterns and provide risk assessment.
- Research what genetic tests are available for the particular disorder.
- Explain the benefits, and limitations of genetic tests.
- Go through a decision making process with the patient and family to help with deciding whether to go ahead with genetic testing or not.
- Arrange for blood samples to be drawn and sent to the testing laboratory.
- Discuss the results of the genetic testing and the implications with respect to such things as career choices and family planning.

Genetic counseling is available in most communities. For additional information about genetic counseling and to find a genetic counselor, contact the National Society of Genetic Counselors (phone: 610-872-7608; website: www.nsgc.org).

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