

ALD Connect Meeting

November 16th and 17th, 2016 - San Diego Wyndham Bayside

Day 1: ALDC CONSORTIUM ACTIVITY

- 7:30 am: Breakfast and Registration
- 8:00 am: Welcome: Introductions and Goals for 2016 Annual Meeting
Janis Sherwood
- 8:15 am: What is the Purpose of ALD Connect? Are We Where We Want to Be?
Florian Eichler
- 9:00 am: Report from Infrastructure Work Group (WG#2)
TBD
- 9:30 am: Update on NeuroBANK and the Patient Portal
Erin Connors
- 10:00 am: Report from Therapeutics Work Group (WG#3)
Kendrick Goss, Rachel Salzman
- 10:30 am: Report from the Industry Advisory Council
Mark Shearman, Masoud Mokhtani, Kendrick Goss
- 11:00 am: Report from Outreach & Advocacy (WG#4)
Kathleen O'Sullivan-Fortin
- 11:30 am: ALD Connect Awards
- 12:00 pm: LUNCH
- 1:00 pm: Newborn Screening for ALD
Stanley Sciortino, Jennifer Kwon, Alex Kemper
- 2:00 pm: Global ALD Efforts
TBD
- 2:45 pm: Group Brainstorm: Next Steps and 5 Year Vision
- 3:45 pm: Summary of Brainstorms
- 4:00 pm: *Board of Directors Closed Working Session**

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Day 2: PATIENT LEARNING ACADEMY

- 8:30 am: Registration and Breakfast
- 9:00 am: Welcome and Introduction to ALD Connect
- 9:15am: Progress in ALD/AMN
Florian Eichler
- 10:00 am: Breakout Session
- 10:30 am: ALD Patient and Carrier Experiences
Ben Lenail and Janis Sherwood
- 11:00 am: Clinical Trials in ALD
Ali Fatemi
- 12:00 pm: LUNCH
- 1:00 pm: Disease Management (to include care protocols, testing, etc)
Irene Hufnagel
- 1:45 pm: Patient Portal: How Patients Can Drive Clinical Trials
Brian Chandler
- 2:15 pm: Endocrine Issues and Their Management in ALD/AMN
Local TBD
- 3:00 pm: Breakout Sessions
- 4:00 pm: Physical Therapy and the Benefits of Exercise
TBD
- 4:30 pm: Patient and Caregiver Stress Management
TBD
- 5:00 pm: Adjourn