TBK1 Gene Information

Key Points

- You have a variant in the *TBK1* gene.
- *TBK1* variants have been associated with frontotemporal dementia (FTD) and amyotrophic lateral sclerosis (ALS), and other neurological symptoms.
- You should talk about this result with your neurologist to understand what this means for you.

TBK1

What is *TBK1*?

TBK1 is a gene that all people have. A gene is an instruction for your body. When there is a variant in the TBK1 gene, it doesn't work well, causing problems related to a condition called *TBK1*-FTD/ALS spectrum. Note that FTD stands for frontotemporal dementia and ALS is amyotrophic lateral sclerosis, but not everyone will be diagnosed with these conditions. People with *TBK1* variants can have changes in how they act (behavior), trouble with speaking, thinking problems, weakness, and trouble walking. Some people with *TBK1* variants can also have other neurologic symptoms including movement problems like those seen in Parkinson's disease. These symptoms can be different for each person.

What does this mean for me?

- Conditions caused by *TBK1* variants can look like Parkinson's disease or other neurologic conditions.
- You should talk to your neurologist or a movement disorder specialist to understand how this result relates to you and your symptoms.
- Please refer to the Association for Frontotemporal Degeneration for more information: https://www.theaftd.org/what-is-ftd/ftd-and-als-ftd-als/

What does this result mean for my family?

- *TBK1* variants are inherited, meaning they are passed down in families. *TBK1* conditions happen when a person has one variant in the *TBK1* gene, from one parent. This is called dominant inheritance.
- Your close family members (like your children, siblings, and parents) have a 50% (1 in 2) chance of having the same *TBK1* variant. However, not everyone with a *TBK1* variant will get symptoms. Sometimes it can remain "silent", meaning it does not cause any problems. Researchers are studying what other things influence whether the gene variant affects people.
- Close family members (like your children, siblings, and parents) may benefit from meeting with a genetic counselor to learn about their risks and genetic testing options.

What should I do next?

- Tell your neurologist about these results.
- Talk to your neurologist, movement disorder specialist, or a neurology genetic counselor if you have more questions or concerns.
- Consider sharing these results with your family members.
- Consider participating in additional studies to help researchers better understand the potential link between *TBK1* variants and Parkinson's disease or its symptoms.

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

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