



July 21-23, 2025

The Logan, Philadelphia, PA

**DAY 1: Monday, July 21**

**SESSION 1 (MORNING)**

**What is the LGS standard of care, where do we fall short, and what can we learn from other disciplines?**

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, PhD
8:20 AM	What is the current Standard of Care for managing children with LGS? Where do we fall short?	Elaine Wirrell, Session Organizer
8:40 AM	What is the current Standard of Care for managing adults with LGS? 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	What are the Standards of Care for managing transition of care in LGS? Where do we fall short?	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?	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	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	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 With What We've Got	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 research could we be doing to advance Evidence Based Care?**

Time (EST)	Talk Title	Moderators/Speakers
8:00 AM	Welcome Back	Tracy
8:15 AM	Family Speaker(s)	TBD
8:30 AM	Building a Better Model	Jennifer Kearney
8:50 AM	Identifying Genetic Markers of LGS	Colin Ellis, Penn
9:10 AM	Identifying imaging markers of LGS	Aaron Warren
9:30 AM	Identifying EEG markers/networks of LGS	John Archer
9:50 AM	Break	-
10:15 AM	Defining LGS in Undiagnosed Adults	Chris McGraw
10:35 AM	Measuring Cognition/Behavior in LGS	TBD
10:55 AM	Characterizing Sleep in LGS	TBD
11:15 AM	One size doesn't fit all: Developing Patient Centric Seizure Action Plans for Developmental and Epileptic Encephalopathies	TBD
11:35 AM	Lunch	-

**SESSION 4 (AFTERNOON)**

**Where do we go from here?**

Time (EST)	Talk Title	Moderators/Speakers
11:30 AM	Lunch	-

12:30 PM	Welcome Back/Intro Breakout Groups	Tracy Dixon-Salazar, PhD
12:50 PM	Breakout 1: TBD	TBD
12:50 PM	Breakout 2: TBD	TBD
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**

<b>Time (EST)</b>	<b>Talk Title</b>	<b>Moderators/Speakers</b>
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**

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