ASSESS ALL ALS Study

Status: RECRUITING

Eligibility Criteria

Age: 18 years and over

This study is also accepting healthy

Healthy Volunteers: volunteers

Inclusion Criteria for ALS participants: 1. Age 18 years or older 2. Capable of providing informed consent 3. Willing to follow study procedures 4. Diagnosis of ALS by a physician 5. Access to a smartphone, computer or tablet, and internet (need not be in the home

•access to a public library or other available computer with internet connection is sufficient) Inclusion Criteria for control participants: 1. Age 18 years or older 2. Capable of providing informed consent 3. Willing to follow study procedures 4. No diagnosis of ALS , Progressive Muscular Atrophy (PMA) or Primary Lateral Sclerosis (PLS) 5. No history of familial ALS/Frontotemporal Dementia (FTD) in a close family member** unless the participant has previously tested negative for the known causative ALS genes. Participants with a family history of singleton ALS are permitted to enroll. * ** Defined by the presence of a known ALS causative gene such as C9orf72 in a family member or a family history suggestive of an inherited ALS/FTD syndrome defined by two family members with a history of ALS and/or FTD. 6. Access to a smartphone, computer or tablet, and internet (need not be in the home

•access to a public library or other available computer with internet connection is sufficient) Exclusion Criteria for all participants: 1. Significant cognitive impairment, clinical dementia, or unstable psychiatric illness, including psychosis, active suicidal ideation, suicide attempt, or untreated major depression \<= 90 days of screening, that would interfere with the study procedure, according to Investigator's judgement. 2. Clinically significant unstable medical condition (other than ALS) (e.g., cardiovascular instability, systemic infection, untreated thyroid dysfunction, malignant and potentially progressive cancer) that would render the participant unlikely to be able to complete 12 months of follow-up, according to Investigator's judgment. Exclusion Criteria for participants undergoing optional Lumbar Puncture 1. Medically unable to undergo lumbar puncture (LP) as determined by the site investigator (i.e., bleeding disorder, a skin infection at or near the LP site, known or suspected intracranial or intraspinal tumor or other cause of increased intracranial pressure). 2. Allergy to Lidocaine or other local anesthetic agents. 3. Use of anticoagulant medication or antiplatelet medications (aside from aspirin 81 mg) that cannot be safely withheld prior to lumbar puncture. 4. Blood dyscrasia, abnormal bleeding diathesis, or the use of dialysis for renal failure. 5. Current pregnancy based on participant self-report 6. Clinical judgement of the site investigator that the participant would be unable to undergo multiple lumbar punctures.

Conditions & Interventions

Conditions:

Amyotrophic Lateral Sclerosis

Keywords:

ALS, Amyotrophic Lateral Sclerosis, biomarker, observational

More Information

Contact(s): ALL ALS Patient Navigator - info@all-als.org

Principal Investigator:

Phase:

IRB

Number:

System ID: NCT06578195

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