



8th Annual ALD Standards of Care Conference

Thursday, March 21, 2024

Standards of Care Conference: Day One

8:00AM – 9:00AM	Breakfast & Registration
9:00AM – 9:15AM	Conference Welcome Elisa Seeger, Founder, ALD Alliance
9:15AM – 9:45 AM	ALD Newborn Screening Roundtable Update Joseph Orsini, PhD, NYS Department of Health
9:45 AM – 10:15 AM	Testicular Cryopreservation Anne Casson, RN, MSN, CPNP, Memorial Sloan Kettering
10:15 AM – 11:00 AM	Reproductive Options for ALD Patients: A Personal Experience Frani Broussard Denenburg, Texas
11:00 AM - 11:20 AM	Minoryx Therapeutics – Nexus Study Update Marc Martinell, PhD, Co-Founder and CEO, Minoryx Therapeutics
11:20 AM - 12:00 PM	The CALYX Clinical Study in cALD Ali Fatemi, MD, CMO, Kennedy Krieger Institute
12:00 PM – 12:30 PM	Living with ALD Post-Transplant: A Teenager’s Perspective Grady Smith, New Hampshire
12:30 PM – 1:30 PM	Lunch Break
1:30 PM – 2:00 PM	ALD Newborn Screening Parent Perspective Jason Williams, Virginia
2:00 PM – 2:30 PM	Seizures in Childhood Cerebral ALD Margie Ream, MD, PhD, Nationwide Children’s Hospital

2:30 PM - 3:00 PM	Incidental and Pathological Findings Reported on Brain MRIs During Routine Surveillance for Boys with ALD seen at Stanford Keith Van Haren, MD, Stanford University
3:00 PM - 3:15 PM	Break
3:15 PM - 3:45 PM	Boys with Advanced Cerebral ALD: A Data Analysis Florian Eichler, MD, Massachusetts General Hospital
3:45 PM – 4:15 PM	Cord Blood Banking for ALD Siblings Christy Duncan, MD, Boston Children’s Hospital
4:15 PM - 4:45 PM	Newborn Screening State Experience: New Jersey Victoria Floriani, MS New Jersey Department of Health
4:45 PM –5:15 PM	Genetic Insights and Biochemical Lessons in ALD Newborn Screening Stephan Kemp, PhD, Amsterdam UMC – University of Amsterdam

Friday, March 22, 2024

Standards of Care Conference: Day Two

8:00AM – 9:00AM	Breakfast
9:00AM – 9:30AM	Newborn Screening Legislative Update & Foundation Updates Miranda McAuliffe, ALD Alliance
9:30AM – 10:00AM	Newborn Screening State Experience: North Carolina Raphael Smith, MS, CGC, UNC Department of Pediatrics
10:00 AM – 10:30 AM	BMT/Gene Therapy Chemo Regimen Protocols in ALD Timothy Olson, MD, PhD, Children’s Hospital of Philadelphia
10:30 AM – 10:45 AM	Gene Therapy Treatment Centers & Support Resources Susan Brisendine, bluebird bio
10:45 AM - 11:15 AM	Update on Gene Therapy for C-ALD Vinod Prasad, MBBS, MD, FRCP (London), bluebird bio
11:15 AM - 11:45 AM	Gene Therapy Update Christy Duncan, MD Boston Children’s Hospital
11:45 AM - 12:15 PM	ALD Newborn Screening Parent Perspective Maranda Judd, North Carolina
12:15 PM – 1:15 PM	Lunch Break

- 1:15 PM – 1:45 PM **ALD CHOP Newborn Screening Follow-Up Model**
Laura Adang, MD, PhD, MSTR, Children’s Hospital of Philadelphia
- 1:45 PM - 2:15 PM **Speaking To Extended Family: Tough Topics in ALD**
Amy Gaviglio, MS, CGC, Connetics Consulting
- 2:15 PM – 2:45 PM **ALD Standards of Care: Pediatric Neurology**
Eric Mallack, MD, MBE, MS, Kennedy Krieger Institute
- 2:45 PM - 3:15 PM **ALD Standards of Care: Pediatric Endocrinology**
Molly Regelmann, MD, The Children's Hospital at Montefiore
- 3:15 PM - 3:45 PM **ALD National Registry and Biorepository Update**
Ashish Gupta, MD, MPH, University of Minnesota

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