PREVENT ALL ALS

Status: Recruiting

Eligibility Criteria

Sex: Male or Female
Age Group: 18 years and over
This study is NOT accepting healthy volunteers

Inclusion Criteria:

- first-degree relative of a known carrier of any Amyotrophic Lateral Sclerosis (ALS) causative gene1 (regardless of whether ALS or Frontotemporal Dementia 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. - 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:

- evidence of neurological signs or symptoms concerning for ALS of FTD - 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) - clinically significant, unstable medical condition

Conditions & Interventions

Conditions:
Rare Diseases, Brain & Nervous System
Keywords:
Clinics and Surgery Center (CSC), ALS, Amyotrophic Lateral Sclerosis, Frontotemporal Dementia, FTD

More Information

Description: Individuals who are carriers of ALS causative gene variants have an increased lifetime risk of developing ALS or a related disorder, Frontotemporal Dementia (FTD). We are doing this research to collect a wide range of biofluid samples, clinical information, and other health and wellbeing information to look for measurable differences that will help us understand how and when the body changes in response to ALS causative gene variants.
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