



7th Annual ALD Standards of Care Conference Thursday, March 16th & Friday, March 17th 2023

Thursday, March 16, 2023

8:00AM – 9:00AM	Breakfast & Registration
9:00AM – 9:15AM	Conference Welcome Elisa Seeger, Founder, ALD Alliance
9:15AM – 10:00AM	ALD Newborn Screening Roundtable Update Joseph Orsini, PhD, NYS Department of Health
10:00AM – 10:30AM	ALD Newborn Screening Parent Perspective DJ and Jennifer McDaniel, Indiana
10:30AM – 11:00AM	Updates on Vitamin D's Effects in ALD Keith Van Haren, MD, Stanford University
11:00AM – 11:15AM	Break
11:15AM – 12:00PM	Neurocognitive & Mental Health Impact of ALD Across the Lifespan: Insights for the Era of Newborn Screening Rene Pierpont, PhD, University of Minnesota
12:00PM – 12:30PM	MRI 101 Sumit Narayan Niogi, MD, Weill Cornell Medical College
12:30PM – 1:30PM	Lunch Break
1:30PM – 2:00PM	ALD Standards of Care: Pediatric Neurology Eric Mallack, MD, NY-Presby/Weill Cornell Medicine
2:00PM – 2:30PM	ALD Standards of Care: Pediatric Endocrinology Molly Regelman, MD, The Children's Hospital at Montefiore
2:30PM – 3:00PM	ALD Newborn Screening Parent Perspective Lauren Wilson, Virginia
3:00PM – 3:30PM	Newborn Screening State Experience: Arizona Fran Altmaier, Health Program Administrator, ADHS of NBS
3:30PM – 3:45PM	Break

- 3:45PM – 4:15PM **Addressing Unmet Need in Boys with Advanced Cerebral ALD**
Florian Eichler, MD, Massachusetts General Hospital
- 4:15PM – 4:45PM **ALD Standards of Care: AMN Patients**
Gerald Raymond, MD, Johns Hopkins Medicine
- 4:45PM – 5:15PM **Newborn Screening State Experience: Ohio**
Margie Ream, MD, PhD, Nationwide Children's Hospital

Friday, March 17, 2023

- 8:00AM – 9:00AM Breakfast
- 9:00AM – 9:30AM **ALD Newborn Screening & Legislative Updates**
Miranda McAuliffe, ALD Alliance
- 9:30AM – 10:00AM **Upcoming Multinational Clinical Trial of Leriglitzone in Adult Cerebral ALD**
Ali Fatemi, MD, CMO, Kennedy Krieger Institute
- 10:00AM – 10:30AM **BMT/Gene Therapy Dual Experience Parent Perspective**
Cynthia Sheffer, LPN, South Carolina
- 10:30AM – 10:45AM **Gene Therapy Treatment Centers & Support Resources**
Susan Brisendine, bluebird bio
- 10:45AM – 12:00PM **Balancing Risks of Transplant & Gene Therapy**
Christine Duncan, MD, Boston Children's Hospital
Troy Lund, MD, PhD, University of Minnesota
- 12:00PM – 1:00PM Lunch Break
- 1:00PM – 1:30PM **Parent Depression and Stress Associated with Newborn Screening for Rare and Variable Onset Disorders: Results from a Cross-Sectional Survey**
Nicole Kelly, MPH, The Children's Hospital at Montefiore
- 1:30PM – 2:00PM **If, When & How: Talking to Your Child's School about ALD**
Conni Calia, NYS Certified School Psychologist and Mental Health Professional

2:00PM – 2:45PM

Adrenal Insufficiency Parenting: What's in Your Toolkit?

Kirsten Finn, BA, BNAT, Kansas

Tara Meady, RN, BSN, MSN, NP-C, Connecticut

Marisa Vutrano, New York

Moderated by: Kristen Fowler, RN

2:45PM – 3:30PM

Family Planning Resource Kit for X- Linked Females

Taylor Kane, Founder, Remember The Girls

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