

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 **Matthew Harms** mh3607@cumc.columbia.edu

Assistant Chair: Benjamin Rix Brooks Benjamin.Brooks@carolinashealthcare.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: Michael Benatar mbenatar@med.miami.edu, **Erik Pioro** PIOROE@ccf.org and **Suma Babu** SBABU@MGH.HARVARD.EDU

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

The 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."

Palliative Committee

Chair: **Raghav Govindarajan** govindarajanr@health.missouri.edu

The mission of this committee is to relieve the suffering of ALS patients and their families through a comprehensive assessment and treatment of physical, psychosocial and emotional symptoms experienced by patients and their caregivers.

Goals:

1. To understand biopsychosocial needs of ALS patients and family caregivers during different stages of ALS
2. Explore patients, caregivers, and healthcare providers' perceptions of palliative care for individuals living with ALS
3. To develop palliative care models of care for ALS patients and their caregivers
4. To develop practice model to integrate palliative care within the multidisciplinary ALS clinic
5. To develop care models of providing hospice and comfort care for ALS patients
6. To develop spectrum of continued care model for caregivers throughout the illness and after the patients' demise

PEACe Committee

Chairs: **Rick Bedlack** richard.bedlack@duke.edu and **Allison Pogemiller** apogemi@yahoo.com

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/Occupational Therapist Committee

Chairs: **Amy Swartz Ellrodt** ALSWARTZ@mgh.harvard.edu and **Katherine Burke**
KMBURKE1@PARTNERS.ORG

Physical therapists and occupational therapists who have been active in NEALS clinical trials determined an interest in forming a research Physical Therapist/Occupational 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 and occupational therapists in developing standards of care, evaluation and assessment measures, and research both Physical Therapy/Occupational Therapy specific and for clinical trials.

Recruitment, Retention, and Experience in ALS Research (RRE Committee)

Chairs: **Sabrina Paganoni** spaganoni@mgh.harvard.edu, **Steve Kolb** Stephen.Kolb@osumc.edu, **Meghan Hall**
Meghan.Hall@DignityHealth.org and **Katrina Madden** maddenka@musc.edu

Scientific breakthroughs and the growing pipeline of candidate therapeutics for ALS offer renewed hope that research will soon bring about new options for people with ALS. Yet, for this to occur, it is critical that research projects and clinical trials be completed in an effective and timely manner. The mission of this committee is to develop strategies to maximize the Recruitment, Retention, and Experience (RRE) of participants in ALS research.

With this goal in mind, the RRE Committee at NEALS will:

- identify challenges, barriers and opportunities for PALS participation in research at NEALS;
- work with the Principal Investigators and study teams of selected NEALS studies to boost RRE of ongoing studies;
- create a shared toolbox of resources and templates that can be used to maximize RRE of future NEALS projects;
- collaborate closely with other relevant NEALS Committees and advocacy groups to promote a culture of partnership among all stakeholders in ALS research.

Research Coordinator Committee

Chairs: Brixhilda Dedi bd2577@cumc.columbia.edu and **Heidi Runk** hrunk@pennstatehealth.psu.edu

The mission of the Research Coordinator Committee is to promote professional development, foster collaborative coordinator training, develop leadership skills, and create a collective repository of forms and templates to maximize day-to-day clinical trial efficiency within the ALS research community.

Goals:

1. To understand the professional and resource needs of NEALS research coordinators
2. To promote professional development opportunities within the NEALS research coordinator community
3. To create a research coordinator-specific mentor program for new NEALS sites and/or research coordinators
4. To develop shared resource materials for pharmaceutical, federal, and NEALS clinical trials
5. To serve as a resource for pharmaceutical, federal, and NEALS investigators providing site level experience-based advice during the protocol development and implementation phase

Research Nurse Committee

Chair: Pamela Kittrell kittrellp@uthscsa.edu

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.

Technology in ALS

Chairs: James Berry jdberry@mgh.harvard.edu, **Sabrina Paganoni** spaganoni@mgh.harvard.edu and **Michael Pulley** michael.pulley@jax.ufl.edu

Technological advances have brought about emerging opportunities to enhance ALS care and research. Innovative technology solutions are poised to improve clinical outcomes and patient satisfaction while reducing costs, and provide valuable patient-centered research tools.

Opportunities to leverage technology in ALS care and research cluster around three usage domains:

- Telemedicine (defined as clinical interactions with the clinical care team);
- Mobile Health and digital monitoring (to support research and ALS drug development);
- Assistive devices (defined broadly as technological solutions to increase patients' interaction with the environment and quality of life).

The mission of the Committee is to build a network of NEALS investigators who are engaged in advancing the use and development of Technology across all three domains of ALS care and research described above:

- The Committee will work to increase awareness about ongoing projects and technology adoption among NEALS members.
- The Committee will review the landscape of technology in ALS care and research and identify opportunities for innovation.
- The Committee will foster collaborative multicenter technology-based projects.

Given the nature and breadth of the issues that the Committee strives to address, Committee members will collaborate closely with other relevant NEALS Committees and Task Forces as well as patient organizations and advocacy groups in order to maximize the impact of technology in ALS.

Upper Motor Neuron Disease Committee

Chairs: Sabrina Paganoni spaganoni@mg.harvard.edu and **Jinsy Andrews** ja2289@cumc.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@vumc.org and **Benjamin Rix Brooks**

Benjamin.Brooks@carolinashealthcare.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.

Veterans Affairs (VA) Committee

Chairs: Colin Quinn Colin.Quinn@uphs.upenn.edu and **Christina Fournier**

Christina.nicole.fournier@emory.edu

The Veterans Affairs hospitals and clinics are distinct care environments, which function outside of the private insurance system. These environments provide their own unique opportunities and challenges. This proposed committee intends to increase communication and cooperation amount the many physicians and ancillary staff providing care to patients with ALS in the VA. Most VA hospitals are formally associated with their local academic medical center, and thus many of our NEALS members hold joint appointments and provide care for veterans with ALS.

Our initial goals are as follows:

1. To establish our membership numbers and clinic characteristics
2. To consider the use of common data forms in our clinics
3. To discuss and support cooperative veteran-centered research projects
4. To utilize the national infrastructure of the VA system to expand NEALS initiatives into the veteran population.

About NEALS 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.