Cross-Sectional Analysis of Biofluid Biomarkers (CABB)
+Healthy Volunteers

The main purpose of this study is to collect blood from people with ALS and related motor neuron diseases (MND) and those without ALS or MND (controls). These samples are used to understand and develop new therapies for ALS and will be shared with researchers across the globe performing promising research. Participants must be at least 18 years of age. The study only requires one-in person visit during which medical history and clinical information will be gathered and blood will be drawn. Urine collection and cerebrospinal fluid collection via spinal tap are optional. People with ALS may also participate in follow-up visits 6 and 12 months later, which may be done in-person, over telephone or by collecting information from medical records.

Principal Investigator: James Berry, MD, MPH

Contact:
Mark Levine-Weinberg
617-643-6252
mlevine-weinberg@partners.org

Speech Motor Impairment in ALS
The Speech and Feeding Disorders Lab at MGH Institute of Health Professions is interested in studying the movements the face and mouth during speech, chewing and swallowing in person's diagnosed with ALS. You will be asked to fill out a health questionnaire as well as to repeat various sounds and sentences while the movements of your face and mouth are recorded. This research aims to help improve the diagnosis and treatments of ALS, and to help develop a new technologies that will help improve communication for people with speech impairments.

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

Answer ALS
Answer ALS is a research study that is helping to create the largest-ever collection of stem cell lines derived from the blood of people with ALS. The collection of cells will be linked to detailed clinical information and a repository of biospecimens. The cell lines and clinical data will be studied in laboratories from across the country that have partnered for this project. Data from these labs will be analyzed individually and together using "big data" analysis techniques to demonstrate why and how motor neurons are affected by ALS, to identify biologically unique subgroups of people with ALS, and to search for new targets for drug therapy.
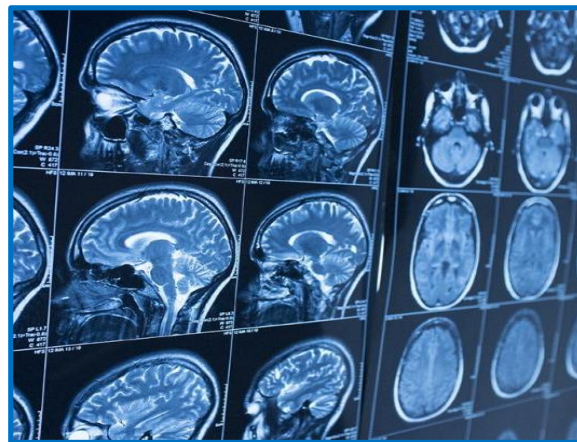
Participants must be at least 18 years of age, and able to follow study tasks. Participants will be asked to come to MGH approximately every 3 months for 1 year, and will be followed by telephone thereafter for as long as they are willing.

Principal Investigator: James Berry, MD, MPH

Contact:
Leah Miller
617-724-7398
lmiller33@mgh.harvard.edu

MASSACHUSETTS GENERAL HOSPITAL
NEUROLOGY

NCRI

Neurological Clinical Research Institute

Biofluid Biomarker & Observational Studies Currently Recruiting

For more information about any of these trials, please contact the listed study coordinator or one of our research nurses:

Melissa Arnold, R.N., (617) 643-5581

Sarah Luppino, R.N., (617) 724-3380

Katie Tee, R.N., (617) 643-6249

Ashley Robichaud, R.N., (617) 643-7290

For more information visit

http://www.massgeneral.org/als/

http://www.alsconsortium.org

Longitudinal CSF (LABB)

The purpose of this research study is to collect blood and cerebrospinal fluid (CSF) to discover and validate ALS biomarkers. A biomarker is any biological marker of disease that allows for diagnosis or tracking of disease severity. Discovery of biomarkers in ALS could help identify the cause of ALS, lead to the development of lab test to diagnose ALS, allow earlier treatment, and/or help monitor response to treatment.

You must be at least 18 years of age, answer brief questions about your medical and family history, and give blood and spinal fluid samples. Your participation would be *up to* three years and would include a visit to the study site every four months.

Principal Investigator: James Berry, MD, MPH

Contact:
Leah Miller
617-724-7398
lmiller33@mgh.harvard.edu

Smartphone App for ALS

This study is recruiting adults with ALS who are smartphone users and are able to download and use a smartphone application. 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 purpose of the research study is to determine how helpful a smartphone application would be in collecting research data and to learn more about disease progression.

Individuals will be in the study for about 3 months and will have the option to extend their participation by another 3 months. Participants must be at least 18 years of age.

Principal Investigator: James Berry, MD, MPH

Contact:
Mehdi Husain
617-643-2499
mhusain@mgh.harvard.edu

Methodology Biomarker Study

This study is recruiting participants with ALS whose symptom onset began less than or equal to two years ago. The purpose of this research study is to look at new methods of measuring ALS symptoms over time to see if these new approaches are better at detecting changes than the currently used methods.

Participation in the study will last for approximately 2 years and will require 7 in-person visits. Participants must be at least 18 years of age, and able to comply with study procedures.

Principal Investigator: Nazem Atassi, MD, MMSc

Contact:
Mehdi Husain
617-643-2499
mhusain@mgh.harvard.edu

Skin Biopsy/Stem Cells for Research in MND
+Healthy Volunteers

Neurodegenerative diseases are diseases in which nerve cells of the brain and spinal cord die. There is a need to understand the cause of these diseases and to develop treatments. Luckily, recent advancements in stem cell technology have allowed us to create a person's own nerve cells by taking a skin biopsy or blood sample. This study wants to use this new technology to make models for neurodegenerative diseases. We hope this will give us a better understanding of the diseases, enable us to use the cells for drug screening, and in the future, develop treatments.

Principal Investigator: James Berry, MD, MPH

Contact:
Tyler Watkins
617-643-7428
ttwatkins@mgh.harvard.edu

Microbiome Assessment
+Healthy Volunteers

The purpose of the research study is to collect stool samples from people with ALS and healthy volunteers. Through comparison of these samples, the researchers hope to learn more about the microbiome (i.e. bacterial strains) in the stool of patients with ALS, as well as find unique biological markers, which could be used to develop new therapies. The stool sample collection will be done at home; you do not need to visit MGH to enroll in this study. You must be at least 18 years of age, answer brief questions about your medical and family history, and give a stool sample. All eligible subjects will provide clinical information and participate in a one-time stool collection. Subjects may enroll in-person at MGH or via phone consent. Stool collection occurs at home. ALS subjects will have the option to participate in up to 2 additional brief visits collecting only clinical information, 3 months and 6 months after the first visit.

Principal Investigator: Katharine Nicholson, MD

Contact:
Maryangel Jeon
617-724-9196
mjeon2@partners.org

Natural History of C9ORF72

This research is being done to define the natural history of the C9orf72 gene mutation in ALS. Natural history means that we will study the natural course of ALS disease progression in people who have a positive C9orf72 mutation. In this study we will collect blood and optional cerebrospinal (CSF) fluid. The information we get from these samples will help us learn more about the C9orf72 mutation in people with C9orf72 ALS.

Principal Investigator: Nazem Atassi, MD, MMSc

Contact:
Mark Levine-Weinberg
617-643-6252
mlevine-weinberg@partners.org