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## 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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