



GENETIC COUNSELING



If you or one of your family members are considering genetic testing, you could benefit from meeting with a genetic counselor to discuss the genetics of ALS and genetic testing. These experts work with healthcare providers, caregivers, and people with ALS to arrange testing, interpret the results, and plan out next steps. They can help in many ways, including:

- Talking through the process, potential benefits, limitations, and risks of getting a genetic test
- Interpreting the results of your genetic test and helping you understand what a specific genetic variant means for your future health and health of you family members
- Assisting with family planning
- Working through the psychological, emotional, and social ramifications of living with your genetic test results

Genetic testing is a personal choice. Some people with ALS want to get their genes tested to better understand the cause of their disease and get clues as to whether other family members might develop it. If someone with ALS has an underlying genetic cause, unaffected family members have the option to have predictive genetic testing to learn if they might develop ALS later in life. Meanwhile, others might prefer not to know, since there are currently no treatments for ALS. A genetic counselor can help you decide if getting tested is the right decision for you.



If you choose to get a genetic test, your genetic counselor can help you sign up for a test, interpret the results, plan next steps, and support you in the long term as questions come up.

QUESTIONS TO ASK A GENETIC COUNSELOR

When you embark on your journey of understanding your ALS with a genetic counselor, you are likely to have a lot of questions for them. Here are a few example questions that could help the conversation get started:

- What will happen at my first visit?
- Are there any support resources available to me?
- What are the medical, financial, and psychological risks of getting a genetic test?
- What is the testing process like?
- How will genetic testing affect my insurance coverage?
- How accurate is genetic testing?
- What will the results of my genetic test tell me?
- What can I do with the information I get?
- How will the results of my test impact my medical care?



WHAT DOES GENETIC COUNSELING COST?

Genetic counseling is typically covered by health insurance. For people who do not have health insurance, genetic counseling sessions typically cost \$150 per hour or more. For patients who have health insurance, the visit would equate to a doctor visit or a specialist copay of \$15 to \$35.

Thanks to a sponsorship from Biogen, the diagnostic company Invitae is offering genetic testing and counseling to people with ALS and their families at no charge. Click [here](#) to learn more.

For more information about genetic counseling or how to find a counselor in your area, please visit the National Society of Genetic Counselors at www.nsgc.org. The [Invitae ALS Identified program](#) is also offering free remote genetic counseling. But before you schedule your first appointment, talk to your doctor to get answers to your initial questions and to get started.

