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 November 2024

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 be completed monthly

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 2-3 hours.

Principal Investigator: James Berry, MD, MPH Sponsor: National Institutes of Health and St. Joseph's Hospital and Medical Center, Phoenix AZ

Enrollment Contact: mghassessallals@mgb.org or call Miranda Durcan at 617-643-9550

Sign up for the MGH ALS Link to Stay Connected to Research:

Mass General Brigham

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

ASSESS ALL ALS: Study Timeline & FAQ

Where are the ASSESS study sites located?
ASSESS ALL ALS is a nation-wide study with 35 sites located across the country, including our site at Massachusetts General Hospital, Boston, MA. See the map below for site locations.

WEST
Barrow Neurological Institute (AZ)
University of California, San Diego (CA)
University of California, Irvine (CA)
University of Colorado Denver (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 Brain and Spine (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)
Emory University (GA)
Indiana University ALS Center (IN)
Our Lady of the Lake Regional Medical Ctr (LA)
NIA/NINDS Clinical Research (MD)
John Hopkins University (MD)
Duke University (NC)
University of Nebraska (NE)
Dartmouth Hitchcock (NH)
Pennsylvania State Medical Center (PA)
Temple University (PA)
Houston Methodist (TX)
Texas Neurology (TX)
Virginia Commonwealth University (VA)

Will I be paid for my participation?
You will be paid to take part in this research study.
ALS in-person Participants: $50 per completed visit
ALS remote Participants: $30 per completed visit
Healthy Volunteers: $50 per completed visit

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.

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.

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 Courtney Uek at 617-724-0783**