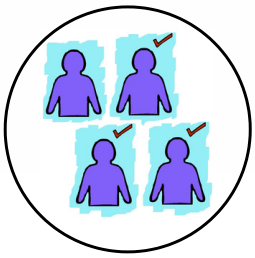
Using your FAMILY SHARING LETTER

People in your family should know about your mutation because they might have inherited it, too. To help you share this news, your genetic counselor can prepare a letter to give to your family. This letter answers questions your relatives might have about the mutation and explains why it puts your family members at higher risk for disease.

Your relatives can choose to take the letter to their health care teams.
The information can help them make decisions about whether to get their own genetic testing.



DECIDE WHO SHOULD RECEIVE THE LETTER

The letter is most useful for parents, children, siblings, aunts, uncles and first cousins. If you know which side of the family the mutation comes from, focus on that side.

Most people don't share the letter with more distant relatives because they can't identify who is most at risk.

However, if you've learned which great-grandparent (or other relative further back) had the mutation, you may be able to identify which distant relatives might have inherited the mutation.

From this group, think about who you can reasonably contact in person, through email or over social media.

If you aren't in a position to give the letter personally to someone, ask yourself if another person in the family could pass on the letter.

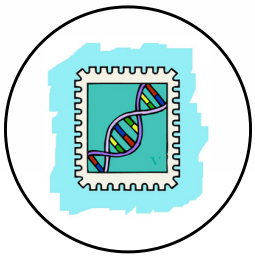


GET THE LETTER READY TO SEND

Add your test results as an attachment to the letter. The report should include the date of testing, the specific test that was performed and the exact variant in the family. Your relatives should show this report to their health care providers to make sure they get the right genetic testing.

If you're uncomfortable sharing personal information, it's fine to black out your name and other private details on the report.

It can be helpful to include a note to introduce the letter. Don't try to interpret the results. Simply let your relatives know that you are sending the letter because you think they might want to know what's going on. The letter is about sharing information, not convincing anyone to get genetic testing if they don't want it.



SEND THE LETTER

Send the letter in a way that fits how you usually communicate.

In some families, emailing to a group works. You could distribute copies at a family reunion or post a message on social media—wherever your family likes to talk. Think about what distribution method would make the most sense for your family.

In other families, large-scale distribution isn't possible. In that case, send the letter to the people you communicate with. Use whatever method feels most comfortable.

To reach as many people as possible, recruit an ally in your family to help. Many families have one member who is in touch with everyone. If this is not you, enlist this person.



FOLLOW UP WHEN IT MAKES SENSE

Expect family members to have different responses. Not everyone feels the same way about genetic testing. Some may immediately get tested. Others may save the information for later or not want to think about it. All reactions are valid.

Follow-up discussions can sometimes help relatives feel more comfortable about getting genetic testing. Just ask if they've given any more thought to testing. Be open to their response, whatever it is.

In some situations, it may make sense to resend a letter to a relative who has not been tested after a year or more. After this time, they may be in a better position to act on the information.

A "No" to genetic testing may not mean "Never." Keep the conversation going when it makes sense.

Find resources for talking to your family about genetic risk at connectmyvariant.org.