Hereditary Cancer Risk Program

Frequently Asked Questions

What is genetic counseling?

Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates:

- Collection and interpretation of family and medical histories to assess the chance of disease occurrence or recurrence
- Education about inheritance, testing, management, prevention, resources and research
- Counseling to promote informed choices and adaptation to the risk or condition

What to expect from my visit?

During the patient's initial visit to the clinic, a genetic counselor will review the personal and family medical history, discuss the role genes play in the development of cancer, and basic genetic concepts. A personalized risk assessment for hereditary cancer, a description of the genetic testing process, as well as information about cancer risk reduction and prevention strategies are discussed in detail. The family history is carefully assessed and the risk of carrying an inherited cancer gene mutation is determined and fully discussed.

An appointment with the Hereditary Cancer Risk Program consists of a consult with both a genetic counselor, and possibly a blood draw, if testing is pursued. There is no need to fast prior to the blood draw. The initial consult lasts an hour to an hour and a half, depending on the questions that arise.

Test results are available in two to five weeks (depending on the test(s) ordered). Results will be discussed in detail at a follow up appointment (we give test results over the phone, but meet patients in person when requested). We then have a thorough discussion about future management recommendations and risk reduction strategies.
What is the cost of testing?
The genetic tests range in cost depending on the specific gene(s) being tested, and if there is a known familial mutation. The costs can be anywhere from $200 to $4000 (or more depending on the test ordered). Most insurance pays for testing, but coverage is dependent on each individual's policy. We will help with the preauthorization process and determine the level of insurance coverage for testing at the time of your visit.

Most, but not all, insurances cover the cost of the genetic counseling visit.

If you have a HMO insurance, it is your responsibility to obtain a referral for genetic counseling prior to our ability to check with your insurance.

The CPT CODE we use is 96040 and the hospital where you have a scheduled appointment is the billing institution.

What about genetic discrimination?
There are federal laws which prohibit health insurance discrimination based on genetic information. The Health Insurance Portability and Accountability Act (HIPAA), which was enacted in 1996, states that genetic information should not be considered a pre-existing condition. Individuals with a genetic mutation cannot be denied health insurance. An individual changing from one group health plan to another cannot be refused coverage. On May 21, 2008, the President signed GINA (Genetic Information Nondiscrimination Act) into law. This law prohibits employers and insurance companies, both private and public, from discriminating against an individual because of their genetic status. Therefore, an individual with any type of health insurance cannot be genetically discriminated against (cannot lose health insurance, nor be dropped from a policy, nor be denied health insurance if switched insurances). This law still does not cover life insurance or disability. For more information, please visit http://www.geneticfairness.org/.

Does genetic testing really make a difference if I already know I have a family history of cancer?
Yes. Genetic testing for inherited cancers helps you and your doctor understand your true risk so you can make the best choices for cancer prevention and early detection.

Who is the most appropriate person to first have cancer genetic testing in my family?
The individual diagnosed with cancer is the most appropriate person to be tested first. However, if this person is unavailable for testing, a family member who is cancer free could be considered for testing.

**Are genetic tests covered by insurance?**

Most health insurance plans pay for these tests, but not all do, and is dependent on your specific policy. 90% of our patients have at least 80% coverage for genetic tests. We can assist in the preauthorization process and most laboratories will determine the level of insurance coverage for testing prior to any testing beginning.

**Who can gain access to my genetic test results?**

Genetic test results are strictly confidential. Under no circumstances will patient results be given to any party without the written consent of the patient.

**What types of cancers are associated with inherited gene mutations?**

Only approximately 10% of all cancers are hereditary. Many different cancers can be related to an inherited gene mutation. The most common are:

- Breast
- Ovarian
- Colon
- Endometrial (uterine)
- Prostate
- Stomach
- Kidney
- Pancreatic
- Melanoma
- Other rare cancers

**What important information can be attained from genetic counseling and screening?**

Genetic counseling and screening can help determine a person's risk of developing certain cancers. This allows implementation of risk-reducing interventions: better screening, surgical prevention, and chemoprevention. This information can be helpful for both an individual as well as their family members in preventing cancer from developing.

**What else should I know about individual and family genetics?**
Genes can be passed down through a woman or a man equally. A father or mother can pass on a gene mutation to his daughter or son.

What is involved with genetic testing?
 Genetic counseling, education, and consent is obtained. Blood is drawn with informed consent and the sample is sent to a lab. DNA extraction and analysis is performed. Results appointment conducted to discuss genetic testing results and implications for medical management.

How soon are results available?
 Anywhere, from 2 to 6 weeks, depending on the specific test ordered.