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## **[Sharing Genetic Test Results With Your Family](#) [1]**

This section has been reviewed and approved by the [Cancer.Net Editorial Board](#) [2], 01/2015

### **Key Messages:**

- It is important to share the information you learn from genetic testing with family members.
- The way you share this information with each family member depends on your relationship with that person.
- Talk with a genetic counselor about how and what to share with family members about your test results.

If you have a strong family history of cancer, you may choose to meet with a genetic counselor and have [genetic testing](#) [3] to learn about your cancer risk. However, be aware that the results of these tests also affect your family members.

For example, you may find out that your child or sibling could have an increased risk of specific types of cancer. That is why if you choose genetic testing you are strongly encouraged to share the results with family members. Even if the result is negative, meaning you do not have a gene mutation, you should share this information. A [genetic counselor](#) [4] can help you with this process.

### **Your genetic test results**

You have a greater than average risk of developing cancer if you test positive for a cancer susceptibility gene mutation. If you have already been diagnosed with cancer, you may have an increased risk of developing other cancers. Learn more about [cancer risk](#) [5].

When you receive the test results, your genetic counselor will discuss the meaning of a positive test result for both you and your family members. Discussing cancer history and genetic testing ahead of time may make sharing test results easier. In some situations, you may want to bring a family member with you to learn the test results so that there is someone who can help share them. You may find it helpful to discuss how your relatives would like you to share the results before you receive them.

When first hearing the results, a person who tests positive for a gene mutation may feel grief, anger, anxiety, or depression. A person may also feel guilt about possibly passing the mutation to his or her child. However, a person may also feel relieved to learn a reason for the cancer in the family and empowered to make medical decisions that lower cancer risk.

## **Sharing positive test results with adult family members**

How you choose to share test results with family members depends on your comfort level and relationship with each family member. For relatives that you do not have a close relationship with, a letter might be a good approach. For closer relatives, you may consider a phone call or face-to-face meeting. A genetic counselor can help you share the information in the way that is most comfortable for you.

The two important scientific pieces of information to share with family members are:

- The specific gene where the mutation was found. Many hereditary cancer syndromes are linked to more than one gene.
- The specific mutation. Gene mutations are commonly given a combination of numbers and letters, such as the 187delAG mutation in the *BRCA1* gene.

This information is what a laboratory will need to test your family members. It is very helpful to provide family members with a copy of your test report. They can take this report with them if they choose to have genetic counseling or testing.

## **What family members choose to do with the information**

Relatives who may have an inherited gene mutation are encouraged to talk with their doctor and a genetic counselor about cancer risk. A genetic counselor can review [cancer screening](#) [6] guidelines and discuss the risks, benefits, and limitations of genetic testing. Your genetic counselor or health care team can help you find qualified genetic professionals near your family members. They can also provide written information to share with your family. Two resources are [National Society of Genetic Counselors](#) [7] and [National Cancer Institute Genetics directory](#) [8].

Not everyone's reaction to genetic testing is going to be the same. Some relatives will be thankful for the information and seek genetic counseling. Others may not want to know the results or have testing. Some family members may feel that knowing the results will make them more anxious about the risk of cancer. Parents may feel guilty about possibly having passed on

an increased cancer risk to their children. Other family members may feel bad if they do not have the gene mutation when other relatives do.

Close family members, such as siblings, children, and parents, should be given recommended cancer screening guidelines. They should also follow the recommendations for people who have a high risk of the cancer until they learn their own genetic testing results.

It is important to be supportive but not pushy when talking to relatives about genetic testing. Everyone should be given the opportunity to make his or her own decision about whether to be tested.

## **Sharing positive test results with children**

Only a few known hereditary cancer syndromes increase the risk of cancer in children. These include [familial adenomatous polyposis \(FAP\)](#) [9], multiple endocrine neoplasia (MEN) [types 1](#) [10] and [type 2](#) [11], and [von Hippel-Lindau syndrome](#) [12] (VHL). If a person in a family tests positive for a gene mutation linked with one of these disorders, it is important for the children at risk to have genetic testing. Children who test positive for the mutation will need to begin cancer screening while they are still children, sometimes as young as infants. Children who test negative for the gene mutation can be spared invasive medical procedures.

It is important for you to explain to your child, according to their age and maturity level, why he or she needs to have testing. You should also let your child know what to expect, since genetic testing can involve drawing blood. A genetic counselor and a medical geneticist, who is a doctor with training in genetic diseases and conditions, can help you talk with your child about genetic testing and the specific condition in the family.

Testing children or adolescents for hereditary cancer syndromes that cause cancer in adults is not recommended. It is important, however, to answer any questions about the family history as openly and honestly as possible. As your children grow older, they may have questions about the family history of cancer. They can be reassured that, despite the family history, there are steps they may be able to take to lower their cancer risk.

## **Sharing negative test results with family members**

If you receive a negative test result, meaning that you do *not* have a specific gene mutation, your genetic counselor will help you understand what this means for you and your family. You may be relieved to know this specific type of cancer does not run in your family. Or, you may be left with more questions if it seems like there has been a high incidence of cancer in the family. After a negative test result, sharing this information with your family may be helpful because they will know that they do not need testing.

## **More Information**

[The Genetics of Cancer](#) [13]

[Collecting Your Family Cancer History](#) [14]

[Hereditary Cancer-Related Syndromes](#) [15]

[Direct-to-Consumer Genetic Testing](#) [16]

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#### **Links**

[1] <http://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/sharing-genetic-test-results-your-family>

[2] <http://www.cancer.net/about-us>

[3] <http://www.cancer.net/node/24895>

[4] <http://www.cancer.net/node/24907>

[5] <http://www.cancer.net/node/25007>

[6] <http://www.cancer.net/node/24972>

[7] <http://www.nsgc.org/>

[8] <http://www.cancer.gov/cancertopics/genetics/directory>

[9] <http://www.cancer.net/node/18852>

[10] <http://www.cancer.net/node/19366>

[11] <http://www.cancer.net/node/19365>

[12] <http://www.cancer.net/node/19322>

[13] <http://www.cancer.net/node/24897>

[14] <http://www.cancer.net/node/30761>

[15] <http://www.cancer.net/node/24905>

[16] <http://www.cancer.net/node/24382>