Mass General Brigham

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

Access for ALL in ALS: PREVENT ALL ALS

Join our observational study for close relatives of individuals affected by ALS

Updated July 2025

How can I benefit by participating in the PREVENT study?

- Receive free, confidential genetic testing and counseling for currently known genes that cause ALS
- Periodic monitoring of your health from our ALS specialized study team
- Participate in research that will further our understanding of ALS and may aid in the development of new treatments
- Get started with clinical care and connect to other research studies should you develop symptoms of ALS while in the PREVENT study

Who can participate?
Adults 18 years and older who:
1) do not have symptoms of ALS, and,
2) have an immediate relative with an ALS-causing gene mutation or compelling family history of ALS.

What happens at a PREVENT visit?
Visit activities may include blood collection, a breathing test, neurological exam, strength testing, speech and cognitive assessments, genetic counseling, and optional spinal fluid collection.

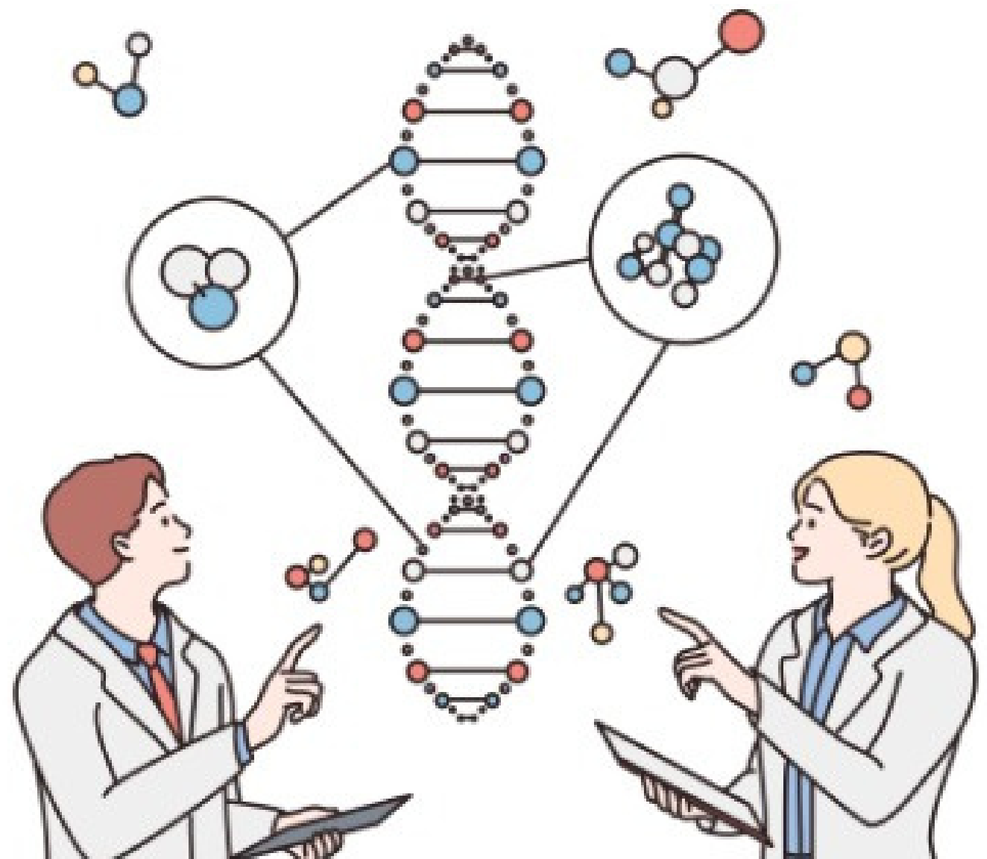
How often do I have to come in for visits?
On-site study visits will occur every 12 months and remote visits will be conducted every 4 months. The length of the study is 3 years.

If you decide to learn your genetic results through the genetic sub-study, you will have 2 additional remote visits: one return-of results visit and one post-return of results visit with our genetic counselor.

Why collect samples of my blood and (optional) spinal fluid?
These samples can help us better understand ALS and how the disease progresses. We hope the information we collect will guide future research to lead to more informed, targeted treatment development for ALS and possible disease prevention.

What happens with my samples?
Your samples are stored in both our on-site ALS Sample Repository and Indiana University's BioSEND Repository. Samples will be shared with collaborators conducting biomarker research upon request.

Will I be reimbursed for my participation?
You may be paid up to $780 for completion of the study. You will receive $30 for each remote visit, $50 for each on-site visit, and $100 for each optional spinal fluid collection.



Principal Investigator: James Berry, MD, MPH & Robert Bowser, PhD
Sponsor: NIH/NINDS & St. Joseph's Hispital and Medical Center
Contact: mghpreventallals@mgb.org or call Courtney Uek at 617-724-0783

Genetic Testing and Counseling in the PREVENT ALL ALS Study

What is the genetic testing process?
You will receive a saliva testing kit, which will be sent to a lab that specializes in genetic testing. You'll have the option to learn your results by enrolling in the genetic sub-study. By having genetic testing through PREVENT, you'll receive continuous support from our genetic counselor.

Can I be in the study if I choose not to learn my genetic results?
Yes, you can be in the study if you choose not to learn your genetic test results. You can discuss your questions and concerns with our genetic counselor at any time.

Is my genetic testing confidential?
Yes, maintaining confidentiality of your genetic testing results is one of our top priorities. Your samples are de-identified and genetic test results will not be placed in your medical records unless you make this request.

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

www.all-als.org/

Site Map

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)

Other Observational ALS Studies at the Healey Center

ASSESS ALL ALS

ASSESS is a part of the ALL ALS nation-wide study. The purpose of ASSESS is to study people diagnosed with ALS as well as healthy volunteers to further our understanding of the disease. The information collected in this study may contribute to future research and development of novel treatments for ALS and similar neurological diseases.

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

DATACUBED

DATACUBED is an observational technology study. The purpose of DATACUBED is to determine the usefulness of using the ALLFTD smartphone app to collect data from individuals with genetic predispositions to ALS or FTD for earlier detection and disease tracking. The study involves game-based assessments and passive data collection and can be completely remote.

Contact: ALSDigitalStudies@mgb.org or call Sravan Mandepudi at 617-643-6036.