



2023 ALD Connect Annual Meeting & Patient Learning Academy

November 3-4, 2023

Preliminary Agenda

Day 1 (Friday, November 3rd)

- 7:30 AM REGISTRATION, BREAKFAST
- 8:00 AM Welcome & Overview of Annual Meeting
Dr. Florian Eichler & Kathleen O’Sullivan-Fortin
- 8:15 AM Bearing Witness: New Technologies and Old Trauma
Dr. Florian Eichler
- 8:45 AM An Update on Vitamin D Trials for ALD
Dr. Keith Van Haren
- BREAKOUT for Recently Diagnosed Patients/Caregivers
Catherine Becker, NP
- 9:15 AM Brain Engraftment
Dr. Troy Lund
- BREAK
- 10:00 AM Morbidities and Mortality in Adults with AMN
Dr. Josh Bonkowsky
- 10:30 AM Multiple Cases of Mosaic X-Linked ALD Identified through Newborn Screening
Dr. Alexandra Keefe
- 11:00 AM Patient Experience Panel
Moderator: Greg Benton
- Noon LUNCH
- 2:30 PM 2022 Emerging Investigators
Chenxu Li, Dr. Hemmo Yska, April Rickle
- 3:00 PM bluebird bio – Gene Therapy Update
Dr. Vinod Prasad

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- 3:30 PM Update on Continued Efficacy and Occurrence of Myelodysplastic Syndrome in the CALD Gene Therapy Trial
Dr. David Williams
- 4:00 PM Minoryx
Dr. Patricia Musolino
- 4:30 PM SwanBio
Dr. Lawrence Hayward
- 5:00 PM OPAL Wearables Outcome Data in AMN
Dr. Amena Smith Fine and Dr. Bela Turk
- 5:30 PM ALD Connect Birthday Party and ALD Connect Awards Presentation
Founding Board Members: Dr. Florian Eichler, Kathleen O’Sullivan-Fortin, Dr. Keith Van Haren, Ben Lenail, Alex Sherman, Dr. Josh Bonkowsky, Dr. Ali Fatemi, Dr. Amber Salzman

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Day 2 (Saturday, November 4th)

- 7:30 AM REGISTRATION, BREAKFAST
- 8:00 AM Overview of ALD Connect
Kathleen O’Sullivan-Fortin
- 8:15 AM International Partners
Leukodystrophy Resource and Research Organisation Inc. - Bob Wyborn
Fundación Lautaro te Necesita –Verónica de Pablo
Alex TLC – Karen Harrison
- 9:00 AM The Grey Zone: My Genetic Test Comes Back 'Variant of Uncertain Significance'
– Now What?
Dr. Stephan Kemp
- 9:30 AM ALD Below the Belt
Dr. Cristina Sadowsky
- 10:00 AM Voice of the Patient - Reflections
Dr. Florian Eichler, Dr. Ali Fatemi, Dr. Amena Smith Fine
- 10:30 AM BREAKOUT SESSION
- Noon LUNCH
- 1:00 PM Academic Studies and Clinical Trials
Clinical Trials for Women with ALD - Dr. Yedda Li
PRO for ALD/AMN - Jennifer Weinstein
Intravenous Administration of Mesenchymal Stem Cells (IV-MSC) for the
Treatment of Cerebral Adrenoleukodystrophy (cALD) - Dr. Troy Lund
- 2:00 PM Transitions in ALD
Moderator: Kathleen O'Sullivan-Fortin
- 2:45 PM ALD Associated Trauma
Moderator: Dr. Amber Salzman
Bruce McClary, LCSW-C, CCM
Jesse Torrey, LAC, MA
- 3:45 PM BREAKOUT SESSION

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- 4:30 PM Ask an Expert: Clinical Panel
Moderator: Kelly Miettunen
Dr. Florian Eichler, Dr. Troy Lund, Dr. Ali Fatemi, Dr. Keith Van Haren, Dr.
Josh Bonkowsky, Dr. Patricia Musolino, Dr. Stephan Kemp
- 5:00 PM Closing Remarks
Dr. Florian Eichler

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