



MEETING AND BREAKOUT COLOR LEGEND

General Info & General Sessions

Meals & Receptions

(open to all attendees)

NEALS Working Group & Committee Meetings

(open to NEALS members)

NEALS Affiliated Trial: Study

Investigator Meetings

(limited to site investigators & study teams)

NEALS Member Training Sessions

(open to NEALS members)

DAY ONE

TUESDAY, OCTOBER 22, 2024



Available to virtual attendees

7:15a – 4:00p	Registration	Opal Ballroom Foyer
7:00 – 8:00a	Clene Nanomedicine EAP Investigators Meeting	Sunset Salon
7:30 – 8:30a	Breakfast	Opal Ballroom Foyer
7:45 – 8:30a	CDC Informational Session: How the National ALS Registry can Support your Research <i>Paul Mehta, MD (National ALS Registry)</i>	Opal Ballroom
8:30 – 10:00a	Opening Session: NEALS Updates, Progress, and Partnerships in ALS Research <i>NEALS Co-Chairs</i> <i>Jinsy Andrews, MD, MSc (Columbia University)</i> <i>James Berry, MD, MPH (Healey & AMG Center for ALS at MGH)</i>	Opal Ballroom
8:50a	NINDS's Investment in ALS Research <i>Walter Koroshetz, MD (National Institute of Neurological Disorders and Stroke (NINDS))</i>	
9:10a	A Collaborative Approach to Advance ALS Research: The Accelerating Medicines Partnership (AMP) ALS <i>Shubhangi Lal, MS, MBA (Foundation for the National Institutes of Health (FNIH))</i>	
9:20a	Updates on Critical Path for Rare Neurodegenerative Diseases (CP-RND) <i>Collin Hovinga, PharmD, MS, FCCP (C-Path)</i>	
9:30a	FDA update on Act for ALS Activities <i>Jacqueline Corrigan-Curray, MD, JD (US Food & Drug Administration)</i>	
9:40a	ALS Research and Care Roadmap for the Next Decade: Insights into the NASEM Report on ALS <i>Suma Babu, MBBS, MPH (Healey & AMG Center for ALS at MGH)</i> <i>Rita Sattler, MSc, PhD (Barrow Neurological Institute)</i>	
9:55a	Q&A	

2024 ANNUAL NEALS MEETING AGENDA*

*Agenda subject to change

DAY ONE

(CONTINUED)

TUESDAY, OCTOBER 22, 2024

10:00a – 10:15a	Break	
10:15 – 10:30a	 Member Initiative Spotlight: Respiratory Care for ALS <i>John Hansen-Flaschen, MD (Penn Medicine)</i>	Opal Ballroom
10:30 – 11:35a	 NEALS Affiliated Trial Session	Opal Ballroom
10:30a	Results and Learnings From the Phase 3 Trial Evaluating Sodium Phenylbutyrate and Taurursodiol in Amyotrophic Lateral Sclerosis (PHOENIX) <i>Sabrina Paganoni, MD, PhD (Healey & AMG Center for ALS at MGH)</i> <i>Leonard van den Berg, MD, PhD (University Medical Center Utrecht)</i>	
10:40a	HIMALAYA trial: Double-blind, placebo-controlled trial of RIPK1 inhibitor (SAR443820) in ALS <i>Nazem Atassi, MD, MBA (Sanofi)</i> <i>Merit Cudkowicz, MD, MSc (Healey & AMG Center for ALS)</i>	
10:50a	ALL ALS: Year 1 Progress and Future Enrollment Goals <i>James Berry, MD, MPH (Healey & AMG Center for ALS)</i> <i>Robert Bowser, PhD (Barrow Neurological Institute)</i>	
11:00a	HEALEY Platform Trial updates what's new for 2025 <i>Merit Cudkowicz, MD, MSc (Healey & AMG Center for ALS)</i>	
11:10a	A Phase 2A Study of TPN-101, A Nucleoside Reverse Transcriptase Inhibitor, in Patients with C9ORF72-Related ALS/FTD <i>Andrew Satlin, MD (Transposon Therapeutics)</i>	
11:20a	Pioneering Progress: Exciting Updates from NEALS-Affiliated Trials <i>Jinsy Andrews, MD, MSc (Columbia University)</i>	
11:25a	Q&A	
11:40 – 12:15	 Stats Corner <i>Moderator: James Berry, MD, MPH (Healey & AMG Center for ALS)</i> <i>Christopher Coffey, PhD (University of Iowa)</i> <i>Eric Macklin, PhD (Healey & AMG Center for ALS at MGH)</i> <i>Melanie Quintana, PhD (Berry Consultants)</i>	Opal Ballroom
12:15 – 1:15p	Lunch	Pool Lawn




2024 ANNUAL NEALS MEETING AGENDA*

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DAY ONE

(CONTINUED)

TUESDAY, OCTOBER 22, 2024

1:20p – 2:20p	 NEALS Research Ambassador Panel: Through the Looking Glass <i>Moderators: Allison Bulat (NEALS; Healey & AMG Center for ALS at M)</i> <i>Layne Oliff, PharmD (ALS Research Ambassador)</i> <i>Mandi Bailey (ALS Research Ambassador)</i> <i>Cassandra Haddad (ALS Research Ambassador)</i> <i>Dave Shulman (ALS Research Ambassador)</i>	Opal Ballroom
2:20 – 2:30p	Break	
2:30 – 3:30p	 Hot Topic Session: ALS Predictive Models: How can they be used for Clinical Trials? <i>Moderator: Jonathan D. Glass, MD (Emory University)</i> <i>David Walk, MD, FAAN (University of Minnesota)</i> <i>Leonard van den Berg, MD, PhD (University Medical Center Utrecht)</i> <i>Melanie Quintana, PhD (Berry Consultants)</i> <i>David Ennist, PhD, MBA (Origent Data Sciences, Inc)</i>	Opal Ballroom
<small>HOT TOPIC IN ALS SCIENCE SESSION. SPONSORED BY</small> 		
3:30 – 4:30p	Big Data Committee Meeting	Opal Sun
3:30 – 4:00p	Pridopidine EAP2 Study Meeting	Beach Salons
4:00 – 4:30p	RAPA EAP Study Meeting	Beach Salons
4:30 – 6:30p	Poster Session 1	Sea Salon & Sand Salon

(End of day 1)

DAY TWO

WEDNESDAY, OCTOBER 23, 2024

7:30a – 4:00p	Registration	Opal Ballroom Foyer
7:45 – 9:00a	Breakfast	Opal Ballroom Foyer
8:00 – 9:00a	REFINE Study Meeting	Sunset Salon
8:00 – 9:00a	Global Site Meeting	Beach Salons
9:00 – 9:10a	 NEALS 30th Anniversary Bike for ALS Initiative <i>Jeremy Shefner, MD, PhD (Barrow Neurological Institute)</i>	Opal Ballroom
9:10 – 9:40a	 NEALS Committee Spotlight: Updates from the Physical Therapist/Occupational Therapist Committee, Nutrition Committee, Respiratory Care and Ventilation Committee, and Palliative Committee <i>Claire MacAdam, PT, NCS (Massachusetts General Hospital)</i> <i>Michele Weaver PT, DPT (Corewell Health)</i> <i>Ambereen Mehta, MD, MPH, FAAHPM (Johns Hopkins)</i> <i>Stephanie Dobak, MS, RD, LDN, CNSC (Jefferson Weinberg ALS Center)</i> <i>Andrea Charvet, PhS, RDN, LDN (Nova Southeastern University)</i> <i>Edward Kasarskis, MD, PhD (University of Kentucky)</i> <i>Eufrosina Young, MD (SUNY Upstate Medical University)</i>	Opal Ballroom
9:40 – 11:30a	 Science Symposium: AI is NOW: Bringing AI into ALS Research <i>Moderators: NEALS Science Advisory Board Co-Chairs</i> <i>Jeffrey Rothstein, MD, PhD (Johns Hopkins University)</i> <i>Timothy Miller, MD, PhD (Washington University in St. Louis)</i>	Opal Ballroom
10:00a	The Genetics of ALS Reveals Potential Novel Therapeutic Targets <i>Michael Snyder, PhD (Stanford University)</i>	
10:25a	What is AI and how can it help us find causes and treatments for ALS? <i>Steven Finkbeiner, MD, PhD (University of California, San Francisco)</i>	
11:00a	Towards Better Understanding of ALS using a Multi-Marker Discovery Approach from a Multi-Modal Database (ALS4M) <i>Xing Song, PhD (University of Missouri)</i>	
11:15a	Use of AI enabled combinatorial analysis of multi-dimensional datasets to develop genetic stratification biomarkers to predict responders to existing and candidate ALS therapies and identify repurposing candidates for clinical trials <i>Steve Gardner, PhD (PrecisionLife)</i>	

2024 ANNUAL NEALS MEETING AGENDA*

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DAY TWO

(CONTINUED)

WEDNESDAY, OCTOBER 23, 2024

11:30a – 12:30p	Lunch	Pool Lawn
12:00 – 1:00p	 NEALS Member Training: Expanded Access, Expanding Hope	Opal Sand
1:10 – 2:10p	 Industry Roundtable <i>Moderator: Nicholas Maragakis, MD (Johns Hopkins University)</i> <i>Lauren Kett, MD, PhD (Amylyx Pharmaceuticals)</i> <i>Simrit Parmar, MD (Cellenkos)</i> <i>Aaron Tansy, MD (PTC Therapeutics)</i> <i>Daniel Fowler, MD (Rapa Therapeutics)</i>	Opal Ballroom
2:15 – 4:15p	HEALEY Platform Trial Meeting	Opal Sand & Sea
2:45 – 3:45p	NEALS Biorepository Informational Session	Opal Ballroom
3:00 – 4:00p	FUSION Clinical Trial in FUS-ALS Study Meeting	Sunset Salon
4:00 – 6:00p	Poster Session 2	Sea Salon & Sand Salon
6:05 – 6:20p	Group Photo	Lobby
6:20 – 7:00p	Abstract Review Committee Mtg (<i>Closed Meeting</i>)	Sunset Salon
6:30 – 9:00p	BBQ Dinner	Pool Lawn

(End of day 2)

DAY THREE

THURSDAY, OCTOBER 24, 2024

7:30a – 1:00p	Registration	Opal Ballroom Foyer
7:45 – 9:00a	Breakfast	Opal Ballroom Foyer
8:00 – 8:55a	ALL ALS Study Meeting	Sand Salon
9:00 – 9:30a	 Revolutionizing ALS Care: The Promise of Brain-Computer Interfaces <i>Moderator: Jinsy Andrews, MD, MSc (Columbia University)</i> <i>Mariska Vansteensel, PhD (University Medical Center Utrecht)</i> <i>Leigh Hochberg, MD, PhD (Mass General Hospital)</i> <i>Adam Fry, PhD (Synchron)</i>	Opal Ballroom
9:30 – 11:55a	 Awards and Abstract Platform Session	Opal Ballroom
9:30a	The Gupta Family Endowed Prize for Innovation in ALS Care <i>Presented by: Merit Cudkowicz, MD, MSc (Healey & AMG Center for ALS at MGH)</i>	
9:40a	Drs. Ayeez and Shelena Lalji & Family Student Scholar Award for Repair and Regenerative Mechanisms in ALS <i>Presented by: Merit Cudkowicz, MD, MSc (Healey & AMG Center for ALS at MGH)</i>	
9:50a	Big Data Committee Award <i>Presented by: Alex Sherman, MS (Healey & AMG Center for ALS at MGH)</i>	
9:55a	Abstract Poster Awards <i>Presented by: Terry Heiman-Patterson, MD (Temple University)</i>	
	 Abstract Platform Presentations	
10:05a	Boosting Clinical Trial Power in ALS with AI-Generated Digital Twins <i>Rachel Mak-McCully, PhD (Unlearn AI)</i>	
10:20a	Ataxin-2 as a target in sporadic ALS: Considerations and strategies for a path forward in light of recent trial data <i>Defne Amado, MD, PhD (University of Pennsylvania)</i>	
10:35a	Pilot Experience with Transcutaneous Carbon Dioxide Monitoring for Patients with Amyotrophic Lateral Sclerosis: A Two Center Prospective Cohort <i>Jason Ackrivo, MD, MSCE (University of Pennsylvania)</i>	

Abstract Platform Presentations
(continued from previous page)

- 10:50a AI for Good: Partnering with AI and Voice Bank Industry to Easily Create On-Device Personal Voice for People with ALS
John Costello, MA, CC-SLP (Boston Children's Hospital)
- 11:05a Development of a Human iPSC-Derived "Corticospinal Tract-on-a-Chip" for ALS Research
Andriana Charalampopoulou, MD (Johns Hopkins University)
- 11:20a Application of 7 tesla susceptibility weighted MRI in the clinical evaluation of suspected motor neuron disease
Jaimin Shah, MD (Mayo Clinic, Jacksonville)
- 11:35a Group Q&A
- 11:55 – 1:00p Lunch** **Opal Ballroom Foyer**
- 12:00 – 1:00p **CARDINALS Study Meeting** **Opal Ballroom**

(End of day 3)