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 Smartphone App for ALS
Enroll and participate from your home!

Sponsor: ALS Finding a Cure
Full Study Name: Feasibility & Sensitivity of a Symptom Monitoring Application in Real Time (SMART) for ALS
Study Length: 12 months
Participants: People with ALS and healthy volunteers
Purpose of Study: To determine the usefulness of a smartphone app in collecting research data and to learn more about disease progression.
Study Assessments: The study asks each participant to use the smartphone application for a few minutes every day by answering a questionnaire/survey, recording your voice and/or performing an on-screen exercise. The study requires participants to download and use the smartphone application using their smartphone device running iOS 8 or higher, or Android 4.1 or higher.
Principal Investigator: James Berry MD, MPH
Enrollment Contacts: ALSdigitalstudies@mgb.org
Amrita Iyer, 617-643-9550; or Tim Royse, 617-643-4968

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
Enrollment Contacts: 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.

**Enrollment Contacts:** neurobooth@mgh.harvard.edu, 857-238-1520

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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

**Enrollment Contacts:** For more information, email ALSdigitalstudies@mgh.org

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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 Currently Enrolling ALS Trials at the Healey Center:

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