PD Nexus

Family Sharing

Parkinson’s Disease Genetic Test Results

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

Before sharing, be prepared personally

- It is normal to feel guilt, worry, relief, or anxiety after receiving your genetic test results. Give yourself time to accept those feelings and adjust to your results.
- Identify someone who can support you through the process of communicating to your family.
- Ask for assistance from a professional, such as a genetic counselor, if needed.

Decide who 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 reduce the risk of disease. At this time, we do not know of any changes in medical care that will significantly lower the chance of someone getting Parkinson’s disease. This may affect whom in your family you share your results with and how urgent it may be.
- Family members who are first-degree relatives (mother, father, sisters, brothers, daughters, and sons) are usually at the highest risk of carrying your same genetic change, followed by second-degree relatives (grandmothers, grandfathers, aunts, uncles, nieces, and nephews).
- The age of the family member is important to consider. Since Parkinson’s disease typically begins in adulthood, medical professionals do not recommend genetic testing for individuals under the age of 18 who do not exhibit symptoms. This is related to the idea that every person should have the right to choose for themselves whether to pursue testing for an adult-onset condition, particularly when they have the maturity to understand all of the implications. In addition, genetic test results for Parkinson’s disease will not typically change medical care (see Genetic testing for relatives below).
- The way genetic test results are communicated can vary. Face-to-face conversations, phone calls, emails, and letters have been used to share results with the family. Each family member may prefer a different way of communication from you.

Prepare yourself before sharing

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

- Anticipate your family member's reactions as well as your own reactions. A wide variety of emotional responses is expected and normal, including reactions of anger or sadness. This is more likely if the genetic test results are positive. Understandably, this may cause you to feel upset. Other family members may express relief and feel empowered by this information.
- Family members without Parkinson's disease who decide to pursue genetic testing may learn they have an increased risk for the disease in their lifetime. Although there are laws that protect people against genetic discrimination in relation to employment and health care (The Genetic Information Nondiscrimination Act of 2008 – also known as GINA), these laws do not protect them against discrimination in relation to life insurance or long-term care insurance. For more information, visit www.ginahelp.org.
- Have a copy of your genetic test results available to provide to your family member, especially if a genetic change was found. This will make the genetic testing process smoother and verify the specific genetic change (variant) if your family member decides to pursue testing. Having other resources for your family members can also be helpful if they want to learn more or if you are unable to answer all of their questions.

Sharing of test results

- First, choose a good time and place to share.
- Your participation in this research study could be a good talking point to start.
- For some, discussion of genetic test results is not a one-time conversation but rather one that evolves over time. Let your family member pace how much information they want to receive at that time.
- Younger children may approach the subject very differently from an adult. You may want to ask children what they want to know and keep it simple. Pace the information you provide over time, letting them be your guide.

Genetic testing for relatives

- Genetic testing is a personal choice; we do not recommend that you "convince your family member" to have genetic testing, even if you think it is the best decision.
- If a genetic change was not identified in your testing, it is typically not recommended that family members get genetic testing. The same test is not likely to be helpful in close relatives.
- If your result is positive, your family members may or may not pursue genetic testing. As mentioned before, this is a very personal decision, which is why testing is not recommended for individuals under the age of 18.

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 about Parkinson's disease.
- Reproductive decision-making.

- Reduce anxiety; some individuals want to know as much information as possible about their personal health when given the option.
- Give themselves time to think about the idea of having a greater chance of developing Parkinson's disease in their lifetime and to prepare emotionally.

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 chance of Parkinson's disease. Therefore, if nothing can be done about it, they prefer not to know their risk.
- Avoid worry and anxiety about their personal chance for having Parkinson's disease in their lifetime.
- Avoid guilt about passing it on to their children.
- Prevent feelings of guilt if the test result is negative and other individuals in the family test positive.
- Concern about genetic discrimination (see above).

After sharing your results, if your family member has further questions about their risk for Parkinson's disease, or if they are interested in pursuing genetic testing, it is recommended that they consult with a genetic counselor. The following website is a useful resource for finding a local genetic counselor: https://www.findageneticcounselor.com/.

References

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

Daly MB, et al. Communicating genetic test results to the family: a six-step, skills-building strategy. Fam Community Health (2001), 24:13-26.

Gaff et al. Process and outcome in communication of genetic information within families: a systematic review. Eur J Hum Genet (2007) 15, 999-1011.

Hartzfeld, D. Familial Amyotrophic Lateral Sclerosis (FALS) and Genetic Testing [website]. Retrieved from http://www.alsa.org/als-care/resources/publications-videos/factsheets/genetic-testing-for-als.html

Pilarski, R. with the National Society of Genetic Counselors (2013) Sharing Testing Results with Children and Other Relatives – Guidance for Your Patients [PowerPoint]. Retrieved from https://www.nsgc.org

For additional information about Parkinson's disease genetics and research visit PDNexus.org

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Understanding & Sharing Genetic Results

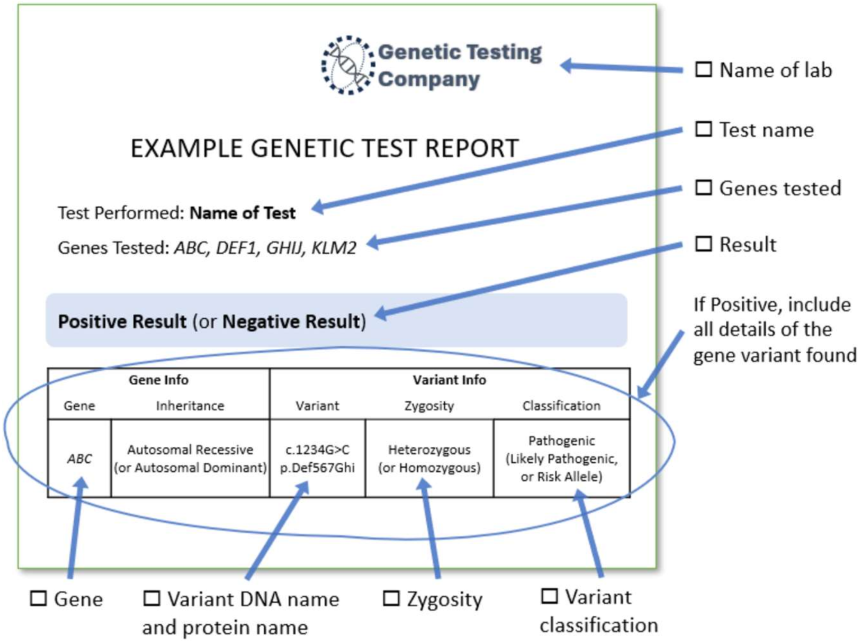
A genetic testing report can contain technical information that may be difficult to understand. This handout can serve as a guide to your testing report to help you identify the important information. For more explanation of specific words and phrases, a glossary of genetic terms can be found at https://www.genome.gov/genetics-glossary.

You may choose to share your genetic testing information with relatives. If possible, sharing a copy of your full test report is ideal. The details below are the key points to share with relatives, especially those who might choose to seek testing.

Important details from your test report:

☐ Name of laboratory/company that did the test
☐ Name of the test and list of genes tested
☐ Result (Positive or Negative)
☐ If Positive, the full gene and variant information:
  - Gene
  - Variant DNA name (starts with a "c.")
  - Variant protein name (starts with a "p.")
  - Zygosity of variant (usually listed as heterozygous or homozygous)
  - Classification of variant (could be listed as pathogenic, likely pathogenic, or risk variant)

Below is an EXAMPLE report:



Genetic Testing Company

EXAMPLE GENETIC TEST REPORT

Test Performed: **Name of Test**

Genes Tested: *ABC, DEF1, GHIJ, KLM2*

Positive Result (or **Negative Result**)

Gene Info		Variant Info		
Gene	Inheritance	Variant	Zygosity	Classification
ABC	Autosomal Recessive (or Autosomal Dominant)	c.1234G>C p.Def567Ghi	Heterozygous (or Homozygous)	Pathogenic (Likely Pathogenic, or Risk Allele)

☐ Name of lab
☐ Test name
☐ Genes tested
☐ Result

If Positive, include all details of the gene variant found

☐ Gene
☐ Variant DNA name and protein name
☐ Zygosity
☐ Variant classification