

# FAMILY SHARING

## PARKINSON'S DISEASE GENETIC TEST RESULTS

This handout is intended to provide guidance for sharing your Parkinson's genetic test results with family members. Deciding if, when, and with whom to share your genetic test results is your personal choice. It is normal to feel concern about how you will share your genetic risk information with family members or how your family members may react.

### 1) Before sharing, be prepared personally

**It is normal to feel guilt, worry, relief, or anxiety after receiving your test results.** Give yourself time to accept those feelings and adjust to your results.

- Identify someone who can support you through the process of disclosure to your family.
- Ask for assistance from a professional, such as a genetic counselor, if needed.

### 2) Decide whom you would like to share your results with, and how

Genetic test results for Parkinson's disease are different from other results because they are usually not "medically actionable." This means they do not prompt a change in medical care to treat Parkinson's disease or reduce the risk of disease. At this time, we do not know of any changes in medical care that will significantly reduce the chance of someone getting Parkinson's disease. This may affect whom you share your results with in your family and how urgent it may be.

Family members who are first-degree relatives (parents, siblings, and children) are usually at the highest risk of carrying your same genetic change, followed by those who are second-degree relatives (grandparents, aunts, uncles, nieces, and nephews).

**The age of the family member is important to consider.** Given Parkinson's disease is typically an adult-onset condition, medical professionals would not recommend genetic testing for anyone under the age of 18. Even though Parkinson's disease does not usually occur early in life, there are still reproductive implications that may be relevant for young-adult family members considering family planning.

**Modes of communication can vary.** Face-to-face conversations, phone calls, emails, and letters have all been used to share genetic results with family. Each family member may prefer a different mode of communication with you.

### 3) Prepare yourself before disclosing

Review the information from your genetic counselor or health care provider and reach out to them if you have any questions. You do not need to be an expert and know everything about your results before talking to your family member.

**Anticipate your family member's reactions as well as your own reactions.** A wide range of emotional responses is expected and normal. Some family members may have negative reactions of anger or sadness (this is more likely if results are positive) and, understandably, this could cause you to become upset. Other family members may express relief and feel empowered by this information.

Family members without Parkinson's disease who choose to pursue genetic testing may learn they have an increased risk for the disease in their lifetime. While there are laws (such as the Genetic Information Nondiscrimination Act of 2008 – also called GINA) that protect them against genetic discrimination relating to employment and health care, these laws do not protect individuals against discrimination relating to life insurance or long-term care insurance. For more information, please visit [www.ginahelp.org](http://www.ginahelp.org) as a resource.

**Have a copy of your test results available** to provide to your family member, especially if a variant was found. This will make the genetic testing process smoother and verify the specific gene variant (mutation) if they decide to pursue testing. Having other resources available for your family members can be helpful as well should they want to learn more or if you are unable to answer all of their questions.



# FAMILY SHARING (CONTINUED)

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### Tips for disclosing your test results

First, find a good place and time to disclose. Let relatives pace how much information they want at a certain time. For some, discussion of genetic test results is not a one-time conversation, but rather one that evolves over time.

If younger children have questions, let them be your guide. You may want to ask them what they want to know and keep it simple. Children may approach the topic very differently from an adult. And again, you can pace the information you give over time.

### Genetic testing for relatives

**Genetic testing is a personal choice;** we do not recommend “talking your family member into” genetic testing, even if you think that is the best decision.

If you have a negative result, and a variant was not identified, genetic testing for family members typically is not recommended. The same test is not likely to be helpful in close relatives. If you have a positive result, relatives may or may not want genetic testing. As noted, this is a very personal decision.

Some reasons why a person without Parkinson's disease would *want* to pursue genetic testing for Parkinson's disease:

- Qualify for research that is furthering our knowledge of Parkinson's disease
- Reproductive decision-making
- Reduce anxiety; some individuals want to know all possible information about their personal health when given the option
- Give themselves time emotionally to consider the idea of having an increased chance of developing Parkinson's disease in their lifetime

Some reasons why a person without Parkinson's disease would *not want* to pursue genetic testing for Parkinson's disease:

- There is no cure or actionable ways to prevent or significantly reduce the risk of having Parkinson's disease. Therefore, if they cannot do anything about it, they would prefer not to know their risk
- Avoid worry and anxiety about their personal risk for having Parkinson's disease in their lifetime
- Avoid guilt about passing it on to their children, or “survivor's guilt” if they test negative when other individuals in the family test positive
- Concern about genetic discrimination (see above)

After disclosure, if your family member has further questions about their risk for Parkinson's disease, or if they are interested in pursuing genetic testing, a consultation with a genetic counselor is recommended. To find a local genetic counselor, the following website is a helpful resource: [www.findageneticcounselor.com](http://www.findageneticcounselor.com).

### References

23andMe. Shared Risk: Talking to Family Members About Genetic Test Results [website]. Retrieved from <https://customer care.23andme.com/hc/en-us/articles/115004545907-Shared-Risk-Talking-to-Family-Members-About-Genetic-Test-Results>.

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