Mass General Brigham

Healey & AMG Center
Sean M. Healey & AMG Center for ALS
at Massachusetts General Hospital

Study of ASSESS ALL ALS

Join our study for People Living with ALS and Healthy Volunteers to impact the future of research and treatments for ALS

Updated July 2025

How can I benefit by participating in the ASSESS study as a Person with ALS?

- Participate in research that will further our understanding of ALS and may lead to the development of new treatments
- Join a nation-wide study designed to include all people with ALS by offering both **in-person** and **fully remote** participation options
- Stay connected to current and future ALS clinical research

How can I help by participating in the ASSESS study as a Healthy Volunteer?

- Participate in research that will further our understanding of ALS, particularly the potential biomarkers of disease progression. The information collected may help future research and the development of new treatments
- Opportunity to engage in ALS research alongside family members, friends, or loved ones who may be impacted by ALS

Who can participate in ASSESS?
There are two groups of participants who may qualify:

ALS Participants: Adults 18 years and older with an ALS diagnosis

Healthy Volunteers: Adults 18 years and older without a diagnosis of ALS **OR** who have tested negative for an ALS-causative gene mutation

How often do I have to come in for visits?

ALS Participants: In-person or remote study visits
Study visits **every 4 months over 2 years, total of 7 visits.** Additional remote digital activities will be completed monthly

Healthy Volunteers: In-person study visits
Study visits **once a year over 2 years, total of 3 visits.** Additional remote digital activities will also be completed

Principal Investigator: James Berry, MD, MPH & Robert Bowser, PHD
Sponsor: NIH/NINDS &St. Joseph's Hospital and Medical Center
Enrollment Contact: mghassessallals@mgb.org or call Miranda Durcan at 617-643-9550

What happens at an ASSESS visit?

All participation includes blood collection, a cognitive assessment questionnaire, and remote digital speech activities. Other activities will vary depending on the group you will be participating in, and may include vital capacity (breathing) test, strength testing, and a functional rating scale questionnaire.

Each visit may be 1-3 hours.

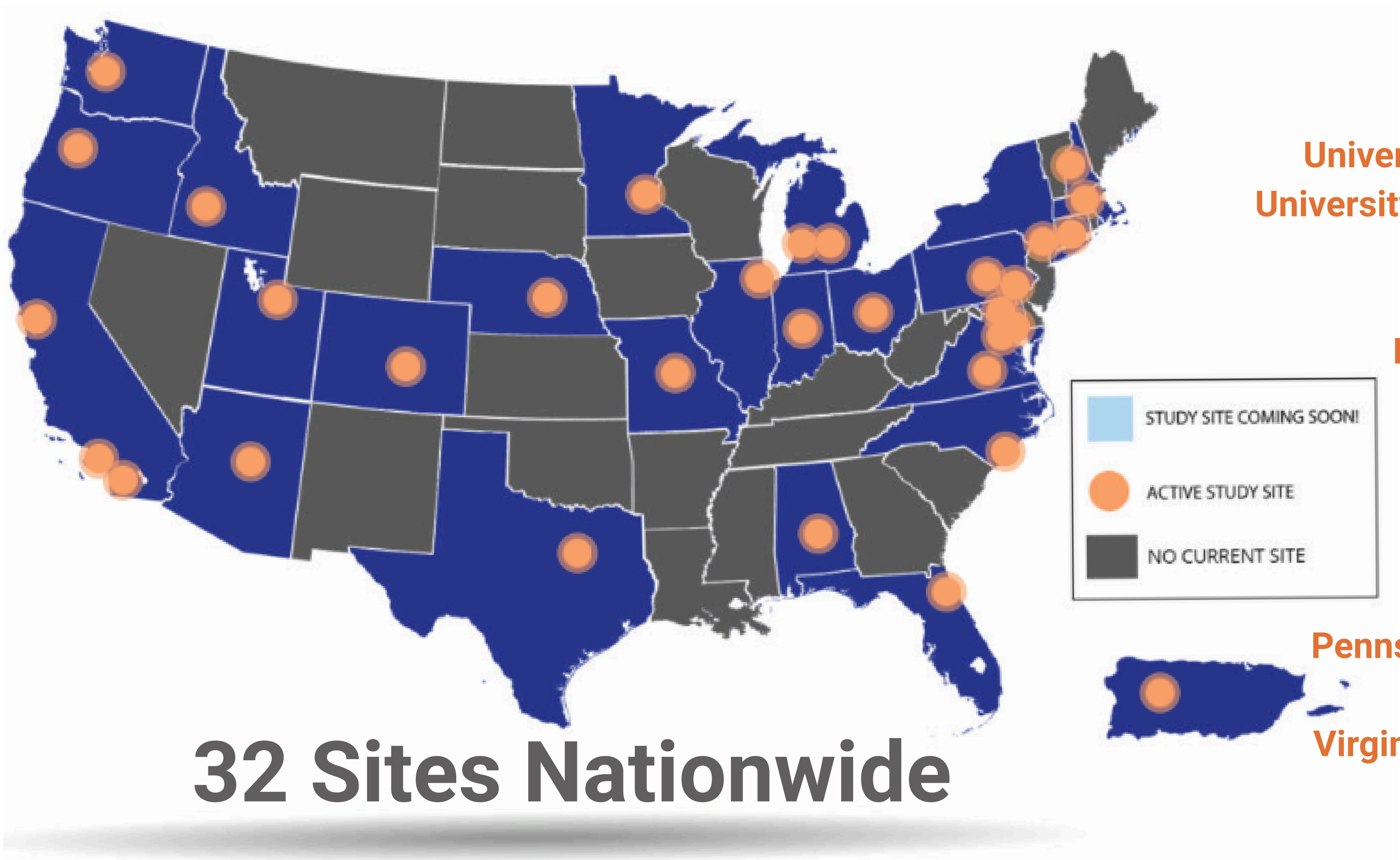
Visit the ALL ALS website to learn more about this study!

www.all-als.org/

Where to Participate

WEST

Barrow Neurological Institute (AZ)
University of California, San Diego (CA)
University of California, Irvine (CA)
University of Colorado, Anschutz Medical (CO)
Georgetown University (DC)
Mayo Clinic (FL)
Saint Alphonsus Regional Medical Ctr (ID)
Northwestern University (IL)
Massachusetts General Hospital (MA)
Henry Ford Health (MI)
University of Michigan (MI)
University of Minnesota (MN)
Washington University (MO)
Columbia University (NY)
Ohio State University (OH)
Providence ALS Center (OR)
Universidad de Puerto Rico (PR)
University of Utah (UT)
University of Washington (WA)



EAST

University of Alabama, Birmingham (AL)
University of California, San Francisco (CA)
Hospital for Special Care (CT)
Indiana University ALS Center (IN)
NIH/NINDS Clinical Research (MD)
Johns Hopkins University (MD)
Duke University (NC)
University of Nebraska (NE)
Dartmouth Hitchcock (NH)
Temple University (PA)
Pennsylvania State Medical Center (PA)
Texas Neurology (TX)
Virginia Commonwealth University (VA)

ASSESS ALL ALS is a nationwide study, with 32 sites located across the country, including our site at Massachusetts General Hospital

Frequently Asked Questions

Will I be paid for my participation?
You will be paid to take part in this research study.
ALS in-person Participants: $75 per completed visit
ALS remote Participants: $50 per completed visit
Healthy Volunteers: $75 per completed visit

What is the purpose of collecting blood samples?
These samples can be analyzed for potential biomarker indicators of ALS disease progression. The goal is to build a library of biological samples and clinical information to help advance ALS research now and in the future.

Will I get my results from this study?
This study is exploratory to discover potential biomarkers, so we are unable to share personalized data.

Sign up for the MGH ALS Link to stay connected to research:

What happens with my samples?
Your samples will be stored at the NINDS Biomarkers Biospecimen and Data Repository, the Biospecimen Exchange for Neurological Disorders at Indiana University, or another biospecimen and data repository selected.

In partnership with ASSESS, PREVENT ALL ALS

PREVENT ALL ALS is a part of the ALL ALS nation-wide study. PREVENT is enrolling people from families impacted by ALS and/or FTD. The purpose is to study people at risk for developing ALS to advance our understanding of underlying early disease changes. The collected information may lead to the development of treatments that target the earliest changes in ALS and allow for possible disease prevention. **Contact:** mghpreventallals@mgb.org or call Anika Allen @ 617-724-9196.