

Updated June 2024

# Understanding ALS Symptoms through Remote Survey Studies

## 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>

**Study Contact:** [alsdigitalstudies@mgb.org](mailto:alsdigitalstudies@mgb.org), or Sydney Hall at 617-643-9005  
Sravan Mandepudi at 617-643-6036

**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 Contact:** Katey Burke, Physical Therapist, at [katherine.burke@mgh.harvard.edu](mailto: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](mailto:mghalsresearch@mgh.harvard.edu) or 617-724-8995