Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS)

Research Areas

- Basic Research

At a Glance

- Status: Active Consortium
- Year Launched: 1995
- Initiating Organization: NEALS
- Initiator Type: Nonprofit foundation
- Rare disease
- Location: International

Abstract

The Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS) brings together researchers who collaboratively conduct clinical research in amyotrophic lateral sclerosis (ALS) and other motor neuron diseases (MNDs).

Mission

The mission of NEALS is to translate scientific advances into new treatments for people with ALS and MNDs as rapidly as possible.

NEALS functions as an academic research consortium, a contract research organization, and a resource tool for the ALS community.

Consortium History
1995: NEALS was formed by nine investigators in the New England area who wanted to develop new clinical research opportunities for patients with ALS.

1995: The clinical trial of Topiramate in ALS became the first NEALS-affiliated ALS trial.

2001: NEALS held its first Annual Meeting to review developments in ALS research, discuss potential new therapies, and prepare research sites for new clinical trials in ALS.

2007: NEALS formed a shared sample repository with samples collected by NEALS members during their clinical research efforts. The samples were made widely available to ALS investigators around the world.

2010: NEALS was thrilled to announce that two NEALS-affiliated, Phase II trials had positive results. The trial sponsors continued on to perform late-stage trials in ALS.

2010: NEALS began to address the clinical research needs of other rare MNDs, including primary lateral sclerosis and hereditary spastic paraplegia. NEALS is working to develop new clinical research efforts in these diseases using the NEALS model of scientific collaboration.

2011: With the help of the ALS Therapy Alliance and the ALS Association, NEALS started new efforts to improve patient access to clinical research information, including launching a new website devoted largely to this cause.

Structure & Governance

NEALS members, or “sites,” are medical institutions equipped to perform clinical trials in ALS and MNDs. Despite its name, NEALS is an international group with more than 100 member sites in North America, Ireland, and Israel. Each member site is required to:

Financing

Donations to NEALS are used to support ongoing therapeutic clinical trials, assist in the development of new clinical trials, and support other research in ALS and other MDS. NEALS also collects an administrative fee of $1,000 at the time an application for access to the sample repository of serum, plasma, cerebrospinal fluid (CSF), whole blood, extracted deoxyribonucleic acid (DNA), and urine samples from NEALS and the Massachusetts General Hospital Neurological Clinical Research Institute (NCRI) research studies of ALS and MND is submitted, in order to offset processing costs.
Data Sharing

Sharing scientific resources is crucial to finding a cure. Over time NEALS has built an extensive ALS sample repository and maintained several trial databases. In the spirit of collaboration, it makes its resources widely available to investigators conducting research in ALS. NEALS and NCRI have a repository of serum, plasma, CSF, whole blood, extracted DNA, and urine samples from NEALS and NCRI research studies of ALS and MND. The repository is partially funded by the ALS Association, and samples from this repository are available to researchers for the purpose of furthering the understanding of ALS or MND and developing disease biomarkers.

NEALS maintains and makes available the de-identified data from its trials, when possible. Currently NEALS has six ALS trial databases available for researchers to mine:

Links/Social Media Feed

Homepage  http://www.alsconsortium.org/index.php
Facebook  https://www.facebook.com/NortheastALSConsortium
Twitter  https://twitter.com/NEALSConsortium
LinkedIn  https://www.linkedin.com/groups?home=&gid=4376686&trk=groups_about-h-logo

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National Institute of Health
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SUNY Upstate Medical University
Tel-Aviv Medical Center
Texas A&M
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University of Virginia
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