

Genetics and Amyotrophic Lateral Sclerosis (ALS)

Is ALS inherited or hereditary?

Most cases (about 90 out of 100, or 90%) of amyotrophic lateral sclerosis (ALS) are **sporadic** meaning they do not run in families. Only about 10 out of 100 (10%) cases of ALS are **hereditary**, meaning they run in the family.

Mutations in the genes that cause ALS are found in people with and without family histories of ALS. Also, there may be genetic causes of ALS that we are not yet able to recognize.

Do other conditions that run in families increase my chances of having an ALS-related gene mutation?

We have learned that some forms of dementia (specifically frontotemporal dementia), psychiatric diseases, and bone disorders may have genes in common with ALS.

Why would I want to be tested?

- Finding a gene related to ALS can help us understand if it is one of the factors that led you to get ALS.
- Family members may want to know if a genetic disorder runs in the family for family planning purposes.
- Some therapies are being developed for specific genetic forms of ALS which may help you.

Why would I *not* want to be tested?

- Some people may not want to know if a genetic disorder runs in the family.
- Having a genetic disorder could have consequences on an at-risk family member's ability to get **certain** forms of insurance, such as life or long-term care.

- Your health coverage and employment is protected against discrimination based on genetics by the Genetic Information Nondiscrimination Act.

How can I get genetic testing for ALS?

Genetic testing for ALS is available with a blood test. It is important to note that most insurance companies do not cover the cost of ALS genetic testing. Talk to your doctor about whether other opportunities exist for genetic testing. Results of genetic testing does not change the medical treatment and management of ALS.

What are common genes that cause familial ALS?

- C9orf72 (30 to 40 out of 100)
- SOD1 (15 out of 100)
- TARDBP (5 out of 100)
- FUS (5 out of 100)

There are other genes associated with ALS that are less common. Most inherited forms of ALS are **autosomal dominant** meaning that there is a 50/50 chance of passing on the gene to a child.

What can I do if I have familial ALS?

Meeting with a genetics counselor is advised if you or any direct family member has the potential of inheriting the ALS gene.

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