

## 2024 NEALS Committee Updates

### **Advanced Practice Provider (APP) Committee**

**Committee Chairs:** Jourdan Milliard, Julia Yasek, Gabriela Lopes

The NEALS APP Committee, a newer committee within the NEALS organization, has focused on establishing a network and fostering connections among Advanced Practice Providers (APPs) working in ALS clinics and involved in research. We have conducted routine meetings to share knowledge and gain feedback on potential projects, with a strong emphasis on addressing patient needs. This year, we sent out a survey to NEALS sites to gather insights on secretion management and treatment practices. The results of this survey will be presented in a poster at the upcoming NEALS conference. Looking ahead, our goal is to gather more comprehensive information regarding the patient experience. Ultimately, we aim to conduct a multi-center study to develop and implement a treatment algorithm for managing thick secretions, incorporating both pharmacological and non-pharmacological approaches.

### **Biorepository Committee**

**Committee Chairs:** Terry Heiman-Patterson, Robert Bowser

Over the past year, the NEALS Biorepository Committee has been actively involved in reviewing and distributing biosamples to support ALS research. Between June 2023 and June 2024, we reviewed 20 sample request applications, including 12 from academic investigators and 8 from industry partners. During this period, we completed distributions for 38 projects, totaling 9,943 vials, which included plasma, serum, whole blood, and cerebrospinal fluid (CSF). Our biorepositories currently store 66,295 vials from 2,169 participants, exclusively from NEALS studies. This inventory includes plasma, serum, CSF, whole blood, and urine aliquots. Over the past five years (2019 - July 2024), the committee has reviewed 125 sample requests (96 original projects and 29 amendments) and served 83 distinct projects. We have distributed 15,053 vials from 1,265 participants, including plasma, serum, CSF, whole blood, and urine aliquots. These efforts highlight our commitment to advancing ALS research through robust biorepository management and distribution.

### **Bulbar Committee**

**Committee Chair:** Gary Pattee

Our subcommittee has continued to work on improving bulbar assessment methods over the past year. This includes refining the clinical bulbar assessment scale and incorporating multiple sites to gather data. Members have also been working on a project titled 'Novel multiplex functional mandibular muscle network as an objective tool for assessment and profiling of bulbar involvement in ALS,' utilizing surface EMG electrodes to assess muscle pairs involved in bulbar functioning. The use of AI to improve sentence banking is being explored, along with further assessment of dysphagia to enhance clinical management of patients with bulbar disease. Future goals include closer interactions with other NEALS

subcommittees, such as the Nutrition and Ventilatory Committees, to improve overall patient care and better define timely PEG placement implementation. There is also a renewed commitment towards including validated bulbar measures in future clinical drug trials.

### **GROW Working Group**

The NEALS Global Research and Outreach Leadership Working Group (GROW), operating under the NEALS Executive Committee, is dedicated to facilitating the participation of global clinical and research sites in NEALS programs and ALS research. Our mission is to create a collaborative global network of ALS clinical research sites, recognizing the critical importance of global research in advancing ALS progress.

This past year, GROW has made significant progress in line with our goals. We held our inaugural international meeting at NEALS, where global sites, both Members and Non-Members, shared their programs. Additionally, we launched a clinical trial survey to assess the current landscape and identify support needs, such as training and networking with industry partners. Our leadership has initiated key conversations with ELATAM, a budding Latin American group, and is building connections in India with groups focused on establishing an ALS Registry and organizing an Indo-US summit on rare diseases in New Delhi. Looking ahead, we are excited to host a meeting at this year's annual NEALS meeting, where global sites will present their program readiness, and industry representatives will discuss potential collaborations, furthering our mission of global ALS research collaboration.

### **NICE Working Group**

#### **Committee Chairs: Allison Bulat, Christina Fournier**

The goal of the NEALS Information and Community Education (NICE) is to provide accessible and evidence-based information and education to the holistic ALS community, including clinicians and people living with ALS. Over the past year, NICE has hosted community webinars and publication reviews to provide educational updates on ALS treatments and genetic testing. Upcoming goals include enhanced partnership with the patient community and ALS organizations, broader dissemination of educational materials, and creating additional short-form content to address areas of community interest in real-time.

### **Nutrition Committee**

#### **Committee Chairs: Stephanie Dobak, Edward Kasarskis**

In 2023-2024, the NEALS Nutrition Subcommittee engaged professionals, PALS, and caregivers through four webinars:

- March 1, 2024: The Benefits of Macronutrients in People Living with ALS: What Should We Eat? (Dr. Ikjae Lee)

- April 25, 2024: Constipation in People Living with ALS: Does Autonomic Dysfunction Play a Role? (Dr. Ghazala Hayat, MD, FAAN, FANA, FAANEM)
- July 26, 2024: Nutrition-Focused Physical Exam for the Patient with ALS (Kay Stolwyk, MS, RD, CDN)
- September 25, 2024: Feeding Tubes for People Living with ALS: What You Need to Know Before Getting One

The committee also commenced a multi-site retrospective chart review study on the tolerance of milk-based protein versus plant-based protein enteral nutrition formulas via gastrostomy tube. Data collection is ongoing, and results are expected to be analyzed in Spring 2025.

### **Palliative Committee**

**Committee Chairs:** Karla Washington, Ambereen Mehta

This summer, the Palliative Subcommittee kicked off its Annual Summer Series webinar with Dr. Samuel Maiser, Chair of Neurology and Medical Director of the ALS Center of Excellence at Hennepin Healthcare. He discussed the challenges of advance care planning in ALS and the potential role and value of ALS-specific advance directives. This led to potential study ideas and the formation of a working group to further develop this concept. If interested in participating, please email Ambereen Mehta or Karla Washington.

The discussions and study ideas from our recent committee meetings have resulted in two completed studies:

- Mehta, A. K., et al. (2023). Quality-of-life assessment instruments used across ALS clinics. *Muscle & Nerve*, 68(6), 865-872. PMID: 37823580
- Washington, K. T., et al. Identifying the unmet needs of people living with ALS: A national survey to inform interdisciplinary palliative care. *American Journal of Hospice & Palliative Medicine*. Accepted April 5, 2024. (In press)

### **Patient Advisory Committee (PAC)**

**Committee Chairs:** Not specified

The NEALS Patient Advisory Committee (PAC) supports the mission of the NEALS Consortium by providing perspectives from lived experiences in NEALS community education and communication. Committee members remain engaged with the patient community, seeking to understand and represent the needs of families affected by ALS. They participate in open dialogue with both the patient community and NEALS members regarding clinical research issues. PAC members also serve on publication review teams as part of the new Publication Review Series, hosted in partnership between the NEALS Information and Community Education Working Group (NICE) and ALS One.

### **PEACE Committee**

**Committee Chairs:** Allison Bulat, Richard Bedlack, Nadia Sethi

The Patient Education and Advocacy (PEACe) Committee includes all ALS Research Ambassadors (graduates of previous Clinical Research Learning Institutes) and NEALS

members interested in collaboration and information sharing among the patient community, science community, drug sponsors, and ALS organizations. The committee holds monthly meetings, featuring four presenters who share project information and collaboration opportunities. This committee integrates with the Clinical Research Learning Institute (CRLI), a two-day program that trains people impacted by ALS to be NEALS ALS Research Ambassadors, by mentoring and supporting all graduates. CRLI classes have been held throughout the US, Canada, and Australia, including specialized training for asymptomatic genetic carriers and veterans. The format has recently expanded to include other disease states, such as FTD.

### **Physical Therapist/Occupational Therapist (PT and OT) Committee**

**Committee Chairs:** Michele Weaver, Claire MacAdam

The PT and OT Committee continues to grow, and we're eager to add more therapists to our group! Over the past few years, we have worked hard to develop helpful resources for PTs and OTs working in ALS Centers. Our group has created an evaluation template that therapists can use during clinic visits. This template can be used as a paper tool or integrated into an EMR system. We have expanded our NEALS PT and OT DropBox to include a multitude of reference articles related to exercise, mobility, medical equipment, pain management, and more. Several NEALS PT and OT members have contributed to the growth of the website "Your ALS Guide" by providing content for sections on exercise, mobility, home modifications, and medical equipment. Additionally, some members have assisted ALSA in creating an online educational course titled Rehabilitative Care for ALS: Guidance for PTs and OTs. Our goal is to connect with PTs and OTs in ALS Centers to promote and encourage excellent standards of care in all areas related to PT and OT.

### **The Recruitment, Retention and Experience (RR&E) Committee**

**Committee Chairs:** Lindsay Pothier and Meghan Hall

The Recruitment, Retention and Experience (RR&E) committee met with companies that are sponsoring NEALS-affiliated trials to help support participant enrollment strategies as well facilitate interactions with the patient community. The committee looks forward to continued engagement with companies as they design, plan, and launch ALS trials.

### **Respiratory Care and Ventilation Committee**

**Committee Chairs:** Christopher D. Lee, Eufrosina Young, Benjamin Rix Brooks

We aim to standardize respiratory diagnostic and treatment outcomes for implementation in ALS clinics and ALS research. NEALS RCV (Respiratory Care and Ventilation) Committee Survey obtained data on current variety of respiratory care practices. NEALS 2024 Community Educational webinars embraced international inputs (USA, Australia and Japan), and launched four respiratory webinars in the summer of 2024. NEALS 2024 RCV Workshop in Clearwater, Florida will allow for hands-on demonstration of respiratory monitoring and equipment.

## **Veterans Affairs (VA) Committee**

### **Committee Chairs: Collin Quinn, Christina Fournier**

The Veterans Affairs (VA) committee strives to increase communication and cooperation among NEALS members that work within the VA Healthcare system. Recent efforts include outreach and educational opportunities to engage veterans living with ALS in research studies, reducing barriers for VA clinicians and staff to partner with NEALS, and exploring opportunities to utilize the national infrastructure of the VA system to expand NEALS initiatives into the veteran population.