

Sharing Genetic Test Results with Adult Family Members

The results from your genetic test have an impact on your family, regardless of whether the results detected a mutation or found that you do not carry the mutation identified in another member of your family. It is important to share the results of your test with all family members regardless of how close or distant to those relatives you are, and assumptions about whether or not the relative would want to know the information should not be made. It is generally accepted that the individual being tested has the responsibility to share the information within their own family. Your healthcare provider cannot assume this role.

We've collected some of the most commonly asked questions regarding sharing test results with family members and hope that the answers listed below will be helpful in creating a plan for sharing information within your family.

How do I find relatives with whom I have lost contact?

Our digital age is making it easier to locate lost relatives. Social media sites such as Facebook and Linked-In are resources that can be used to search for relatives. On-line white pages, peoplefinders.com, and genealogy websites are also effective at finding family members. Adoption agencies can be contacted to attempt to locate relatives who were placed for adoption. Fertility centers can also be contacted to attempt to locate sperm and egg donors and other children of donors.

How should I notify my distant family members?

If you are trying to contact a relative that you may not be close with and can't pick up the telephone to call, consider sending an e-mail or letter. Introduce yourself, how you are related, and the reason for your contact. In your initial contact be careful about oversharing information. At first, be general and explain that you've learned some important genetic information that may be relevant to them and their branch of the family. Determine when it would be a good time to talk. Then, once you've established contact, share more details and facts about the genetic information that has been learned and their next steps. Share information about how to locate a genetic counselor in their area and where to read more information. Relatives who live in the Connecticut area can make an appointment with Smilow Cancer Genetics and Prevention at 203-200-4362. Other family members can find a genetic counselor in their area using the "Find a Genetic Counselor" tool at www.nsgc.org. Consider sharing a copy of your summary letter, a fact sheet on the topic, or websites.

Should I notify the men in my family if the gene mutation that I have is primarily associated with "female" cancers (i.e., BRCA1/BRCA2)?

Absolutely. Men and women have an equal chance of carrying (or not carrying) a mutation associated with any hereditary cancer syndrome. It is a common myth that the men in the family cannot carry a mutation associated with hereditary breast and ovarian cancer, when in fact male carriers can also be at increased risk for certain cancers (e.g. male breast cancer, prostate cancer).

Their children (daughters and sons) can also be at increased risk to have inherited the familial mutation.

How do I notify estranged relatives?

It can be challenging to re-contact family members after months or years of no contact, or after a serious illness. While this can be challenging, we encourage patients with positive test results to attempt to contact relatives at risk to inherit the familial mutation, as this information is pertinent to their healthcare. Enlisting other family members who may be in closer contact with these relatives can be helpful. If you know how to contact these relatives, consider enlisting the help of your genetic counselor. You may be able to sign a consent form allowing family members to gain access to your genetic test results through the clinic that you were seen for genetic counseling. Together, you and your genetic counselor may also be able to write a family letter that can be shared with relatives, either anonymously or more openly.

What is the best way to reach out to family members with mental, intellectual, and/or physical differences?

It is helpful to navigate these situations with the help of other family members and relevant care providers. If your relative has someone who is legally responsible for their medical decisions, contact them first to discuss the importance of the genetic information to that person's medical care and to determine the next steps. Medical providers, social workers, psychologists, and care providers who work directly with your relative may be useful contacts to develop a plan for their medical care.

What if my relative does not want to know?

This can be challenging, especially if you feel differently. While it is important to respect the beliefs and feelings of your relatives, sometimes it can be helpful to give the relative some time to process and research the information on their own and at their own pace. Give them some room at first and then consider revisiting the issue at a different time.

Before reaching out to your relatives, prepare yourself for the different possible responses and reactions you may receive. It is important to understand that negative reactions such as anger, frustration, sadness, and disinterest are typically not directed at you personally. It is normal to have fear of negative reactions by at-risk relatives. What relatives decide to do upon learning this information from you is their choice. They may choose to see a genetic counselor for their own genetic testing, or they may not be interested in doing so. Regardless of what they do with the information, your decision to share the information with them empowers them to make their own choices.

If you are interested in meeting with a genetic counselor to discuss your family history, which family members to contact, and develop a plan for contacting your family members, please call our office at 203-200-4362 to schedule an appointment.