

ASSESS ALL ALS ACCESS FOR ALL IN ALS

Advancing the Future of ALS Research



The ASSESS ALL ALS study is 1 of 2 research studies offered in the Access to ALL in ALS (ALL ALS) Consortium. The ASSESS study consists of 2 groups:

- people currently living with ALS
- people not living with ALS and not genetically at risk of developing ALS (also known as healthy volunteers or controls)

The study observes participants for up to 2 years through clinical assessments, neurological, cognitive, and behavioral examinations, and biological sample collection.

What Can You Expect?

Participants Living with ALS:

- 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 attend onsite or remote visits every 4 months for up to 2 years.
- 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 monthly.

Healthy Volunteers/ Controls:

- 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 attend onsite visits once a year for up to 2 years.
- Assessments: Review the assessments listed in the "Participants Living with ALS" section of this brochure. The assessments completed by controls will be the same (with a few exceptions).

IMPORTANT NOTE: Complete remote participation is available for people living with ALS!

Participant Benefits

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

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

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.

Eligibility Criteria

People Living with ALS:

- Need ALS diagnosis

NOTE: People can end their participation in the study at any time for any reason!

Healthy Volunteers (Controls):

- No diagnosis of ALS, Primary Lateral Sclerosis (PLS), or Progressive Muscular Atrophy (PMA).
- No familial ALS and/or Frontotemporal Dementia (FTD) in a close family member unless you have tested negative for the known ALS-related genetic variants.

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