

Thursday, August 1, 2024

8:00 - 9:00 AM	Breakfast	
9:00 - 9:30 AM	Welcome and Opening	Leah MyersJenny BurkeKaren Ho, PhD
9:30 - 10:40 AM Session 1	 SCN2A, From Research to HOPE SCN2A Genetics and Inheritance 	 Stephan Sanders, BMBS, PhD Danielle Twum, PhD Émile Moura, MS, CGC
11:00 - 12:30 PM Session 2	Updates On Research You Participated In	 Alfred L. George, Jr., MD Caitlin Hudac, PhD Kevin Bender, PhD Louise M. Tiranoff, PhD Brad Bryan, PhD
12:30 - 1:30 PM	Lunch and Scientific Poster Session	
1:30 - 3:00 PM Session 3	 Autism from age 2-34 Cortical Visual Impairment and Other Ophthalmology Concerns 	 Catherine Lord, PhD Donny W. Suh, MD, FAAP, MBA, FACS Shaden H. Yassin, MD, PhD
3:00 - 4:30 PM Session 4	 Current Approach to Epilepsy Management Across the SCN2A Spectrum Treating Complex Patients - a Collaborative Approach 	 Heather Olson, MD Anjalee Galion, MD Maija Steenari, MD
4:30 - 6:30 PM	Scientific Poster Session	
6:30 - 8:30 PM	Remembrance and Awards Dinner	



Friday, August 2, 2024

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8:00 - 9:00 AM	Breakfast	
9:00 - 10:40 AM Track 1	 Ethical Considerations in Clinical Trial Participation Palliative Care and Hospice: an Extra Resource for Your Family 	 Cara Hunt Ashley Schmitz, BSN, RN, CHPPN
9:00 - 10:40 AM Track 2	 The Importance of Self-Care: Addressing and Preventing Caregiver Burnout Identifying and Accessing Support for Cortical Visual Impairment 	 Dr. Julie H. Lee, LMFT Rebecca Hommer, PhD
10:40 - 12:00 PM Track 1	 Neurodevelopmental Diagnoses in SCN2A: Practical Insights and Advances in Research Challenging Behavior: Strategies for Clinical Evaluation and Management 	 Natasha Ludwig, PhD Carly van der Heide, MD, PhD
10:40 - 12:00 PM Track 2	 Epilepsy Syndromes in the SCN2A Spectrum Seizures 101: Seizure Types, Seizure Safety, Emergencies and Seizure Action Plans 	 Heather Olson, MD Gretchen K. Von Allmen, MD, FACNS



12:00 - 1:00 PM	Lunch and Scientific Poster Session	
1:00 - 2:20 PM Track 2	 What is Autonomic Dysfunction and What Are the Different Ways That it Can Present? Intracranial Neuromodulation in Epilepsy Channelopathies 	 Keith Coffman, MD Sandipan Bankim Behari Pati, MD
2:40 - 4:00 PM Track 1	 ABLE vs Special Needs Trusts: An In-Depth Discussion Developing an IEP That Sets Your Child Up For Success 	 Kacy Seitz, ChFC, CLTC, ChSNC Gloria Ruiz / Task CA
2:40 - 4:00 PM Track 2	 Orthopedic Issues Commonly Reported in SRDs Food for Thought: A Conversation on Blenderized Tube Feeding and Ketogenic Diet Therapy 	 Jonas Owen, MD / Oussama Abousamra, MD Katherine Bennett MPH, RD / Sarah Quon, RD, CLC
4:00 - 5:15 PM	Industry Fireside Chat: Clinical Trial Participation	 Shawn Egan Cara Hunt Representatives from: Neurocrine Biosciences Tevard Biosciences Longboard Pharmaceuticals
4:00 - 6:00 PM	Scientific Poster Session	
6:00 - 9:00 PM	Warrior Dance Party and Dinner	