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, were uninformative, or demonstrated that you do not carry the mutation identified in another member of your family. While there is no legal obligation to share the results from your test with relatives, you may feel ethically or morally responsible to share test results that could have a significant impact on the health and well-being of your family members. Your health care provider cannot assume this role. It is generally accepted that the individual being tested has the responsibility to disseminate the information within their own family. However, this can be complicated by family dynamics, individual beliefs, and the physical location of your relatives.

What your relatives will or will not want to know should never be assumed. All family members should have equal access to the information from genetic testing, regardless of how close or distant you are to that relative. Even if you are not interested in sharing your own genetic status, family members should be notified that there is some important medical information that is available to them. It is not your job to act as gatekeeper of the family genetic results, and doing so could be harmful to your relatives.

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 disseminating 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. Our program website (https://medicine.yale.edu/cancer/patient/specialty/genetics/) lists several databases and resources for locating family members.

**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 overshar ing information. You may take your relatives off-guard or catch them at a less than perfect time and risk sharing information that they are not prepared to learn. 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. Resist the temptation to over-share the personal decisions you have made to take charge of your medical care based on your test results.
**Should I notify the men in my family?**
Absolutely. Men and women have an equal chance of carrying (or not carrying) a mutation associated with any hereditary cancer syndrome. Many patients wrongly assume that the men in their 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. Despite this, these relatives should not be excluded from such information. 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. Your genetic counselor may provide permission for your relatives to contact them directly, therefore bypassing you and allowing the relative to gain access to the information they are interested in learning.

**Do family members with challenges (i.e. mental, intellectual, or physical) need to know?**
Do not try to make this decision on your own. If your relative has someone who is legally responsible for their medical decisions, contact them first to discuss the relevance 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 his/her 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 in a non-pressured atmosphere.

Before reaching out to your relatives, prepare yourself for the different possible responses and reactions you may receive. While an anticipated negative reaction is not reason to avoid reaching out to your family members, it is important to take care of yourself and understand that any anger or frustration you may encounter is not directed at you personally. You are simply relaying the information.

If you are interested in meeting with a genetic counselor to discuss your family history, which at-risk 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.