



## ALD Identifying Standards of Care Meeting

Wythe Hotel  
80 Wythe Ave  
Brooklyn, NY 11249

January 16-17, 2020

### Thursday January 16<sup>th</sup>

8:00-9:00 Registration/Breakfast

8:30-9:00 Welcome

9:00-9:30 ALD NBS Roundtable Update  
Michele Caggana, ScD, FACMG NYS Department of Health

9:30-10:00 Texas NBS Experience  
Rachel Lee, PhD TX Department of Health

10:00-10:30 Outcomes of Newborn Screening for ALD in NY  
Beth Vogel, MS, CGC NYS Department of Health

10:30-11:00 A Parent's Experience – Jennifer Mahoney

11:00-11:15 BREAK

11:15-11:35 ALD Parent's Guide Miranda McAuliffe

11:35-12:00 ALD Family Education  
Kris Rothleutner  
bluebird bio

12:00-12:30 Minimizing Neurocognitive Effects of X-ALD in Newborn Screening Era  
Rene Pierpont, PhD. Univ. of Minnesota

12:30-1:30 LUNCH

1:30-2:00 Novel Cellular Therapies Derived from Cord Blood Monocytes for Children  
with Leukodystrophies  
Joanne Kurtzberg, MD Duke University

**2:00-2:30 Systematic Review and Meta Analysis for the MRI Surveillance Guidelines**  
**Eric Mallack, MD** **Weill- Cornell Medicine-NYP**

**2:30-3:15 Multidisciplinary Approach**  
**Mabel Yau, MD; Hillary Raynes, MD; Lissette Estrella, MD**  
**Mount Sinai**

**3:15-3:45 Transplant for ALD** **Paul Orchard, MD**  
**University of Minnesota**

**3:45-4:00 BREAK**

**4:00-4:30 Human Endocannabinoid System** **Rita Hedrick**

**4:30-5:00 Medical Marijuana: A Personal Experience** **Jesse Torrey**

**5:00-5:30 A Parent's Perspective** **Katie Mullen**

**6:30 - 8:30 Brooklyn Bowl**  
**Dinner and Bowling**  
**61 Wythe Ave**

## **Friday January 17<sup>th</sup>**

**8:00-9:00 BREAKFAST**

**9:00-9:30 Newborn Screening and Functional Testing**  
**Stephan Kemp, PhD** **Amsterdam Univ. Medical Center**

**9:30-10:00 Endocrinology Practices in ALD**  
**Molly Regelman, MD** **Montefiore**

**10:00-10:30 Parent's Experience** **Kerri Denies**

**10:30-11:00 Physical Medicine & Rehabilitation**  
**Brian Wishart, DO** **Massachusetts General Hospital**

**11:00-12:00 ALD Database/Registry Discussion** **Paul Orchard, MD**  
**Adeline Vanderveer, MD**  
**Elisa Seeger**

**12:00-1:00 LUNCH**

<b>1:00-1:15</b>	<b>NBS for ALD Toolkit</b>	<b>Sara Castegini</b> bluebird bio <b>Emily Fields</b> bluebird bio
<b>1:15-1:45</b>	<b>Early Signs and Symptoms of Cerebral ALD</b> <b>Florian Eichler, MD</b>	<b>Massachusetts General Hospital</b>
<b>1:45-2:00</b>	<b>Min 102 for CCALD</b> <b>Uwe Meya</b>	<b>Minoryx Therapeutics</b>
<b>2:00-2:30</b>	<b>Dutch Experience</b> <b>Rinse Barendsen</b>	<b>Amsterdam Univ. Medical Center</b>
<b>2:30-3:00</b>	<b>Q &amp; A Session</b>	

**Thank you to our sponsors for making this meeting possible:**



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