PREVENT ALL ALS Study

Status: RECRUITING

Eligibility Criteria

Age: 18 years and over

This study is NOT accepting healthy

Healthy Volunteers: volunteers

Inclusion Criteria:

1. Age 18 years or older 2. Capable of providing informed consent 3. Willing to follow study procedures 4. First-degree relative of a known carrier of any ALS causative gene1 (regardless of whether ALS or FTD has actually been symptomatic in the family) OR First-degree relative of an individual with ALS and/or FTD in a family with a "compelling family history" of ALS/FTD, regardless of whether genetic testing has occurred in symptomatic family members. A "compelling family history" is defined as a pedigree with at least 2 close relatives who had ALS or FTD, with at least one of those family members having had ALS. 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)

Exclusion Criteria:

1. Evidence of neurological signs or symptoms concerning for ALS of FTD, at the discretion of the site investigator which will be communicated to the applicant along with referral for appropriate clinical follow-up. 2. Significant cognitive impairment, clinical dementia, or unstable psychiatric illness, including psychosis, active suicidal ideation, suicide attempt, or untreated major depression \<= 90 days (about 3 months) of screening, which in the opinion of the Investigator would interfere with the study procedures 3. Clinically significant, unstable medical condition (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. Inclusion Criteria for Genetic Testing Results Sub-study 1. Age 18 years of age or older 2. Capable of providing informed consent 3. Willing to follow study procedures 4. Currently enrolled in the PREVENT ALS Study

Conditions & Interventions

Conditions:
Amyotrophic Lateral Sclerosis
Keywords:
ALS, Amyotrophic Lateral Sclerosis, Biomarker, Observational, at-risk

More Information

Contact(s): ALL ALS Patient Navigator - info@all-als.org
Principal Investigator:
Phase:
IRB
Number:
System ID: NCT06581861

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