

2026 Annual NEALS Meeting

Key:

NEALS Member Training Sessions, Workshops, and Networking Events (open to all NEALS members)

General Info & General Sessions (open to all attendees)

NEALS Affiliated Trial: Study Investigator Meetings (limited to site investigators & study teams)

NEALS Committee meetings (open to NEALS members)

Tuesday, October 27

- **8:00 AM:** **Registration**
- **7:30 AM – 12:30 PM:** Respiratory Care & Ventilation Committee Workshop
Moderators: Eufrosina Young, MD; Benjamin Brooks, MD; John Coleman, MD; and Lisa Wolfe, MD
Presenters: Pamela Cazzolli, RN; Philip Choi, MD; Won Lee, MD; and Zachary Simmons, MD
- **10:00 AM – 11:00 AM:** Recruitment, Retention, and Experience in ALS Research Committee Meeting
- **10:00 AM – 11:00 AM:** Upper Motor Neuron Committee
- **11:00 AM – 12:00 PM:** Research Coordinator Committee Meeting
- **11:30 AM - 1:30 PM:** **Lunch**
- **12:00 PM – 1:00 PM:** Palliative Committee Meeting
- **12:00 PM – 1:00 PM:** Imaging Committee Meeting
- **12:00 PM - 2:30 PM:** Clinical Research Staff Training & Development Workshop
Leads: Lindsay Heyd, Heidi Runk, CCRC; and Lia Tamburello
Presenters: Nicholas Maragakis, MD
- **1:00 PM – 2:00 PM:** Advanced Practice Provider Committee Meeting
- **2:00 PM – 3:00 PM:** Big Data Committee Meeting
- **2:00 PM – 3:00 PM:** Technology in ALS Committee Meeting TBD
- **3:00 PM – 7:30 PM:** Outcome Measures Training
Leads: Gale Kittle, RN, MPH and Jourdan Milliard, FNP-C
- **3:00 PM – 4:00 PM:** NEALS Information & Community Education (NICE) Working Group (Closed Session; Invite Only)
- **3:00 PM – 4:00 PM:** Genetic ALS, FTD and Related Phenotypes Committee Meeting
- **3:30 PM – 4:30 PM:** **Refreshment Break**
- **4:00 PM – 5:00 PM:** Physical Therapist & Occupational Therapist Committee Meeting
- **4:00 PM – 5:00 PM:** Nutrition Committee Meeting
- **4:00 PM – 6:00 PM:** Site Investigator Training
Leads/Presenters: Senda Ajroud-Driss, MD; Christina Fournier, MD; Lindsay Heyd; and Meghan Hall, MS, CCRA
- **5:00 PM – 6:00 PM:** Clinical Research Nurse Committee Meeting
- **5:00 PM – 6:00 PM:** Respiratory Care and Ventilation Committee Meeting

Wednesday, October 28

- **7:00 AM – 8:30 AM:** **Breakfast & Registration**
- **7:15 AM – 8:15 AM:** **LUMINA Study Meeting**
- **7:15 AM – 8:15 AM:** **Global Research & Outreach Working Group (GROW) Meeting**
- **8:30 AM - 9:00 AM:** **Opening Session**
Jinsy Andrews, MD, MSc (New York University) and Nicholas Maragakis, MD (Johns Hopkins)
- **9:00 AM – 10:30 AM:** **The Next Frontier in Amyotrophic Lateral Sclerosis (ALS): Integrating Clinical Care, Research, and Lived Experience for People at Genetic Risk of ALS/FTD**
Moderator: Nicholas Maragakis, MD (Johns Hopkins)

Pre-symptomatic ALS/FTD and disease prevention: a view from the vanguard
Michael Benatar, MD, PhD (University of Miami)

Title TBD
Mark Garret, MD (Dartmouth Hitchcock Medical Center)

Supporting the Journey, Empowering Choice: Predictive Genetic Counseling in ALS/FTD
Laynie Dratch, SCM, CGC (Penn Comprehensive ALS Center)

Building the Next Frontier: Connecting Care, Research, and Lived Experience
Cassandra Haddad, MSN (ALS Research Ambassador)

Developing a care approach for individuals at genetic risk of ALS/FTD
Terry Heiman-Patterson, MD (Temple University)

Racing Against the Clock: Patient Advocates as Key Architects of the Self Cure
Yentli Soto Albrecht, PhD (University of Pennsylvania)
- **10:30 AM – 10:50 AM:** **Break (Sponsored by Acelot)**
- **10:50 AM – 12:25 PM:** **NEALS Affiliated Trial Session**
Session Lead: Jinsy Andrews, MD, MSc (New York University)

10:50 AM – 11:05 AM: Co-Chair Summary Roundup

Presentations:

- 11:05 AM – 11:20 AM: Study Update 1
- 11:20 AM – 11:35 AM: **Update on ATLAS, a presymptomatic interventional study of tofersen in SOD1-ALS**
Steve Garafalo, PhD (Biogen)
- 11:35 AM – 11:50 AM: **LUMINA: AMX0114 ALS Study Update**
Sabrina Paganoni, MD, PhD (Sean M. Healey & AMG Center for ALS at Mass General) and Lauren Kett, MD, PhD (Amylyx Pharmaceuticals)
- 11:50 AM – 12:05 PM: Study Update 4
- 12:05 PM – 12:25 PM: **Seamless Therapy Development in ALS**
Merit Cudkowicz, MD, MSc (Sean M. Healey & AMG Center for ALS at Mass General)

• **12:25 PM – 2:00 PM: Lunch**

• 12:45 PM – 3:15 PM: Concurrent Sessions

- 12:45 PM – 1:45 PM: VITALS Study Meeting
- 12:45 PM – 1:45 PM: PIONEER-ALS Study Meeting
- 12:45 PM – 1:45 PM: HEALEY Platform Trial Study Meeting (Closed Session; Invite Only)
- 12:45 PM – 3:15 PM: **NEALS Bulbar Symposium—Multisystem Committee Update**
Lead: Gary Pattee, MD (Neurology Associates, P.C.)

John Costello, MA, CCC-SLP (Boston Children's Hospital)
Benjamin Rix Brooks, MD (Clinical Trials Planning LLC)
Lauren Tabor Gray, PhD, SLP (NOVA Southeastern University)
Yana Yunusova, PhD, CCC-SLP (University of Toronto)
- 1:00 PM – 3:00 PM: **PT/OT Optimizing Function Across the ALS Continuum: PT & OT Considerations for Clinical Practice**
Leads: Stephanie Johnson, OTR/L, PhD, MHS (Augusta University) and Michele Weaver, PT, DPT, NCS (Corewell Health)

Matt Abisamra, OTR/L, CDRS (Shepherd Center)
Kayla Chomko, PT, DPT, NCS (NOVA Southeastern University)
Lauren Nidiffer, PT, DPT (Ohio Health ALS Clinic)
Lizbeth Valdez James, MSW (NOVA Southeastern University)
- 2:00 PM – 3:00 PM: ALL ALS Study Meeting

○ 2:00 PM – 3:00 PM: Healey MyMatch Study Meeting (Closed Session; Invite Only)

○ 2:00 PM – 3:10 PM: **Lightning Science Talks**
Session Leads: Sami Barmada, MD, PhD (University of Michigan) and Jeffrey Rothstein, MD, PhD (Johns Hopkins University)

2:05 PM – 2:25 PM Science Presentations (3 minutes each):
2:25 PM – 2:35 PM Audience Q&A

2:40 PM – 2:57 PM Clinical Presentations (3 minutes each):
2:57 PM – 3:07 PM Audience Q&A

● 3:15 PM – 3:30 PM: **Break**

● 3:30 PM – 4:30 PM: **Industry Roundtable: Advancing TDP43-Relevant Therapeutic Targets**
Session Lead: Nicholas Maragakis, MD (Johns Hopkins University)

*Irina Antonijevic, MD, PhD (Trace Neuroscience)
Martin Engel, PhD (Neurizon)
Angela Genge, MD, FRCP(C) (QurAlis)
Isaac Klein, MD, PhD (Dewpoint Therapeutics)
Katie Planey, PhD, MBA (Acelot)
Olga Uspenskaya, MD, PhD (VectorY Therapeutics)*

Audience Q&A

● 4:30 PM - 6:30 PM: **Poster Session 1**

● 5:30 PM – 7:00 PM: **The Palliative Story Exchange**

*Moderators: Richard Leiter, MD, MA (The Palliative Story Exchange)
and Lisa Keefauver, MSW (The Palliative Story Exchange)*

Thursday, October 29

● 7:00 AM – 8:30 AM: **Breakfast & Registration**

● 7:15 AM – 8:15 AM: **ALSTARS Study Meeting**

● 7:15 AM – 8:15 AM: **PREVAiLS Study Meeting**

● 7:15 AM – 8:15 AM: **CDC Informational Session: How the National ALS Registry can Support your Research**

Session Lead: Paul Mehta, MD (CDC)

- **8:30 AM – 9:30 AM:** **Embedding the ALS Patient Journey into Clinical Development, Care Delivery, and Advocacy: A Research Advisory Panel**
Moderator: Michael Robinson, MD (ALS Research Ambassador)

William Benjamin Nowell, PhD, MSW (Regeneron)
John Driskell Hopkins (Hop On A Cure)
Christina Fournier, MD (Emory University)
- **9:30 AM – 9:50 AM:** **Break (Sponsored by Acelot)**
- **9:50 AM – 10:50 AM:** **Innovative Approaches to Clinical Trial Design**
Moderator: Jinsy Andrews, MD, MSc (New York University)

Suma Babu, MBBS, MPH (Sean M. Healey & AMG Center for ALS at Mass General)
Sabrina Paganoni, MD, PhD (Sean M. Healey & AMG Center for ALS at Mass General)
- **10:50 AM – 11:50 AM:** **Stats Corner: NfL — The Biomarker That Rocks Every Role**
Moderator: Lori Chibnik, PhD (MGH Biostatistics)

Eric Macklin, PhD (MGH Biostatistics)
Giorgio Paulon, PhD (Berry Consultants)
Peng Sun, PhD (Biogen)
Jianing Wang, PhD (MGH Biostatistics)
- **11:50 AM – 1:10 PM:** **Lunch**
- **12:05 PM – 1:05 PM:** **Concurrent Sessions**
 - **12:05 PM – 1:05 PM:** **ARMOR-Insmed Study Meeting**
 - **12:05 PM – 1:05 PM:** **Study Meeting TBD**
 - **12:05 PM – 1:05 PM:** **NEALS Biorepository Informational Session**
Moderators: James Berry, MD, MPH and Ikjae Lee, MD (Columbia University)

Nadine Bakkar, PhD (Barrow Neurological Institute)
Katie Irwin, MD, PhD Student (Johns Hopkins University)
Hande Ozdinler, PhD (Northwestern University Feinberg School of Medicine)
Ghazaleh Sadri-Vakili, MS, PhD (Sean M. Healey & AMG Center for ALS at Mass General)
 - **12:05 PM – 1:05 PM:** **Networking Lunch: Sustaining Multidisciplinary Clinics: Funding Challenges and Strategic Solutions (NEALS Members)**

○ 12:05 PM – 1:05 PM: **Networking Lunch: Mentorship and Career Growth with Senior Researchers (NEALS Members)**

• 1:15 PM – 1:30 PM: **Co-Chair Announcement**

• 1:30 PM – 3:30 PM: **Science Symposium: AI in ALS: From Bench Insights to Bedside Impact**

Session Leads: Sami Barmada, MD, PhD (University of Michigan), Timothy Miller, MD, PhD (Washington University ALS Center) and Jeffrey Rothstein, MD, PhD (Johns Hopkins University)

1:55 PM – 2:20 PM: **Title TBD**

Steve Finkbeiner, MD, PhD (Gladstone Institutes)

2:20 PM – 2:45 PM: **Connecting the Clues in ALS: An Investigation Across Datasets**

Juro Gottweis (Independent Researcher) and Luka Rimanic, PhD (Google)

2:45 PM – 3:10 PM: **Early Identification of ALS Using Advanced Machine Learning and Real-World Data**

(Virtual) Vahid Esmaeili, PhD (Volv Global) and (Virtual) Christophe Lo Bianco, PhD (Novartis)

3:10 PM – 3:20 PM: **SAVA AI: A Collaborative Platform Connecting Clinicians, Sites, Sponsors, and Patients to Enable Real-Time Clinical Trial Matching**

Natalia Luchkina, PhD (EverythingALS), and Christian Rubio, MBA (EverythingALS)

3:20 PM – 3:30 PM: *Abstract presenter TBD*

• 3:30 PM – 3:50 PM: **Break**

• 3:50 PM – 4:50 PM: **Hot Topic Session: Causal Inference in ALS: What are the Data for Environmental Exposures?**

Session Lead: Jonathan Glass, MD (Emory University)

• 4:50 PM – 6:30 PM: **Poster Session 2**

• 6:30 PM – 6:45 PM: **Group Photo**

• 6:45 PM – 9:00 PM: **Annual Beachside Dinner**

Friday, October 30

- **7:00 AM – 8:30 AM:** **Breakfast**
- **7:15 AM – 8:15 AM:** **FUNCTION ALS Study Meeting**
- **7:15 AM – 8:15 AM:** **Study Meeting TBD**
- **8:30 AM – 9:30 AM:** **Lessons from Novel Therapies: Beyond ALS**
Session Lead: Jinsy Andrews, MD, MSc (New York University) or Nicholas Maragakis, MD (Johns Hopkins University)

Kevin Flanigan, MD (Ohio State University)
Charlotte Sumner, MD (Johns Hopkins University)
- **9:30 AM – 10:15 AM:** **The Power of Partnership: Updates from the NEALS ALS Organizations Forum**
Session Lead: Jinsy Andrews, MD, MSc (New York University)

Kuldip Dave, PhD (The ALS Association)
Kristen Cocoman (ALS United)
- **10:15 AM – 10:30 AM:** **Break**
- **10:30 AM – 10:50 AM:** **Awards**
Session Lead: Jinsy Andrews, MD, MSc (New York University)

The Gupta Family Endowed Prize for Innovation in ALS Care
Presented by: Merit Cudkowicz, MD, MSc (Sean M. Healey & AMG Center for ALS at Mass General)

Drs. Ayeez and Shelena Lalji & Family Student Scholar Award for Repair and Regenerative Mechanisms in ALS
Presented by: Merit Cudkowicz, MD, MSc (Sean M. Healey & AMG Center for ALS at Mass General)
- **10:50 AM - 11:05 AM:** **Abstract Awards**
Session Lead: Terry Heiman-Patterson, MD (Temple University)

Basic Science Award
Presented by: Terry Heiman-Patterson, MD (Temple University)

Clinical Investigation Award
Presented by: Terry Heiman-Patterson, MD (Temple University)

Upper Motor Neuron Achievement Awards
Presented by: Christine Hendrickson, ARNP (Spastic Paraplegia Foundation Ambassador)
- **11:05 AM - 12:50 PM:** **Platform Presentations**

Session Lead: Terry Heiman-Patterson, MD (Temple University)

11:07 AM – 11:22 AM: Presentation 1

11:23 AM – 11:38 AM: Presentation 2

11:39 AM – 11:54 AM: Presentation 3

11:55 AM – 12:10 PM: Presentation 4

12:11 PM – 12:26 PM: Presentation 5

12:27 PM – 12:42 PM: Presentation 6

12:43 PM – 12:50 PM: Audience Q&A

- **12:50 PM – 2:00 PM:** **Lunch**
- 1:10 PM – 2:10 PM: ALS Organizations Forum
- 1:10 PM – 2:10 PM: Study Meeting TBD