

# Genetic Testing Sub-Study

**PREVENT ALL ALS**



## What is the Genetic Testing Sub-Study?

It is an **optional** sub-study available for people enrolled in the PREVENT study who are interested in learning more about their personal genetic information and its potential link to their risk of developing ALS.

## What is Genetic Counseling?

**Genetic counseling** is a medical practice where licensed genetic counselors assess the risk of people developing certain diseases and disorders based on their family history and/or testing of their DNA. Genetic counselors educate, support, and guide you through this process to guarantee patient understanding and medical and psychological well-being.

## What is Genetic Testing & What do my results tell me?

In the sub-study, your DNA is tested for approximately 30 genes associated with ALS. **Genetic testing** will determine if there is a change in the DNA that may be associated with an increased risk for developing ALS.

Understanding your genetic test results and their potential implications can be complicated, which is why meeting with a genetic counselor before and after you receive your test results is an essential part of this process.

## Schedule

- 1:** Pre-test genetic counseling
- 2:** Remote DNA sample collection
- 3:** Genetic counseling to discuss test results
- 4:** Follow-up call
- 5:** Any additional counseling (if needed)

Email us for more information:  
 [info@all-als.org](mailto:info@all-als.org)

Visit our Website via QR Code:  
 [all-als.org](http://all-als.org)



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## Can I Join the Sub-Study?

You may be able to join the Genetic Testing Sub-Study if:

- 1:** You are already enrolled in the PREVENT ALL ALS study.
- 2:** You have not previously had genetic testing for ALS-related genes.

If you are interested in discussing the option of genetic testing with a genetic counselor, please reach out to your PREVENT site coordinator. Please know that meeting with a genetic counselor does not mean you must follow through with the genetic-testing. You can change your mind at any point, prior to receiving your results.

## Frequently Asked Questions

### 1) Is genetic testing free?

Yes. Genetic testing and counseling are provided at no cost to you if you are enrolled in the PREVENT study.

Please Note: if additional support is needed due to significant mental health concerns as a result of genetic testing, those services may not be covered.



### 2) Can genetic testing & counseling be done remotely?

Genetic testing & counseling usually takes place virtually, with in-person options at select sites. An at-home kit is used for DNA collection.

### 3) Will the genetic testing results be shared?

You will receive a copy of your results during the meeting with your genetic counselor. These results will be “de-identified” before being shared for research. This means they will be identified via a study ID, and not include your name or any other identifiable personal information.

Please Note: your PREVENT study team will receive these results, but they will not be shared with your personal medical doctor, health insurance, or any other medical provider unless you wish for them to be disclosed.