PREVENT ALL ALS

ACCESS FOR ALL IN ALS

Advancing the Future of ALS Research

The PREVENT ALL ALS study is 1 of the 2 research studies offered in the Access to ALL in ALS (ALL ALS) Consortium. The PREVENT study enrolls people at risk of developing ALS.

The study observes participants for up to 3 years through clinical assessments, neurological, cognitive, and behavioral examinations, and biological sample collection.

Study Objectives

1) Help researchers develop a better understanding of ALS and improve future clinical trials and treatments.

2) Make ALS research opportunities more accessible to the public.

3) Increase engagement with the ALS community.

Participant Benefits

The data and biological samples collected will be essential in accelerating ALS research and in the development of drugs and other therapies.

PREVENT participants are truly making a difference and leading the charge in creating a world without ALS.

What Can You Expect?

- First: Research staff will make sure you are eligible and understand the study requirements. You will sign a "consent form". Find the eligibility requirements on the back of this brochure.
- Visit Schedule: You will have visits every 4 months for up to 3 years. Most visits are done remotely, except for the 4 yearly onsite visits at Baseline, Year 1, Year 2, & Year 3.
- Assessments: During each visit, a set of tests and biological sample collection will be done, including muscle-functionality tests, cognitive screenings, blood collection, and optional lumbar punctures (spinal taps). Also, a set of remote digital assessments and speech tasks will be assigned every 4 months.

Genetic Testing Sub-Study

PREVENT offers an optional genetic testing sub-study for people that have not already received testing for ALS-related genetic variants.

- Participants have an introductory meeting with a genetic counselor to review sub-study details.
- If you qualify, genetic-testing is completed via an at-home saliva kit.
- Participants have a minimum of 2 more meetings with a genetic counselor to review their results.

Eligibility Criteria

You must be ONE of the following:

- A known carrier of an ALS-related genetic variant.
- A first-degree relative (parent, sibling, child) of a carrier of an ALS-related genetic variant.
- A person with a "compelling family history" of ALS and/or Frontotemporal Dementia (FTD).
- ***Note: Eligibility at discretion of site staff. Official screening required.*

You are unable to participate if you are:

- Experiencing symptoms of ALS or FTD.

NOTE: Participants can end their participation in PREVENT at any time for any reason!

Frequently Asked Questions

How will my data and/or samples be used?

Your collected data and biological materials will be stored in protected databases and facilities. Your traceable, private information will be separated from your data, then your data will be shared with vendors and researchers.

Site Locations?

There are 30+ sites located throughout the US. Visit the ALL ALS website for a Site Map that lists all of the site locations and the related site contact information.

I'm Interested. Where do I start?

Fill out the Participant-Interest Form on the ALL ALS website, scan the QR code, or email us.

Visit our Website via QR Code:
https://www.all-als.org

Email us for more information:
info@all-als.org