# ANNUAL MEETING & Patient Learning Academy

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

## THURSDAY, NOVEMBER 5

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

## FRIDAY, NOVEMBER 6

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| **8:00 AM** | **Welcome & ALD Connect Overview** |
| **8:45 AM** | **Using Genomics to Understand ALD: Gene Kids, BeginNGS, and Data Sharing**<br>Dr. Josh Bonkowsky · University of Utah |
| **9:15 AM** | **New Mechanisms and New Therapies**<br>Dr. Florian Eichler · Massachusetts General Hospital |
| **9:45 AM** | ***Break*** |
| **10:00 AM** | **Emerging Investigators**<br>Dr. Chelsey Reed (Johns Hopkins School of Medicine) · Dr. Eda Kabak (Amsterdam UMC) |
| **10:30 AM** | **Patient Panel** |
| **11:30 AM** | **ALD Connect Awards & Group Photo** |
| **Noon** | ***Lunch***<br>*Auction* |
| **1:00 PM** | **ALD Hope**<br>Riham Badawy<br>**Global Experiences of Women with ALD**<br>Taylor Kane · Remember The Girls<br>**Fundación Lautaro te Necesita**<br>Verónica de Pablo |
| **1:30 PM** | **Stress Less: A Practical Approach to Adrenal Insufficiency Monitoring, Diagnosis, and Management in ALD**<br>Dr. Molly Regelmann · Children's Hospital at Montefiore Einstein |
| **2:00 PM** | **BREAKOUT SESSION** |
| **3:00 PM** | **The VUS Crisis in Population Screening: Why Biochemistry Remains Essential**<br>Dr. Stephan Kemp · Amsterdam UMC |
| **3:30 PM** | **Parent Perspective**<br>Adlers |
| **3:45 PM** | ***ABCD1* Variant Curation Process**<br>Julie Cohen, ScM, CGC · Kennedy Krieger Institute |
| **4:15 PM** | **Clarity in the Crystal Ball – Predicting Phenotypes with Biomarkers**<br>Dr. Troy Lund · University of Minnesota |
| **4:45 PM** | **Minoryx**<br>Dr. Arun Mistry |
| **5:00 PM** | **Poster Session, Research Fair, NMDP Donor Drive, Book Signing** |

**CONCURRENT**
**Tai Chi**
Jennifer Keller
Kennedy Krieger Institute

***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

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

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