

## 2022 ALD Connect Annual Meeting & Patient Learning Academy

#### November 11-12, 2022 Royal Sonesta Harbor Court Baltimore-Baltimore, MD

### **Preliminary Agenda**

# Day 1 (Friday, November 11th)

7:30 am	REGISTRATION, BREAKFAST, & WELCOME TO THE ANNUAL MEETING
8:00 am	Dr. Florian Eichler & Kathleen O'Sullivan-Fortin Welcome & Overview of Annual Meeting
8:15 am	<b>Dr. Troy Lund</b> Sharing is Good, Especially When it Comes to Peroxisomes
8:45 am	<b>Dr. Quentin Raas</b> Insights on a Zebrafish Model of ALD
9:15 am	<b>Yorrick Jaspers</b> Lipidomic Biomarkers in Plasma Correlate with Disease Severity in X-linked Adrenoleukodystrophy
9:45 am	BREAK
9:55 am	Roberto Montoro ALD in a Dish
10:25 am	<b>Dr. Eric Mallack</b> Updates in Imaging in Cerebral ALD
11:00 am	Patient Experience Panel
12:00 pm	LUNCH ALD Connect Awards Presentation
1:00 pm	Dr. Amena Smith Fine & Jennifer Keller Wearable Sensors to Assess Sensory-Motor Function in AMN



1:45 pm Dr. Marc Engelen International Recommendations for the Management of X-ALD 2:15 pm **BREAK** 2:25 pm Dr. Patricia Musolino Cerebral ALD in Children 3:00 pm Dr. Joe Hacia Mouse Models for Peroxisome Research Ask an Expert: Industry Panel (facilitated by Amber Salzman) 3:30 pm 4:30 pm **Omar Sherbini** GLIA CTN: Current Initiatives & Next Steps 4:40 pm Dr. Florian Eichler Towards a Brighter Future: Innovation, Research & Progress in ALD 5:00 pm Closing Remarks Day 1



#### **Day 2** (Saturday, November 12<sup>th</sup>)

7:30 am REGISTRATION, BREAKFAST, & WELCOME TO THE PATIENT

LEARNING ACADEMY

8:00 am Kathleen O'Sullivan-Fortin

Welcome to the PLA & Introduction to ALD Connect FDA EL-PFDD Update & Community Call Updates

8:25 am Dr. Stephan Kemp

Variants of Uncertain Significance: Friend or Foe

9:00 am Natalie Grant

Women's Studies in ALD

9:30 am Adaptive Exercise Panel (facilitated by Ben Lenail)

10:00 am BREAK

10:10 am Dr. Keith Van Haren

U01 Funding & Status

10:30 am MaryAnn McCarthy

ALD: The Bitter and the Sweet

11:15 am BREAKOUT SESSION 1

12:00 pm **LUNCH** 

1:00 pm Ask an Expert: Gene Therapy

1:45 pm Dr. Jona Ramirez and Dr. Swathi Sethuram

Adrenal Insufficiency

2:15 pm Dr. Cristina Sadowsky

The Neurogenic Bladder in ALD

2:45 pm Jesse Torrey

The Burdens (and Joys) of Caregiving



3:15 pm Jennifer Keller

Fall Prevention in ALD & AMN

3:45 pm BREAK

3:55 pm BREAKOUT SESSION 2

4:30 pm Ask an Expert: Clinical Panel

5:00 pm Closing Remarks Day 2