

Understanding ALS Symptoms through Remote Survey Studies

UPDATED JUNE 2023

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: Diagnosis of ALS, live in US

Purpose: Social determinants of health include non-medical factors that influence individual health outcomes. To explore how social determinants of health (SDOH) may influence ALS disease progression, and how identifying these SDOH may lead to the development of non-medication-based interventions to improve health outcomes, prolong survival, and improve quality of life for all people living with ALS, we will be exploring the social and community aspects of SDOH. Within this context, this includes factors such as social support, discrimination, and spirituality.

Study Assessments: You will be asked to complete a number of surveys at baseline and then every three months, up to one year. There will be no in-person visits. You can complete the surveys on your own time at home. We will collect the following information throughout this study:

- Demographic, medical history, and disease history information
- Revised ALS Functional Rating Scale
- Surveys asking about your social support, stress and coping, and use of religious coping
- Survey asking about depression

Principal Investigator: James D. Berry, MD

Sponsor: None

Enrollment Information: Please find the information sheet here: <https://redcap.partners.org/redcap/surveys/?s=3YFFM3KKPDHDCXH4>

Study contact: If you have questions, please contact Amrita Iyer, Clinical Research Coordinator, at Alyer2@mgh.harvard.edu or 617-743-9550



Scan 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

Sponsor: None

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

Study contact: If you have questions, please contact Katey Burke, Physical Therapist, at Katherine.Burke@mgh.harvard.edu or 617-726-1844



Scan 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