



## **ALD Connect Meeting**

November 17<sup>th</sup> and 18<sup>th</sup>, 2017 – Bethesda Marriott 5151 Pooks Hill Rd, Bethesda, MD 20814

### **Day 1: ALDC CONSORTIUM ACTIVITY**

- 7:30 am: Breakfast and Registration
- 8:00 am: Welcome: Introductions and Goals for 2017 Annual Meeting  
*Ali Fatemi*
- 8:15 am: The Therapeutic Landscape of ALD and AMN  
*Florian Eichler*
- 9:00 am: Clinical Trial Readiness for Rare Neurological Diseases: FDA and NIH Perspective  
*Devanand Jillapalli, M.D. – OOPD, FDA / Jill Morris, Ph.D. – NINDS, NIH*
- 10:00 am: BREAK
- 10:30 am: The ALD Database and the Need for Translational Metabolism in Newborn Screening  
*Stephan Kemp*
- 11:15 am: Newborn Screening for ALD  
*Ann Moser, Elisa Seeger*
- 12:00 pm: ALD Connect Awards
- 12:15 pm: LUNCH
- 12:45 pm: Industry Panel: Updates on Trial Plans
- 2:00 pm: Outreach and Advocacy for ALD  
*Jean Kelley*
- 2:45 pm: Learning from Others: Patient Engagement Across Rare Disease  
*Ronald Bartek, Margie Frazier*
- 3:30 pm: BREAK
- 3:45 pm: Group Brainstorm and Wish List for 2018  
*Ben Lenail, Keith Van Haren*
- 4:45 pm: Summary of Brainstorms



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### **Day 2: PATIENT LEARNING ACADEMY**

- 7:30 am: Registration and Breakfast
- 8:00 am: Welcome and Introduction to ALD Connect
- 8:15 am: Progress in ALD/AMN  
*Florian Eichler, Christine Duncan*
- 9:00 am: ALD and AMN Patient Experiences  
*Ben Lenail, Paul Rojas*
- 9:30 am: Data Sharing – The Patient’s Voice Makes a Difference  
*Alex Sherman*
- 10:00 am: Physical Therapy and the Benefits of Exercise  
*Christopher Joseph, Jeniffer Keller*
- 10:45 am: Enhancing Quality of Life for Advanced Cerebral ALD  
*Bob Wyborn*
- 11:30 am: Taking Care of a Newborn with ALD  
*Tara Meady*
- 12:00 pm: Patient Portal Update  
*Alex Sherman*
- 12:15 pm: LUNCH
- 1:00 pm: Fighting the Odds, Transformative Patient Experiences  
*Kyle Bryant*
- 1:45 pm: Young ALD Carriers  
*Taylor Kane*
- 2:15 pm: Endocrine Issues and Their Management in ALD/AMN  
*Aniket Sidhaye*
- 3:00 pm: Breakout Session
- 4:00 pm: Adjourn