

NEALS

Northeast Amyotrophic Lateral Sclerosis Consortium



A Collection and Repository Study to Find Biomarkers in Patients with ALS

The drive to more rapidly develop effective therapies for ALS also highlights the importance of early disease detection and ability to monitor disease progression. Clinical measures of muscle and nerve function are currently used to both diagnose ALS and follow disease progression. During the past decade, tremendous advancements have occurred in the discovery of a variety of biomarkers for the diagnosis and treatment of many human diseases. Biomarkers are defined as any characteristic that can be accurately measured in the body and used as an indicator of normal or disease processes. Biomarkers may be genetic (such as SOD1 mutations for a familial form of ALS), proteins or products of metabolism.

Recent scientific advancements have identified potential protein biomarkers for ALS. Most of these biomarkers have been discovered in the cerebrospinal fluid (CSF). It is crucial to repeat these findings in a much larger number of samples to better evaluate the ability of the biomarkers to accurately predict ALS. We must also determine if these biomarkers can not only be recognized in the CSF but also detected in the blood. We anticipate that some of these biomarkers may also help predict treatment outcome.

In collaboration with the ALS Association, an NIH funded study to collect CSF and blood from 250 individuals with ALS, suspected of having ALS or another motor neuron disease, and healthy individuals is currently underway to perform this critical task. Dr. Robert Bowser from the University of Pittsburgh and Dr. Merit Cudkowicz from Massachusetts General Hospital are the leaders of this investigation. Their grant application for this study won one of the prestigious NIH Challenge awards funded from the American Recovery and Reinvestment Act of 2009 (ARRA stimulus funds). Your help and participation is now required to successfully perform this important study.

Currently, 30 medical centers around the country are participating in this study. They are collecting CSF and blood samples from people with ALS, people with neurological disorders that have similar clinical features to ALS including hereditary spastic paraparesis (HSP), primary lateral sclerosis (PLS), pure lower motor neuron (LMN) syndromes, multiple sclerosis (MS) and people with no known neurological disorders.

Participants must be at least 30 years of age and be willing to have blood and CSF drawn for the study. There are follow up phone calls and visits approximately every 6 months.

All samples that are collected will be placed in a sample repository for use in future ALS research studies. The sample repository is available for use by ALS researchers and scientists across the world to better understand the disease. We have already provided samples from this repository to 6 different scientists searching for biomarkers in ALS. By participating in this study, you will be helping us to better understand, prevent, diagnose or treat ALS.

We need the help of the ALS community to build this ALS sample repository. If you are interested in learning more about this study you may contact the Coordination Center at:

1-877-458-0631

or

mghneuroclinicaltrialsunit@partners.org

You may also contact the individual study coordinator at a medical center closest to you:

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