



July 21-23, 2025

The Logan, Philadelphia, PA

DAY 1: Monday, July 21

SESSION 1 (MORNING)

How do we currently manage LGS, 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	What is evidence based care and why do we want it?	Tracy Dixon-Salazar,
8:10 AM	Caregiver of a Child with LGS: Share your story. How do you think about transition of care?	Jennifer Fischer
8:15 AM	Caregiver of an Adult with LGS: Share your story. How did transition of care go?	Stephen Feather
8:20 AM	How do we currently manage LGS in children? Where do we fall short?	Elaine Wirrell, Session Organizer
8:40 AM	How do we currently manage LGS in adults? Where do we fall short?	Fabio Nascimento, Session Organizer
9:00 AM	Developing Evidence Based Guidelines - The Cystic Fibrosis Experience	TBD
9:20 AM	Break	-
9:40 AM	How do we currently manage transition of care? Where do we fall short in the DEEs?	Ann Tilton, CNF
10:10 AM	What can we learn from transition of care programs for congenital heart disease?	Emily Ruckdeschel, CHOP
10:40 AM	Panel Discussion: How do we prioritize the gaps in evidence based care in LGS?	Renee Shellhaas, Session Organizer
11:20 AM	Lunch	-

SESSION 2 (AFTERNOON)

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

Time (EST)	Talk Title	Moderators/Speakers
12:20 PM	Welcome Back	Fred Roedl, Board Chair
12:25 PM	Family Speaker(s) - How evidence might have helped make decisions about treatment across the lifespan	TBD
12:35 PM	Introduction to Session	Scott Perry, Session Organizer
12:40 PM	Build a team - Pediatric Epilepsy Research Consortium LGS Special Interest Group as an example of research	Debopam Samanta
1:00 PM	Growing the Team - Training adult providers to care for rare epilepsies	Elizabeth Gerard, Session Organizer
1:20 PM	Barriers to multidisciplinary complex care in adulthood	Alexa King
1:40 PM	Building Consensus: Where are we now?	Juliet Knowles
2:00 PM	Break	-
2:25 PM	Using the Electronic Health Records (EHR) to Generate Natural History	Jillian Mckee, CHOP
2:45 PM	Mining Big Data to determine Evidence Based Care	Zach Grinspan
3:05 PM	Hospital IT's View of Data Acquisition- Barriers to implementation	George Morris
3:20 PM	Putting the patient in charge	Michael Hammer
3:40 PM	Building the Best Note - Panel Discussion	Scott Perry, Session Organizer
4:20 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
8:00 AM	Welcome Back	Tracy Jennifer Gelinias, MD, PhD, Session Organizer
8:05 AM	Session Introduction: What do we need to do now to advance evidence-based care across the lifespan?	Organizer
8:15 AM	Family Speaker: What evidence is needed now for children in order to make decisions?	TBD
8:20 AM	Family Speaker: What evidence is needed now for adults in order to make decisions?	TBD
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	Identify EEG/Network Markers of DEEs and LGS in Children and Adults	John Archer
9:25 AM	Identifying the Best Stimulation Approaches to Seizures	George Ibrahim/John Ralston
9:45 AM	Break	-
10:15 AM	Defining LGS in Undiagnosed Adults: How do we Find Them?	Chris McGraw
10:35 AM	Measuring Cognition and Behavior in LGS	Kette Valente
10:55 AM	Characterizing Sleep in LGS	Gita Gupta
11:15 AM	One size doesn't fit all: Developing Patient Centric Seizure Action Plans for DEEs	Eric Pina Garza
11:35 AM	Lunch	-

SESSION 4 (AFTERNOON)

Where do we go from here?

Time (EST)	Talk Title	Moderators/Speakers
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11:30 AM	Lunch	-
12:30 PM	Welcome Back/Intro Breakout Groups	Tracy Dixon-Salazar, PhD
12:50 PM	Breakout 1: TBD	Scott Perry
12:50 PM	Breakout 2: TBD	Jim Wheless
12:50 PM	Breakout 3: TBD	TBD
2:30 PM	Break	-
2:50 PM	Come back together. Each group shares what they discussed.	Scott Perry
4:30 PM	Closing Remarks	Tracy Dixon-Salazar, PhD
4:45 PM	Session Ends	-

DAY 3: Wednesday, July 23

SESSION 5 (MORNING)

Industry Partner Talks - Evidence Based Care Research Updates

Time (EST)	Talk Title	Moderators/Speakers
7:30am	Breakfast	
8:00am	Talk 1	
8:15am	Talk 2	
8:30am	Talk 3	
8:45am	Talk 4	
9:00am	Talk 5	
9:15am	Talk 6	
9:30am	Talk 7	
11:00am	Meeting Ends	

SESSION 6 (AFTERNOON)

Focus Groups

Time (EST)	Talk Title	Moderators/Speakers
	FG 1: Welcome & Intro Focus Group Topic: Goals:	
	FG 2: Welcome & Intro Focus Group Topic: Goals:	
	FG 3: Welcome & Intro Focus Group Topic: Goals:	