



GENETIC TESTING FOR ALS



Researchers have linked ALS to mutations in more than 30 genes. Genetic testing can identify if someone with ALS has a specific genetic cause for their disease symptoms. Whether or not to get a genetic test is a personal choice. Below we answer your questions about genetic testing so you can make the decision that is right for you.

WHAT CAN A GENETIC TEST TELL ME?

Abnormalities in specific genes are associated with both familial and singleton, or sporadic, ALS. Knowing your genetic test results may help you determine the cause of your ALS, direct you towards specific gene-targeted clinical trials, and can make you aware of risks to other family members.

WHAT DOES GENETIC TESTING INVOLVE?

In most cases, you'll travel to a doctor's office or hospital and a healthcare professional will take a blood or saliva sample. A few weeks later, you'll get your results, which will tell you if any abnormalities were identified in the known ALS-associated genes. Your doctor or [genetic counselor](#) will talk you through the results, either in person or by telephone.



WHAT DOES GENETIC TESTING COST?

Health insurance plans will often cover the cost of genetic testing when it is recommended by a physician. Different health insurance providers might cover different tests, so it is important to speak to your insurance company before getting tested to ask about whether they will cover it.

WHAT ARE THE RISKS OF GENETIC TESTING?

Genetic testing results can impact other family members. One should also be aware of privacy protection and potential insurance discrimination risks. More information can be found [here](#) or at [GINAhelp.org](#).

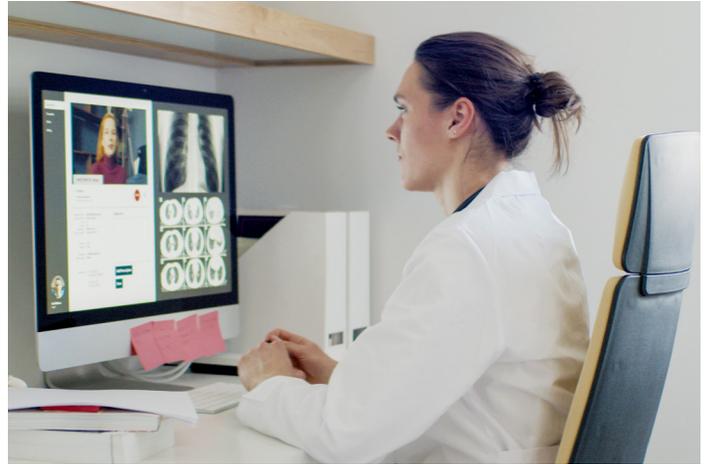
FREE GENETIC TESTING THROUGH ALS IDENTIFIED

The [ALS Identified program](#) offers genetic testing to people with ALS and their families at no charge. The test looks at more than 20 genes that are associated with ALS, including the C9ORF72 gene. It is available to people with ALS and people with a family history of ALS in the U.S. and Puerto Rico. Only a doctor can order this test for you, and you may take this test at home or in a doctor's office.

HOW DO I TALK TO MY DOCTOR ABOUT GENETIC TESTING?

Your doctor may be your best source for answers to your questions about genetic testing, but sometimes, it can be difficult to start the conversation. Here are some questions that you can use to get your conversation started:

- Why should I get a genetic test?
- What are the benefits and limitations of a genetic test?
- How long will it take for me to get my results? How will I receive them?
- What should I do after I get my results?



THE ALS GENETICS DISCUSSION GUIDE

The ALS Association developed the ALS Discussion Guide to help people with ALS, caregivers, and healthcare providers talk about the genetics of ALS. View the guide [here](#).

