



July 21-23, 2025

The Logan, Philadelphia, PA

DAY 1: Monday, July 21

SESSION 1 (MORNING)

How do we currently manage LGS across the lifespan, where do we fall short, and what can we learn from other disease states?

Time (EST)	Talk Title	Moderators/Speakers
7:00 AM	Breakfast	-
8:00 AM	Welcome and Opening Remarks	Fred Roedl, Board Chair
8:05 AM	Session 1 Introduction: What is evidence based care and why do we want it?	Tracy Dixon-Salazar, PhD
8:25 AM	Caregiver of a Child with LGS: Share your story (across the lifespan, covers peds and transition care)	Jennifer Fischer
8:30 AM	Caregiver of an Adult with LGS: Share your story (across the lifespan, covers peds, transition, and adult)	Stephen Feather
8:35 AM	How do we currently manage LGS in children? Where do we fall short?	Elaine Wirrell, MD - Session Organizer
8:55 AM	How do we currently manage LGS in adults? Where do we fall short?	Fabio Nascimento, MD - Session Organizer
9:15 AM	Developing Evidence Based Guidelines - The Cystic Fibrosis Experience	Michael Schechter, MD, MPH of VCU
9:45 AM	Break	-
10:00 AM	How do we currently manage transition of care? Where do we fall short in the DEEs?	Ann Tilton, CNF
10:30 AM	What can we learn from transition of care programs for congenital heart disease?	Emily Ruckdeschel, CHOP
11:00 AM	Panel Discussion: How do we prioritize the gaps in evidence based care in LGS?	Renee Shellhaas & Scott Perry, Session
11:55:00 AM	Session 1 Wrap Up	Tracy Dixon-Salazar, PhD
12:00 PM	Lunch	-

SESSION 2 (AFTERNOON)

What methods can we use to advance evidence based care across the LGS lifespan?

Time (EST)	Talk Title	Moderators/Speakers
1:00 PM	Welcome Back	Fred Roedl, Board Chair
1:05 PM	Caregiver Perspective - How evidence might have helped make decisions about treatment across the	Kathy Leavens
1:10 PM	Introduction to Session 2A: What methods can we use to advance evidence based care across the LGS	Scott Perry, Session Organizer
1:15 PM	Building a team - Pediatric Epilepsy Research Consortium LGS Special Interest Group as an example of	Deborah Samanta
1:35 PM	Growing the Team - Training adult providers to care for rare epilepsies	Elizabeth Gerard, Session Organizer
1:55 PM	Barriers to multidisciplinary complex care in adulthood	Alexa King
2:15 PM	Building Consensus: Where are we now?	Juliet Knowles, MD, PhD
2:35 PM	Break	-
3:00 PM	Using the Electronic Health Records (EHR) to Generate Natural History	Jillian Mckee, CHOP
3:20 PM	Mining Big Data to determine Evidence Based Care	Zach Grinspan, MD, MS
3:40 PM	Acquiring Data from the Hospital IT's View - Barriers to implementation	George Morris
4:00 PM	Putting the patient in charge	Michael Hammer
4:20 PM	Building the Best Note - Panel Discussion & Session 1A Wrap Up	Scott Perry, Session Organizer
4:40 PM	Session 2B: Evidence Based Care from Industry Partner Perspective	Tracy Dixon-Salazar
4:45 PM	Lundbeck/Longboard (10 mins)	Dennis Dlugos, MD
4:55 PM	One Syndrome, Many Causes: Understanding the diverse genetics of LGS	Karthik Rajasekaran
5:05 PM	UCB LGS & Fintepla: What's New, What's Next? (15 min)	Amelie Lothe
5:20 PM	Novel Drug Formulations for Patients Suffering with DEEs	Howard Franklin, MD
5:30 PM	Harmony (10 mins) Clemizole (EPX-100): a novel treatment in development for LGS	Anna Jeong, MD
5:40 PM	Session 2B Wrap-up	Tracy Dixon-Salazar, PhD
5:50 PM	Session Ends	-
6:00 PM	Dinner	-

DAY 2: Tuesday, July 22

SESSION 3 (MORNING)

What do we need to do now to advance LGS evidence-based care across the lifespan?

Time (EST)	Talk Title	Moderators/Speakers
7:00 AM	Breakfast	-
8:00 AM	Welcome Back	Tracy Dixon-Salazar
8:05 AM	Session 3 Introduction: What do we need to do now to advance evidence-based care across the lifespan?	Jennifer Gelinas, MD, PhD, Session Organizer
8:15 AM	Family Speaker: What evidence is needed now for children in order to make decisions?	Bertha Guillen
8:20 AM	Family Speaker: What evidence is needed now for adults in order to make decisions?	Jamie Riley
8:25 AM	Learning from Animal Models: Where are we Limited?	Juliet Knowles, MD, PhD
8:45 AM	Identifying Genetic Markers of LGS and Associated DEEs in Children and Adults: Are All Genetic Conditions the Same?	Pete Crino, MD, PhD, Session Organizer

9:05 AM	Knowing the cause of your child's seizures: is it genetic? -Understanding the cause of seizures vs. the cause of LGS -Seeking Genetic Testing, the family perspective -How to get started with genetic testing today -Session close	Tracy Dixon-Salazar, PhD (5 min) Tiffany Johnson (5 Min) Mary Freivogel, MS, CGS (5 Min)
9:25 AM	LGS Learn from Every Patient Database	Tracy Dixon-Salazar, PhD
9:35 AM	Identifying EEG/Network Markers of DEEs and LGS in Children and Adults	Jennifer Gelinas, MD, PhD, Session Organizer
9:55 AM	Identifying the Best Stimulation Approaches to Seizures	John Rolston
10:15 AM	Break	-
10:30 AM	Defining LGS in Undiagnosed Adults: How do we Find Them?	Chris McGraw
10:50 AM	Measuring Cognition and Behavior in LGS	Kette Valente
11:10 AM	Characterizing Sleep in LGS	Gita Gupta
11:30 AM	Developing Patient Centric Seizure Action Plans for DEEs - One size doesn't fit all:	Eric Pina Garza
11:50 AM	Session 3 Wrap-up	Jennifer Gelinas
11:55 AM	Thinking ahead to Session 4	Tracy Dixon-Salazar, PhD
12:00 PM	Lunch	-
SESSION 4 (AFTERNOON)		
Where do we go from here?		
Time (EST)	Talk Title	Moderators/Speakers
1:00 PM	Welcome Back/Intro Breakout Groups	Tracy Dixon-Salazar, PhD
1:15 PM	Transition to Breakouts	
1:20 PM	Breakout Discussion Topic 1: <i>Determined during Day 1</i>	Scott Perry, MD
1:20 PM	Breakout Discussion Topic 2: <i>Determined during Day 1</i>	TBD
1:20 PM	Breakout Discussion Topic 3: <i>Determined during Day 1</i>	TBD
2:20 PM	Transition to Main Ballroom	
2:25 PM	Discussions - What did we learn and what do we do next?	Scott Perry
3:25 PM	Meeting Wrap-up	Tracy Dixon-Salazar, PhD
3:35 PM	Closing Remarks	Fred Roedl
3:40 PM	Session Ends	-