

Family Studies Program

SAMPLE PATIENT LETTER FOR APPROVED RELATIVE(S)

It is important to approach your relatives about the subject of genetic testing with sensitivity and respect for each relative's preferences and personal situation, and to encourage them to discuss any questions they may have with a genetic counselor. Keep in mind that not everyone in your family may wish to be informed about your genetic testing results.

Every family has its own ways of communicating, and even people within the same family may communicate in different ways. Some people prefer to discuss sensitive health matters in person, some may prefer to talk by telephone, and some people may feel more comfortable communicating in writing. Whatever way you and your family choose, it is often helpful to send a letter to follow up on your discussion with each of your relatives. The following is an example of what you may write in a letter that informs a relative of your test result, and tells them about the option of participating in the Ambry Family Studies Program:

Dear Family Member,

As you may know, I recently had genetic testing to look for genetic changes (mutations) related to risk for a genetic condition or disease. Mutations in certain genes can increase a person's risk for disease, and they can help explain why a certain condition runs in a family. My genetic test did not detect any mutations that are known to cause increased disease risk, but the test did find a genetic change called a "variant of unknown significance." This means that it is not currently known if this genetic change increases disease risk. Since it is unclear what this test result means, using our family medical history is still the best way to determine disease risk and what type of monitoring or screening we should receive.

The laboratory that performed my genetic test may offer familial variant testing to some of my family members to see if they also have the genetic change that was found in my sample. The lab tests family members to get more information to help determine if the genetic change is associated with disease risk. However, it is important to remember that the lab still may not have a clear answer about the meaning of the genetic change even after testing more relatives.

I understand that not everyone will want to participate in familial variant testing. I also know that thinking about genetic testing and risk for a genetic condition or disease can be difficult. If you are interested in participating in familial variant testing, or if you just want to learn more about it, I would be happy to go with you to see a genetic counselor or I can help you find a genetic counselor to meet with on your own.

I have included a copy of my genetic test result for you in case you want to discuss it with your doctor or a genetic counselor. My doctor will be notified if more information becomes known about the genetic change that was found in my sample, and I will be sure to share any new information with you as well.

If you want to see a genetic counselor, you can ask your doctor for a referral, or you can find a genetic counselor near you at nsgc.org. Please call me if you want to talk about this some more or if you have any questions.