



GENETIC TESTING:

WHAT IT MEANS FOR YOUR HEALTH AND YOUR FAMILY'S HEALTH



What is genetic testing?

Genetic testing looks at your genetic material, such as DNA and RNA, and molecules, such as proteins. This type of testing can find genetic differences that can affect your health.

What can I learn from genetic testing?

The results of genetic testing may help to:

- ◆ Diagnose a disease.
- ◆ Find genetic differences that have caused your already diagnosed disease.
- ◆ Find genetic differences that may increase your risk for getting a disease.
- ◆ Find genetic differences that you could pass on to your children.
- ◆ Guide your health care provider to choose the best treatments for your disease.

When should I talk with my health care provider about genetic testing?

You may want to ask your health care provider about genetic testing if you:

- ◆ Have a family history of an inherited disease, such as muscular dystrophy or sickle cell anemia.
- ◆ Have a history in your family of cancer, particularly breast or colon cancer.
- ◆ Have parents, brothers or sisters, or other relatives who have developed common diseases, such as heart disease or Parkinson's disease, before they were 50 years old.
- ◆ Are thinking of having a baby and you or your partner have a family history of an inherited disease, or if either of you belongs to an ethnic group with an increased risk of certain genetic diseases. For example, people who are of Ashkenazi Jewish ancestry have an increased risk to have a baby born with Tay-Sachs disease.

How is genetic testing done?

Genetic tests are done on a small sample of tissue or fluids from your body, such as:

- ◆ Blood
- ◆ Cells swabbed from inside your mouth (cheek swab)
- ◆ Saliva
- ◆ Hair
- ◆ Skin
- ◆ Tumors
- ◆ The amniotic fluid that is around a baby during pregnancy (obtained during a procedure called amniocentesis)

The sample is sent to a laboratory that tests it for certain differences in your genetic material. The laboratory provides a written report of your test results, usually to your health care provider who then talks with you about the report. Your provider may suggest that you also talk to a genetic counselor, who can help you to understand what the test results mean for you and your family.

What are some issues I should know about if I am thinking of having a genetic test?

If you are trying to decide whether or not to have a genetic test, here are some issues you should know about when you are making that decision:

- ◆ Whether or not there are ways to prevent or treat the disease for which you (or your child) are being tested?
- ◆ The cost of the genetic testing and whether your health insurance will cover the cost.
- ◆ The availability of genetics professionals who can talk with you about all of the benefits and possible risks of genetic testing.
- ◆ A federal law called the Genetic Information Nondiscrimination Act (GINA) was passed in May 2008 to help protect you against employment and insurance discrimination based on your genetic test results and other personal genetic information.

Where can I get more information about genetic testing?

You can learn more about genetic testing from these Web sites provided by the National Institutes of Health.

- ◆ Genetics and Rare Diseases Information Center –
<http://rarediseases.info.nih.gov/GARD>
- ◆ National Human Genome Research Institute – Genetic Testing –
<http://www.genome.gov/Pages/Health/PatientsPublicInfo/GeneticTestingFactSheet.pdf>
- ◆ National Human Genome Research Institute – Genetic Information Nondiscrimination Act (GINA) –
<http://www.genome.gov/10002328>
- ◆ Genetics Home Reference –
<http://ghr.nlm.nih.gov/handbook>
- ◆ Medline Plus –
<http://www.nlm.nih.gov/medlineplus/genetictesting.html>
- ◆ National Cancer Institute –
<http://www.cancer.gov/cancertopics/UnderstandingCancer/genetesting>
- ◆ The Collaboration, Education and Genetic Test Translation (CETT) Program –
<http://www.cettprogram.org>



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