*5th Annual ALD Standards of Care Conference*

January 13-16, 2021



GENERAL MEETING

Thursday, January 14 - Friday, January 15, 2021

11:00AM - 1:00PM & 2:00PM - 4:00PM Eastern

Thursday, January 14, 2021

11:00AM - 11:15AM: **Welcome**

Elisa Seeger, Miranda McAuliffe & Sarina Rao

11:15AM - 11:45AM: **ALD Newborn Screening Roundtable Update**

Michele Caggana, ScD, FACMG - *NYS Dept. of Health*

11:45AM - 12:00PM: **Legislative Updates**

Elisa Seeger,  Miranda McAuliffe, Emily Fields - bluebird bio

12:00PM - 12:30PM: **GVHD**

Jaap-Jan Boelens, MD, PhD - *MSKCC*

12:30PM - 1:00PM: **Newborn Screening Parent Experience**

Sarah Tong - *Massachusetts*

1:00PM - 2:00PM: BREAK

2:00PM - 3:00PM: **Neurology and Endocrinology Guidelines**

**NYS Lab Project**

Eric J. Mallack, MD - *NY-Presbyterian*/*Weill Cornell Medicine*

Molly O. Regelmann, MD - *The Children’s Hospital at Montefiore*

3:00PM - 3:30PM: **ALD Registry**

Paul Orchard, MD - *University of Minnesota*

3:30PM - 4:00PM: **Neurodevelopmental Testing in ALD**

Aram Kim, MD - *UPMC Children’s Hospital of Pittsburgh*

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Friday, January 15, 2021

11:00AM - 11:30AM: **Newborn Screening Parent Experience**

Amanda Valdez - *Minnesota*

11:30AM - 12:00PM: **ALD CME Webinar Overview**

Chris Napolitan, Vice President - *PRIME Education*

12:00PM - 1:00PM: **Updates in Vitamin D**

Josh Bonkowsky, MD, PhD - *University of Utah*

Keith Van Haren, MD - *Stanford University Medical Center*

1:00PM - 2:00PM: LUNCH

2:00PM - 3:00PM: **Telehealth for ALD Panel**

Led by: S. Ali Fatemi, MD, CMO - Kennedy Krieger Institute

Catie Becker, NP - *Massachusetts General Hospital*

Chris Porter - *Travere Therapeutics*

Amena Smith Fine, MD, PhD - *Kennedy Krieger Institute*

3:00PM - 4:00PM: **Navigating the Psychological Impact of ALD:**

**Family Panel & Discussion**

Led by: Rene Pierpont, PhD - *University of Minnesota*

Jill Smith, ALD Parent - *New Hampshire*

Tara Meady, RN, ALD Parent - *Connecticut*

Sydne Pantaleon, ALD Parent - *Illinois*

-END GENERAL MEETING-

ALD FAMILY DAY

Saturday, January 16, 2021

12:45PM - 3:00PM

12:45PM: Please sign on early so that we can work out any technical difficulties ahead of time!

1:00PM – 1:30PM: Q&A with ALD Experts - Dr. Regelmann & Dr. Mallack

1:30PM – 1:50PM: Meet author Jackson Grant from “The Donut That Roared”

1:50PM – 2:30PM: Magic Show by Steve the Magician

2:30PM – 3:00PM: Free Talk

Thank you to our Sponsors for making this possible!!!



