

# ALD Connect Meeting

November 16<sup>th</sup> and 17<sup>th</sup>, 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 Sciotino, 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