

Updated December 2024

Currently Enrolling Digital Observation & Biomarker Studies

Why are digital biomarker studies important for ALS Research?

Digital biomarkers are helping us revolutionize ALS research by changing the way we gather and analyze data. By utilizing tools like wearable technology and smartphone applications, we are finding new and more accurate ways to understand and assess ALS symptoms. In the future, these new tools can be used to not only improve patient care, but also make clinical drug trials more accurate and efficient.



Study of Respiratory Comorbidity Detection Using Digital Devices

Sponsor: ALS Association

Full Study Name: Respiratory Comorbidity Detection Using Digital Devices

Study Length: 18 months

Participants: People living with ALS who qualify for breathing support and use assistive devices for mobility. We are also looking for volunteers who have not been diagnosed with ALS or have a relative with confirmed genetic ALS.

Purpose of Study: We aim to improve monitoring of respiratory complications like pulmonary embolisms or deep vein thromboses in ALS patients using smartwatch sensors. The study could help develop better detection and treatment methods.

Study Assessments: Participants will have visits every three months for a total of seven in person visits. At the visits, participants will undergo imaging, blood tests, ALS clinical exams, and symptom surveys.

Principal Investigator: James Berry MD, MPH

Contact Information:

ALSdigitalstudies@mgb.org

Study of Speech Motor Impairment in ALS

Enroll and participate from your home!

Sponsor: National Institutes of Health

Full Study Name: Speech motor impairments in ALS

Study Length: Up to 4 remote sessions, of up to 2.5 hours each

Participants: People with ALS

Purpose of Study: To learn more about speech symptoms experienced by people with ALS, in order to help improve the diagnosis and treatment of ALS

Study Assessments: You will be asked to fill out a health questionnaire and repeat various sounds and sentences while the movements of your face and mouth are recorded. Study sessions can be completed remotely using your own computer or device.

Principal Investigator: Dr. Jordan Green, Ph.D., CCC-SLP

Contact Information: Speech and Feeding Disorders Lab Staff, speechfeedinglab@mghihp.edu, 617-724-6347

For more information:

Email ALSdigitalstudies@mgb.org

OR Judi Carey, Research Access Nurse,

mghalsresearch@mgh.harvard.edu or 617-724-8995

Study of NeuroBooth

In-person on Wang 8!



Sponsor: Massachusetts Life Sciences Center, National Institutes of Health

Full Study Name: Neurobooth: Creating new technologies to diagnose & measure neurological diseases

Study Length: 40 minutes with follow ups every 3 months

Participants: People with ALS and healthy controls

Purpose of Study: To create new digital tools to measure speech, movement, and cognition in people with and without neurological diseases. Our goal is to improve the accuracy of diagnosis and the ability to discover effective treatments.

Study Assessments: You will be guided through a 40-minute assessment inside of the Neurobooth that will measure your motor skills, eye movements, speech, and thinking. During this time, you will complete tasks on a computer, record your movements and speech with cameras and a microphone, and wear sensors on your body. We may ask you to repeat these tasks when you return for your regular clinic appointments for up to 3 years.

Principal Investigator: Dr. Anoopum Gupta, M.D., Ph.D.

Contact Information:

neurobooth@mgh.harvard.edu, 857- 238-1520

Study of ActiMyo

Wearable Devices

Sponsor: Sysnav

Full Study Name: Digital Biomarkers in ALS - Beiwe and Actimyo

Study Length: 12 months, 5 in-person visits

Participants: People with ALS who walk with or without assistive devices

Purpose of Study: We are using an app and two wearable sensor devices to create large data sets that clinicians can use to gain a better understanding of ALS progression. ALS researchers are exploring new ways to collect meaningful data to accelerate drug discovery and support the use of these technologies in clinical trials.

Study Assessments: The study lasts one year. Each participant will download an app and wear watch-like sensors on their wrist and ankle daily. A photo of the sensor on a wrist is included in this brochure. The app will prompt you to complete tasks every two weeks. We expect these tasks to take you about 5-10 minutes. Participants will also be asked to complete in person visits every three months.

These visits can sometimes be done on the same day as other visits to Mass General.

Principal Investigator:

James Berry, MD, MPH

Contact Information:

ALSdigitalstudies@mgb.org

Wearable Wrist Sensor



Stay Connected to ALS Research

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



<https://lp.constantcontactpages.com/su/saTzwlp/ALSLink>

View All ALS Clinical Research at the Healey Center:



<https://www.massgeneral.org/neurology/als/research/als-clinical-trials>