



ALD Connect Meeting

November 17th and 18th, 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