Looking to Become More Active in NEALS? 
Join a NEALS Committee!

**Big Data Committee**  
**Chair:** Alex Sherman avsherman@mgh.harvard.edu  
The goal of Big Data Committee is to introduce new pathways to capture, aggregate, harmonize, distribute and analyze ALS-related information. Some of the important topics this committee discusses and contributes to are discovery of new data sources, development of new platforms and tools, as well as Common Data Elements, data harmonization, and incentive models for research collaboration and data contribution, consumption, analyses and publishing.

**Biorepository Committee**  
**Chairs:** Robert Bowser Robert.Bowser@DignityHealth.org and Terry Heiman-Patterson terry.heiman-patterson@temple.edu  
NEALS has established a repository of biofluids collected from numerous clinical trials and clinical research studies. The Biorepository Committee is responsible for the oversight of this repository and the distribution of biofluids and tissues to investigators for scientific research purposes. An on-line application for samples is available at the NEALS website. The Biorepository Committee reviews all applications and judges the potential impact of the study, research design and the investigator. Priority is given to NEALS investigators. Should the committee raise concerns with an application, the applicant is contacted to address the concerns before approval of an application. Publications generated by the use of the repository samples should acknowledge the NEALS Biorepository as the source of samples, and the applicant is advised to further acknowledge or provide co-authorship to the PI of the study that collected the biofluid or tissue samples.

**Bulbar Committee**  
**Chair:** Gary Pattee glpattee@gmail.com  
The aim of this committee is to investigate and understand the pathology, clinical implications and best treatment strategies of Bulbar MND, including the development of speech and swallowing biomarker parameters throughout disease progression.

**fALS/FTD Committee**  
**Chairs:** Claire Flaherty-Craig cflahertycraig@hmc.psu.edu and Timothy Miller millert@neuro.wustl.edu  
**Assistant Chair:** Benjamin Rix Brooks Benjamin.Brooks@carolinashelseare.org  
The fALS/FTD working group focuses on clinical care, research, and clinical trials for these genetic and phenotypically defined subsets of ALS. Given the overlap of ALS and FTD in the most common form of fALS, there are many shared areas of interest between fALS and FTD. The fALS/FTD working group promotes treatment advances in ALS by building on existing relationships with all ALS/FTD researchers, toward the common goal of applying evidence based research to advance clinical treatment.

**Imaging Committee**  
**Chairs:** Nazem Atassi natassi@partners.org, Michael Benatar mbenatar@med.miami.edu and Erik Pioro PIOROE@ccf.org  
The goals of the Imaging Committee are to advance imaging in ALS by standardizing data acquisition parameters between interested NEALS sites and by developing a NEALS Imaging Core of sites ready to participate in multicenter neuroimaging studies. The committee’s main focus is on the discovery, standardization, and application of imaging biomarkers within the scope of ALS drug development and clinical trials. This committee strives to complement the ongoing European/International efforts (NiSALS) and will closely collaborate with related NEALS committees and task forces.
Nutrition Committee  
**Chairs: Anne-Marie Wills** awills@partners.org and **Edward Kasarskiks** edward.kasarskis@uky.edu  
This mission of this committee is to define through research the best nutritional interventions for ALS. The working group will consist of interested physicians, nurses and Registered Dietitians and will initially start by sharing best clinical practices and surveying the current practices and recommendations of all dietitians working with NEALS clinics. The committee will work towards publishing a guideline for ALS nutrition similar to the "European Huntington's Disease Network Standards of Care Dietitians Group recommendations."

PEACE Committee  
**Chair: Rick Bedlack** richard.bedlack@duke.edu  
A NEALS committee dedicated to utilize education and advocacy to empower patients with ALS to have a greater understanding and a greater role in research.

Physical Therapist Committee  
**Chairs: Peggy Allred** Peggy.Allred@csbs.org and **Sara Feldman** Sara.Feldman@tuhs.temple.edu  
Physical therapists who have been active in NEALS clinical trials determined an interest in forming a research Physical Therapist Sub-committee within NEALS. This highly motivated group developed a mission statement and goals for the sub-committee and elected co-chairs. This sub-committee will be an asset to NEALS not only in the conduction and regulation of clinical trial measures, but also to increase the knowledge base of issues related to movement and function in ALS through independent research.  
**Mission Statement:** Our mission is to promote and encourage involvement of physical therapists in developing standards of care, evaluation and assessment measures, and research both Physical Therapy specific and for clinical trials.

Research Nurse Committee  
**Chair: Darlene Sawicki** dsawicki1@partners.org  
The Nursing Research Committee was established to further nursing science as it relates to ALS, to foster professional development and leadership, and to influence the future of ALS research with evidence-based research. The Committee encourages all nurses in NEALS to participate.

Upper Motor Neuron Disease Committee  
**Chairs: Nazem Atassi** natassi@partners.org and **Jinsky Andrews** ja2289@cumn.columbia.edu  
The NEALS Upper Motor Neuron Disease (UMND) Taskforce committee is dedicated to improving care and quality of life while furthering scientific understanding and developing treatments for people with upper motor neuron (UMN) disorders, including Primary Lateral Sclerosis (PLS) and Hereditary Spastic Paraparesis (HSP).

Ventilation Committee  
**Chairs: Christopher D. Lee** christopher.lee@Vanderbilt.Edu and **Benjamin Rix Brooks** Benjamin.Brooks@carolinash光彩care.org  
To improve ALS survival and quality of life by facilitating research collaboration for systematic study of **accurate** and **timely** diagnosis and **timely** and **effective** treatment of respiratory failure in ALS; to improve awareness of **effective** and **timely** use of NIV and cough assist machines and the dangers of oxygen by developing a variety of educational and outreach activities aimed at ALS physicians, PALS and CALS.
COMMITTEES *(from the NEALS Bylaws)*
The Executive Committee will establish standing committees by soliciting the opinions of the voting members. The members of each standing committee will elect chairs for their committee. The standard duration of membership in any standing committee will be three years. Ad hoc work groups will be established by the Executive Committee as needed. The term of membership on such work groups will be determined by the task at hand. The continuing need and benefit of each standing committee will be addressed annually.

Chairs and members of the standing committees may be re-appointed for successive terms, provided that appointments ensure a broad representation of NEALS sites. Standing committees, therefore, should not have more than one member from the same affiliated institution.

Other standing committees may be established via member or membership proposal or recommendation, and implemented upon final approval of the Executive Committee.

**To Form a NEALS Committee:**
Any NEALS member wishing to establish a standing Committee may do so by submitting a proposal and Committee mission statement to the NEALS Executive Committee, along with Committee goals and a list of NEALS members interested in serving on the Committee. The establishment of any NEALS Committee is based upon final approval of the Executive Committee.