

BENEFITS AND RISKS OF GENETIC TESTING

For Family Members of People Who Have or Had ALS

Benefits	Risks
<p>Medical Benefits: If you find out you have a specific ALS-associated mutation, you might be able to join a clinical trial that could lead to a better outcome for you or people who have ALS in the future.</p> <p>Family Planning Benefits: Understanding your genetic background can also help you make decisions about family planning. Depending on your age and stage in life, you can also work with a counselor or fertility specialist to develop a plan to reduce the chance that the variant gets passed down to your children.</p> <p>Financial Benefits: Finding out that you will likely get ALS early on will enable you to make choices related to future finances for you and your family. It can impact the insurance coverage you choose, timing for stopping work, and long-term lifestyle choices such as a single-story home rather than a multi-level. It may also allow for financial legacy planning for your family.</p> <p>Psychological Benefits: Many people who seek out genetic testing believe that knowledge is power. If it turns out you do not have any mutation that is strongly associated with ALS, you might be relieved that you are unlikely to develop the disease. If you test positive, the certainty might bring relief. Participating in a clinical trial can be empowering and having a clearer picture of your future may provide a level of understanding and ability to plan.</p>	<p>Physical Risks: The physical risks associated with getting a genetic test are very small. All the test requires is a blood sample or, in some cases, a saliva sample.</p> <p>Legal Risks: When someone gets a genetic test, they might be opening themselves up to discrimination. In the U.S., the law protects against genetic discrimination in health insurance and employment, but not in disability, long term care, or life insurance. We recommend securing disability, long term care, and life insurance prior to getting a genetic test. Learn more at http://ginahelp.org/.</p> <p>Psychological Risks: Genetic testing can cause fear, anxiety, and depression, triggered by concern for yourself and your family. Waiting for results is often an emotionally challenging time. Genetic testing results can create strain in marriages and among families. Your results can reveal information about your chance of getting ALS. Also, your results may affect family planning, for example, if you carry a mutation that greatly increases the chance of your children getting ALS.</p>