

**2018 Annual NEALS Meeting Agenda\***

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**TUESDAY**

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<b>Time</b>	<b>Event</b>	<b>Location</b>
08:00 am – 09:00 am	<i>Continental Breakfast</i>	Opal Ballroom Foyer
08:00 am – 4:00 pm	Registration	Opal Ballroom Foyer
08:00 am – 09:00 am	<b>Natural History Consortium Mtg</b> <i>David Walk, MD (Univ. of Minn)</i>	Sea Shore
08:00 am – 09:00 am	<b>Retigabine Study Mtg</b> <i>Brian Wainger, MD (MGH)</i>	Sea Side
08:30 am – 12:30 pm	Outcomes Training Session	Opal Sea
12:00 pm – 1:00 pm	<b>Actemra Study Mtg</b> <i>Shafeeq Ladha, MD (BNI)</i>	Beach Breeze
<b>12:30 pm – 1:30 pm</b>	<b>Lunch</b>	<b>Opal Foyer</b>
12:45 pm – 1:45 pm	<b>Physical Therapist Committee Mtg</b> <i>Peggy Allred, PT (Cedars Sinai); Sara Feldman, PT (Temple)</i>	Sea Watch
12:45 pm – 1:45 pm	<b>Mexiletine II Study Mtg</b> <i>Michael Weiss, MD (Univ. of Washington)</i>	Sea Shore
12:45 pm – 1:45 pm	<b>Biorepository Committee Mtg</b> <i>Robert Bowser, PhD (Barrow); Terry Heiman-Patterson, MD (Temple)</i>	Sunset
1:00 pm – 2:00 pm	<b>Nutrition Committee Mtg</b> <i>Anne-Marie Wills, MD (MGH); Edward Kasarskis, MD (UKY)</i>	Beach View
1:30 pm – 3:30 pm	Medical Monitoring Training Session <i>Jinsy Andrews, MD, MSc (Columbia); Christopher Coffey, PhD (Univ. of Iowa)</i>	Sand Salon
2:00 pm – 3:30 pm	Site Management I Training Session	Opal Sand
2:00 pm – 3:00 pm	<b>CABB Study Mtg</b> <i>James D. Berry, MD (MGH)</i>	Sea Side
2:00 pm – 3:00 pm	<b>BIO-03 Study Mtg</b> <i>Shafeeq Ladha, MD (BNI)</i>	Beach Breeze
2:00 pm – 4:00 pm	Ventilation Committee Symposium	Opal Sea
2:00 pm – 4:00 pm	NEALS Bulbar ALS Update Session	Opal Sun
3:30 pm – 5:30 pm	ATLIS Refresher Meeting for CENTAUR Sites	Sea Shore
3:45 pm – 5:15 pm	Site Management II Training Session	Beach Salon
<b>4:15 pm – 6:15 pm</b>	<b>NEALS Member/Industry Partner Roundtable</b>	<b>Opal Sand/Sea</b>
<b>6:15 pm – 7:45 pm</b>	<b>Welcome Reception</b>	<b>Event Lawn</b>

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**WEDNESDAY**

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07:45 am – 09:00 am	<i>Continental Breakfast</i>	Opal Ballroom Foyer
08:00 am – 4:00 pm	Registration	Opal Ballroom Foyer

08:00 am – 09:00 am	<b>Palliative Committee</b> <i>Raghav Govindarajan, MD (Missouri)</i>	Sunset
08:00 am – 09:00 am	<b>Bulbar Committee</b> <i>Gary Pattee, MD (Nebraska)</i>	Beach Breeze
08:00 am – 09:00 am	<b>Recruitment &amp; Retention Committee</b> <i>Sabrina Paganoni, MD (MGH); Steve Kolb, MD (OSUMC); Meghan Hall (BNI); Emily Engel (MGH); Katrina Madden (MUSC)</i>	Sea Shore/Sea Side
08:00 am – 09:00 am	<b>Imaging Committee</b> <i>Nazem Atassi, MD, MMSc (MGH); Erik Pioro, MD, PhD (Cleveland Clinic); Michael Benatar, MD (U. Miami)</i>	Sand Salon
08:00 am – 09:00 am	<b>DIALS Study Mtg</b> <i>Katharine Nicholson, MD (MGH)</i>	Sea Watch
<b>09:10 am – 12:00 pm</b>	<b>General Session: Meeting Opens</b> <i>NEALS Co-Chairs Jonathan Glass, MD and Timothy Miller, MD, PhD</i>	<b>Opal Ballroom</b>
09:10 am – 09:45 am	<b>Welcome &amp; Consortium Accomplishments</b>	
09:45 am – 10:45 am	<b>Right to Try and Expanded Access Discussion</b> <i>James Russell, MD (Lahey); Jinsy Andrews, MD, MSc (Columbia)</i>	
10:45 am – 12:00 pm	<b>NEALS Trial Updates</b>	
	C9ORF72 Natural History and Biomarkers – <i>Timothy Miller, MD, PhD (Wash. U)</i>	
	ALS Testing Through Home-based Outcome Measures (ALS AT HOME) – <i>Jeremy Shefner, MD, PhD (BNI)</i>	
	A Phase 2 Pharmacodynamic Trial of Ezogabine (Retigabine) on Neuronal Excitability in Amyotrophic Lateral Sclerosis – <i>Brian Wainger, MD (MGH)</i>	
	A Phase 2 Randomized, Placebo Controlled Trial of Tocilizumab in ALS Subjects – <i>Shafeeq Ladha, MD, (BNI)</i>	
	Genetic Testing Practice Survey Results – <i>Jennifer Roggenbuck, MS, LGC (OSUMC)</i>	
11:00 am – 3:45 pm	<i>Poster Set-Up</i>	<i>Opal Foyer</i>
<b>12:00 pm – 1:30 pm</b>	<b>Lunch</b>	<b>Sand Foyer Lawn</b>
12:15 pm – 1:15 pm	New Member Q&A	Beach View
12:15 pm – 1:15 pm	<b>Answer ALS Study Mtg</b>	Sand Salon
12:15 pm – 1:15 pm	<b>Research Nurse Committee</b> <i>Pamela Kittrell, MSN, RN, CCRC (UT Health)</i>	Beach Breeze
12:15 pm – 1:15 pm	<b>NeuroBANK Informational and Training Session</b>	Sea Watch
12:15 pm – 1:15 pm	<b>VA Committee</b> <i>Christina Fournier, MD (Emory); Colin Quinn, MD (UPenn)</i>	Sunset

12:15 pm – 1:15 pm	<b>Technology in ALS Committee</b> <i>James Berry, MD (MGH); Sabrina Paganoni, MD (MGH); Michael Pulley, MD (UF Jacksonville)</i>	Sea Shore/Sea Side
<b>1:30 pm – 3:45 pm</b>	<b>Abstract Platform Presentations</b> <i>Terry Heiman-Patterson, MD (Temple)</i>	<b>Opal Ballroom</b>
1:35 pm	<b>Best Clinical Screening Tools for Early Detection and Accurate Monitoring of Dysphagia in ALS: Development of the Physiologic Risk Index of Swallowing Impairment (PRISIM)</b> <i>Plowman, E. University of Florida, Gainesville</i>	
1:50 pm	<b>Computer assessment of speech in a successful ALS treatment trial</b> <i>Smith, R. Center for Neurologic Study</i>	
2:05 pm	<b>Use of a Time to Event Strength Measure in a Phase 3 ALS Trial</b> <i>Shefner, J. Barrow Neurological Institute</i>	
2:20 pm	<b>High plasma levels of organic pollutants negatively impact survival in amyotrophic lateral sclerosis</b> <i>Goutman, S. University of Michigan</i>	
2:35 pm	<b>Framing a Palliative Approach to ALS: Eliciting Stakeholder Perspectives on the Realities of Living with ALS.</b> <i>Kukulka, K. University of Missouri</i>	
2:50 pm	<b>Interuser Reliability of the Penn UMN Score in ALS</b> <i>Quinn, C. University of Pennsylvania</i>	
3:05 pm	<b>Cromolyn Sodium Treatment is Neuroprotective and Delays Disease Progression in SOD1G93A Mouse Model of Amyotrophic Lateral Sclerosis</b> <i>Sadri-Vakili, G. Massachusetts General Hospital</i>	
3:20 pm	<b>BrainGate pilot clinical trials: Harnessing motor cortical signals for the control of communication devices by people with ALS</b> <i>Hochberg, L. Massachusetts General Hospital</i>	
3:35 pm	Member Abstract Poster Awards	
3:45 pm – 4:45 pm	<b>Poster Session: Group A</b>	Opal Foyer
4:15 pm – 5:15 pm	<b>NeuroBANK Informational and Training Session</b>	Sea Watch
4:45 pm – 5:45 pm	<b>Poster Session: Group B</b>	Opal Foyer
5:50 pm – 6:15 pm	<b>Industry Poster Blitz</b>	Opal Foyer
<b>6:25 pm</b>	<b>NEALS Member Photo</b>	<b>Lawn</b>
<b>6:30 pm – 9:30 pm</b>	<b>BBQ on the Lawn</b>	<b>Event Lawn</b>
<b>9:30 pm</b>	<b>Live Music</b>	<b>Shephard's Beach Resort</b>

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**THURSDAY**

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07:45 am – 09:00 am	<i>Continental Breakfast</i>	Opal Ballroom Foyer
08:00 am – 12:00 pm	Registration	Opal Ballroom Foyer
08:00 am – 09:00 am	<b>Centaur Study Mtg</b> <i>Sabrina Paganoni, MD (MGH)</i>	Opal Sand
08:00 am – 09:00 am	<b>fALS/FTD Committee</b> <i>Claire Flaherty, PhD (Penn State); Matthew Harms, MD (Columbia)</i>	Sea Shore
08:00 am – 09:00 am	<b>Big Data Committee</b> <i>Alex Sherman (MGH)</i>	Opal Sea
08:00 am – 09:00 am	<b>Ventilation Committee</b> <i>Christopher Lee, MD (Vanderbilt); Benjamin R. Brooks, MD (Carolinas)</i>	Sea Side
<b>09:15 am – 12:00 pm</b>	<b>Science Symposium</b>	<b>Opal Ballroom</b>
	<b>Science Update</b>	
09:15 am – 10:00 am	<i>Robert Brown, MD, DPHIL (UMass); Jeffrey Rothstein, MD, PhD (Johns Hopkins); Timothy Miller, MD, PhD (Wash. Univ.)</i>	
10:00 am	<b>Untying the Gordian Knot of ALS and FTD – Should We?</b> <i>Bruce Miller, MD (University of California, San Francisco)</i>	
10:45 am	<b>What Should We Do About Cognitive and Behavioral Changes in ALS?</b> <i>Orla Hardiman, BSc, MD, FRCPI, FTCD, MRIA (Trinity College Dublin)</i>	
11:30 am	<b>Innovative Statistical Design and Analysis in ALS</b> <i>Christopher Coffey, PhD (University of Iowa)</i>	
<b>12:00 pm – 1:00 pm</b>	<b>Lunch</b>	<b>Opal Foyer</b>
12:00 pm – 1:00 pm	<b>UMN Committee</b> <i>Nazem Atassi, MD, MMSc (MGH); Jinsy Andrews, MD, MSc (Columbia); Sabrina Paganoni, MD (MGH)</i>	Opal Sea
12:15 pm – 1:15 pm	<b>T-Reg Study Mtg</b>	Opal Sun
1:15 pm – 2:15 pm	<b>GTAC Study Mtg</b> <i>Matthew Harms, MD (Columbia)</i>	Sea Shore
2:00 pm – 3:00 pm	<b>PEACe Committee</b> <i>Rick Bedlack, MD (Duke); Allison Pogemiller</i>	Sea Side
<b>3:00 pm</b>	<b>NEALS Meeting Closes</b>	

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*\*Agenda subject to change*