ANNUAL MEETING & Patient Learning Academy

November 5–7, 2026 | Hyatt Regency · Salt Lake City, Utah

THURSDAY, NOVEMBER 5

6:00 PM	**ALD Connect-ions Happy Hour at Contribution Cocktail Lounge** Hosted by ALD Connect Ambassadors	

FRIDAY, NOVEMBER 6

8:00 AM	**Welcome & ALD Connect Overview**	
8:45 AM	**Using Genomics to Understand ALD: Gene Kids, BeginNGS, and Data Sharing** Dr. Josh Bonkowsky · University of Utah	CONCURRENT **ALD-101 for Newly Diagnosed Families** Hannah Hart, LGC
9:15 AM	**New Mechanisms and New Therapies** Dr. Florian Eichler · Massachusetts General Hospital	
9:45 AM	***Break***	
10:00 AM	EMERGING INVESTIGATORS **Characterization of the female mouse model of adrenomyeloneuropathy** Dr. Chelsey B. Reed · Johns Hopkins School of Medicine **From radiology to pathology: In search of the pathological correlation of qMRI abnormalities in X-ALD** Dr. Eda Kabak · Amsterdam UMC	
10:30 AM	**Patient Panel**	
11:30 AM	**ALD Connect Awards & Group Photo**	
Noon	***Lunch*** · *Auction*	
1:00 PM	**The Guest That Never Leaves** Riham Badawy, P.Eng. · ALD Hope **Global Experiences of Women with ALD** Taylor Kane · Remember The Girls **Fundación Lautaro te Necesita** Verónica de Pablo	
1:30 PM	**Stress Less: A Practical Approach to Adrenal Insufficiency Monitoring, Diagnosis, and Management in ALD** Dr. Molly Regelmann · Children's Hospital at Montefiore Einstein	
2:00 PM	BREAKOUT SESSION	
3:00 PM	**Grey Zone Project: C26:0-LPC for VUS Reclassification and Risk Assessment in Adrenoleukodystrophy** Dr. Stephan Kemp · Amsterdam UMC	
3:30 PM	**Parent Perspective** Adlers	
3:45 PM	**The ABC's of ABCD1 Variant Interpretation** Julie S. Cohen, ScM, CGC · Kennedy Krieger Institute	CONCURRENT **Tai Chi** Jennifer Keller Kennedy Krieger Institute
4:15 PM	**Clarity in the Crystal Ball – Predicting Phenotypes with Biomarkers** Dr. Troy Lund · University of Minnesota	
4:45 PM	**Minoryx** Dr. Arun Mistry	
5:00 PM	**Poster Session, Research Fair, NMDP Donor Drive, Book Signing**	

Disclaimer: *This is a preliminary agenda. Presenters, session titles, and topics are subject to change. The topics listed are representative of the content expected to be covered at the meeting. Some presenters may choose not to make recordings of their sessions available after the meeting. Please email info@aldconnect.org with any questions.*

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SATURDAY, NOVEMBER 7

8:00 AM	**Our Common Ground** Dr. Keith Van Haren · Stanford University
8:30 AM	**Clinical Applications of Plasma miRNA and Metabolomic Profiling in Adrenomyeloneuropathy** Dr. Bela Turk (Kennedy Krieger Institute) and Dr. Jaspreet Singh (Henry Ford Health)
9:00 AM	**Nervonic Acid for Adrenoleukodystrophy: From Biological Rationale to Clinical Translation** Dr. Reena Kartha · University of Minnesota
9:30 AM	**Developing a new RNA-editing strategy for ALD gene therapy** Dr. Amanda Blackwell · University of Utah
10:00 AM	**ABCD1 Foundation** Dr. Anna Majchrowska-Kielak **From Patients to Partners: The Manus Alba Story** Alessandro Maggi · Manus Alba **Família ALD Brasil** Rafael Leal Machado
10:30 AM	**Life Between Appointments: Finding Purpose, Joy, and Community While Living with ALD** Jesse Torrey, LPC
11:00 AM	**BREAKOUT SESSION**
Noon	***Lunch*** · *Patient-Led Planning Committee*
1:00 PM	**The Role of Cholesterol Trafficking in ALD** Courtney Demmitt-Rice · University of Utah
1:30 PM	**Leukodystrophy Australia** Claire Kingsley **From Gratitude to Responsibility** Dr. María Teresa Martínez Rísquez · ALD-X España **Living with ALD: My Story and the Korean ALD Community** Dr. Eul Sik Jung · Korea ALD
2:00 PM	***Break***
2:15 PM	**Gene and Cell Therapies (Panel Discussion)** Moderator: Dr. Florian Eichler · Massachusetts General Hospital
3:00 PM	**Ask the Experts**
4:00 PM	**Closing Remarks**

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