



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 Workshop or Training Sessions

(open to NEALS members)

DAY ONE

TUESDAY, OCTOBER 22, 2024

All times shown in ET

7:45a – 8:30a	CDC Informational Session: How the National ALS Registry can Support your Research <i>Paul Mehta, MD (National ALS Registry)</i>
9:00 – 10:25a	Opening Session: NEALS Updates, Progress, and Partnerships in ALS Research Session Lead: Jinsy Andrews, MD, MSc (Columbia University) <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>
9:20a	NINDS's Investment in ALS Research <i>Walter Koroshetz, MD (National Institute of Neurological Disorders and Stroke (NINDS))</i>
9:40a	FDA update on Act for ALS Activities <i>Jacqueline Corrigan-Curray, MD, JD (US Food & Drug Administration)</i>
9:50a	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>
10:00a	Updates on Critical Path for Rare Neurodegenerative Diseases (CP-RND) <i>Collin Hovinga, PharmD, MS, FCCP (C-Path)</i>
10:10a	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>
10:20a	Q&A
10:25 – 10:40a	Break

2024 ANNUAL NEALS MEETING AGENDA*

*Agenda subject to change

DAY ONE

(CONTINUED)

TUESDAY, OCTOBER 22, 2024

All times shown in ET

- 10:40a – 10:55a** **Member Initiative Spotlight: Respiratory Care for ALS**
Session Lead: James Berry, MD, MPH (Healey & AMG Center for ALS at Mass General)
John Hansen-Flaschen, MD (Penn Medicine)
- 10:55 – 11:55a** **NEALS Affiliated Trial Session**
Session Lead: Jinsy Andrews, MD, MSc (Columbia University)
- 10:55a Results and Learnings From the Phase 3 Trial Evaluating Sodium Phenylbutyrate and Taurursodiol in Amyotrophic Lateral Sclerosis (PHOENIX)
Sabrina Paganoni, MD, PhD (Healey & AMG Center for ALS at MGH)
Leonard van den Berg, MD, PhD (University Medical Center Utrecht)
- 11:05a HIMALAYA trial: Double-blind, placebo-controlled trial of RIPK1 inhibitor (SAR443820) in ALS
Nazem Atassi, MD, MBA (Sanofi)
Merit Cudkowicz, MD, MSc (Healey & AMG Center for ALS)
- 11:15a ALL ALS: Year 1 Progress and Future Enrollment Goals
James Berry, MD, MPH (Healey & AMG Center for ALS)
Robert Bowser, PhD (Barrow Neurological Institute)
- 11:25a HEALEY Platform Trial updates what's new for 2025
Merit Cudkowicz, MD, MSc (Healey & AMG Center for ALS)
- 11:35a A Phase 2A Study of TPN-101, A Nucleoside Reverse Transcriptase Inhibitor, in Patients with C9ORF72-Related ALS/FTD
Andrew Satlin, MD (Transposon Therapeutics)
- 11:45a Pioneering Progress: Exciting Updates from NEALS-Affiliated Trials
Jinsy Andrews, MD, MSc (Columbia University)
- 11:55 – 12:30p** **Break**
- 12:30 – 1:05p** **Stats Corner**
Session Lead: James Berry, MD, MPH (Healey & AMG Center for ALS at Mass General)
Christopher Coffey, PhD (University of Iowa)
Eric Macklin, PhD (Healey & AMG Center for ALS at MGH)
Melanie Quintana, PhD (Berry Consultants)

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DAY ONE

(CONTINUED)

TUESDAY, OCTOBER 22, 2024

All times shown in ET

1:05p – 2:05p

NEALS Research Ambassador Panel: Through the Looking Glass
Session Lead: James Berry, MD, MPH Healey & AMG Center for ALS at Mass General)

Moderators: Allison Bulat (NEALS; Healey & AMG Center for ALS at Mass General)

Layne Oliff, PharmD (ALS Research Ambassador)

Mandi Bailey (ALS Research Ambassador)

Cassandra Haddad (ALS Research Ambassador)

Dave Shulman (ALS Research Ambassador)

2:05 – 2:20p

Break

2:20 – 3:20p

Hot Topic Session: ALS Predictive Models: How can they be used for Clinical Trials?

Session Lead: Jonathan D. Glass, MD (Emory University)

David Walk, MD, FAAN (University of Minnesota)

Leonard van den Berg, MD, PhD (University Medical Center Utrecht)

Melanie Quintana, PhD (Berry Consultants)

David Ennist, PhD, MBA (Origent Data Sciences, Inc)

HOT TOPIC IN ALS SCIENCE SESSION SPONSORED BY



3:30 – 4:30p

Big Data Committee Meeting

3:30 – 4:30p

Poster Session 1

(End of day 1)

2024 ANNUAL NEALS MEETING AGENDA*

*Agenda subject to change

DAY TWO

WEDNESDAY, OCTOBER 23, 2024

All times shown in ET

- 9:00 – 9:45a **Global Site Meeting**
- 9:45a – 10:00a **Day 2 Kickoff: Exciting CRLI Update and Future Vision**
James Berry, MD, MPH Healey & AMG Center for ALS at Mass General)
- 10:00 – 10:10a **NEALS 30th Anniversary Bike for ALS Initiative**
Jeremy Shefner, MD, PhD (Barrow Neurological Institute)
- 10:10 – 10:40a **NEALS Committee Spotlight**
Session Lead: Jeremy Shefner, MD, PhD (Barrow Neurological Institute)
- 10:12a **Physical Therapist/Occupational Therapist Committee Updates**
Claire MacAdam, PT, NCS (Massachusetts General Hospital)
Michele Weaver PT, DPT (Corewell Health)
- 10:19a **Palliative Committee Updates**
Ambereen Mehta, MD, MPH, FAAHPM (Johns Hopkins)
- 10:26a **Nutrition Committee Updates**
Stephanie Dobak, MS, RD, LDN, CNSC (Jefferson Weinberg ALS Center)
Andrea Charvet, PhD, RDN, LDN (Nova Southeastern University)
Edward Kasarskis, MD, PhD (University of Kentucky)
- 10:33a **Respiratory Care and Ventilation Committee Updates**
Eufrosina Young, MD (SUNY Upstate Medical University)
- 10:40 – 11:00a **Break**
- 11:00 – 12:50a **Science Symposium: AI is NOW: Bringing AI into ALS Research**
Session Leads: NEALS Science Advisory Board Co-Chairs
Jeffrey Rothstein, MD, PhD (Johns Hopkins University)
Timothy Miller, MD, PhD (Washington University in St. Louis)
- 11:20a **The Genetics of ALS Reveals Potential Novel Therapeutic Targets**
Michael Snyder, PhD (Stanford University)
- 11:45a **What is AI and how can it help us find causes and treatments for ALS?**
Steven Finkbeiner, MD, PhD (University of California, San Francisco)
- 12:20p **Towards Better Understanding of ALS using a Multi-Marker Discovery Approach from a Multi-Modal Database (ALS4M)**
Xing Song, PhD (University of Missouri)
- 12:35p **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**
Steve Gardner, PhD (PrecisionLife)

2024 ANNUAL NEALS MEETING AGENDA*

**Agenda subject to change*

DAY TWO

(CONTINUED)

WEDNESDAY, OCTOBER 23, 2024

All times shown in ET

12:50p – 1:30p

Break

1:30 – 2:30p

Industry Roundtable

Session Lead: Nicholas Maragakis, MD (Johns Hopkins University)

Lauren Kett, MD, PhD (Amylyx Pharmaceuticals)

Simrit Parmar, MD (Cellenkos)

Aaron Tansy, MD (PTC Therapeutics)

Daniel Fowler, MD (Rapa Therapeutics)

2:40 – 3:40p

Poster Session 2

3:00 – 4:00p

HEALEY Platform Trial Meeting

(End of day 2)

- 10:00 – 10:40a** **Revolutionizing ALS Care: The Promise of Brain-Computer Interfaces**
Session Lead: Jinsy Andrews, MD, MSc (Columbia University)
- Mariska Vansteensel, PhD (University Medical Center Utrecht)*
Adam Fry, PhD (Synchron)
Leigh Hochberg, MD, PhD (Mass General Hospital)
- 10:40 – 11:05a** **Awards**
Session Lead: Jinsy Andrews, MD, MSc (Columbia University)
- 10:40a The Gupta Family Endowed Prize for Innovation in ALS Care
Presented by: Merit Cudkowicz, MD, MSc (Healey & AMG Center for ALS at MGH)
- 10:50a Drs. Ayeez and Shelena Lalji & Family Student Scholar Award for Repair and Regenerative Mechanisms in ALS
Presented by: Merit Cudkowicz, MD, MSc (Healey & AMG Center for ALS at MGH)
- 11:00a Big Data Committee Award
Presented by: Alex Sherman, MS (Healey & AMG Center for ALS at MGH)
- 11:05 – 11:15a** **Break**
- 11:15 – 1:15p** **Abstract Awards and Platform Presentations**
Session Lead: Terry Heiman-Patterson, MD (Temple University)
- 11:15a Abstract Poster Awards
Presented by: Terry Heiman-Patterson, MD (Temple University)
- 11:25a Boosting Clinical Trial Power in ALS with AI-Generated Digital Twins
Rachel Mak-McCully, PhD (Unlearn AI)
- 11:40a Ataxin-2 as a target in sporadic ALS: Considerations and strategies for a path forward in light of recent trial data
Defne Amado, MD, PhD (University of Pennsylvania)
- 11:55a Pilot Experience with Transcutaneous Carbon Dioxide Monitoring for Patients with Amyotrophic Lateral Sclerosis: A Two Center Prospective Cohort
Jason Ackrivo, MD, MSCE (University of Pennsylvania)

Abstract Platform Presentations

(continued from previous page)

- 12:10p 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)
- 12:25p Development of a Human iPSC-Derived "Corticospinal Tract-on-a-Chip" for ALS Research
Ariana Charalampopoulou, MD (Johns Hopkins University)
- 12:40p Application of 7 tesla susceptibility weighted MRI in the clinical evaluation of suspected motor neuron disease
Jaimin Shah, MD (Mayo Clinic, Jacksonville)
- 12:55p Group Q&A
- 1:00 – 2:00p **CARDINALS Study Meeting**

(End of day 3)