

Understanding ALS Symptoms through Remote Survey Studies

UPDATED FEBRUARY 2024

Study of Social Determinants of Health in ALS

Enroll and participate from your home!

Full Study Name: Social Determinants of Health and ALS Disease Progression

Study Length: Up to 5 visits over a 12-month period

Participants: People over the age of 18 with a diagnosis of ALS living in the US

Purpose: In this research study, we want to learn about how non-medical factors known as Social Determinants of Health (SDOH) impact the progression of ALS. SDOH can include where a person lives, what career they chose, or whom a person lives with. The data collected from this study can be used to develop targeted programs and resources that may improve the quality of life for families impacted by ALS.

Study Assessments: You will be asked to complete several surveys from your home every 3 months for up to one year. Each session will take 30-60 minutes. We may also collect relevant medical information from you throughout the study.

Principal Investigator: James D. Berry, MD

Enrollment Information: To read more about the study and begin participation now, click here

<https://redcap.partners.org/redcap/surveys/?s=3YFFM3KKPDHDCXH4>

Contact Clinical Research Coordinators: Amrita Iyer, Tim Royse, and Sydney Hall. If you would like more information, you can contact them at alsdigitalstudies@mgb.org or 617-643-9005

Scan QR Code For More Details on SDOH Survey Study



Study of Cervical Collars in ALS

Enroll and participate from your home!

Full Study Name: Cervical Collar Survey Study in ALS

Study Length: Single site visit

Participants: Diagnosis of ALS, or related motor neuron disease (MND)

Purpose: collect patient feedback on different cervical collars (neck braces) to help guide clinician recommendations around neck support.

Study Assessments: You will be asked to fill out several surveys at a single time point from your home. There are no in-person visits for this study. You can complete the surveys on your own time. We will collect the following:

- Demographic and disease history information
- Information about neck pain and fatigue, and your use experiences with different neck braces
- Revised ALS Functional Rating Scale

Principal Investigator: Dr. Sabrina Paganoni

Enrollment Information: Please find the information sheet here: <https://redcap.partners.org/redcap/surveys/?s=M7MW7KHRRMLA7CFF>

Study contacts: Katey Burke, Physical Therapist, at katherine.Burke@mgh.harvard.edu or 617-726-1844

Scan QR Code For More Details on Cervical Collar Survey Study



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>

For more information:

Contact the research coordinator listed for studies you are interested in OR Judi Carey, Research Access Nurse, mghalsresearch@mgh.harvard.edu or 617-724-8995