



July 9 - 11, 2026 | Orlando, FL

Agenda subject to change as speakers and sessions are finalized.

July 17 THURSDAY – JULY 9, 2026

Arrival & Community Connection

Time (ET)	Session	Presenter(s)
1:00 - 6:30 pm	Registration & Help Desk Open <i>Check-in, materials pickup, and attendee support.</i>	
1:00 - 6:30 pm	 Sunshine Social: The Fun Starts Here <i>Interactive welcome experience with connection stations, family activities, exhibitor engagement, and informal networking.</i>	

July 17 FRIDAY – JULY 10, 2026

Time (ET)	Session	Presenter(s)
7:00 - 8:00 am	Breakfast & Open Care Conversations <i>Small-group conversations where families can ask questions directly to experts in genetics, treatment, and support services.</i>	

LGS Today: Where We Stand

Time (ET)	Session	Presenter(s)
8:00 - 8:10 am	Welcome	
8:10 - 8:25 am	Keynote: Living with LGS <i>Personal reflections on decades of progress in LGS care and advocacy.</i>	-Fred Roeld, MBA, Board Chair, LGS Foundation

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8:25 - 8:40 am	State of LGS: Diagnosis, Treatment & Care <i>Overview of where we stand today in diagnosis, treatment, care, and research.</i>	-Tracy Dixon-Salazar, PhD, Executive Director, LGS Foundation
8:40 - 8:55 am	Title: TBD - Epidemiology & Standard of Care <i>Evidence-based review of current LGS definitions, comorbidities, and best practices.</i>	-Scott Perry, MD
8:55 - 9:10 am	Title: TBD - How can we treat seizures based on your loved one's seizure patterns and the time of day they occur? <i>Exploring how seizure timing and patterns influence treatment decisions.</i>	-Aditi Trivedi, MD
9:10 - 9:20 am	Lived Experience Perspectives <i>Short reflections on navigating complex treatment decisions.</i>	-LGS Caregiver Experts
9:20 - 10:00 am	Bringing It All Together: Families and Professionals in Conversation <i>Interactive discussion bridging clinical insight and caregiver realities.</i>	-Featured Speakers & Caregiver Experts
10:00-10:15 am	Group Photo	
10:15-10:30 am	Refreshment Break	

Transforming LGS Care Today

Time (ET)	Session	Presenter(s)
10:30-10:45 am	Title: TBD - Where Is LGS Care Strong? Where Are the Gaps? <i>Identifying progress and areas needing innovation.</i>	-Renee Shellhass, MD, MS
10:45-11:00 am	Title: TBD - What Does Optimal Care Include? <i>Defining what high-quality, coordinated LGS care looks like.</i>	-Babitha Haridas, MD
11:00-11:15 am	Lived Experience Perspectives <i>Real-world insight on pediatric, transition, and adult care experiences.</i>	
11:15-12:00 pm	Bringing It All Together: Families and	-Featured Speakers &



	Professionals in Conversation <i>Discussion on research priorities, data needs, and system improvements.</i>	Caregiver Experts
12:00-1:15 pm	Lunch & Family Mingle <i>Lunch with optional hosted discussion tables.</i>	

Workshop Block 1:1 (Concurrent)

Time (ET)	Session	Presenter(s)
1:15-2:45 pm	A: Precision Diagnosis & DEE Signatures <i>Understanding seizure types, genetics, and comorbidities to personalize care planning.</i>	-Tracy Dixon-Salazar, PhD, Executive Director, LGS Foundation -Renee Shellhaas, MD, MS -Aditi Trivedi, MD
1:15-2:45 pm	B: Rethinking Challenging Behavior <i>Brain-first framework for understanding and responding to behavioral challenges.</i>	-Eileen Devine, LCSW, Brain First Parenting -Tiffany Johnson, LGS Foundation
1:15-2:45 pm	C: Mapping Your LGS Care Roadmap <i>Building a lifespan care strategy from diagnosis to adulthood.</i>	-Dave F. Clarke, MBBS, ABPN -Dave Burdette, MD -Jennifer Griffin, Director of Family Support, LGS Foundation
2:45-3:15 pm	Refreshment Break	

Workshop Block 1:2 (Concurrent)

Time (ET)	Session	Presenter(s)
3:15-4:45 pm	D: Surgery & Neuromodulation <i>Evaluating surgical and device-based treatment options and decision-making frameworks.</i>	-Scott Perry, MD -LGS Caregiver Experts
3:15-4:45 pm	E: Devices for LGS <i>Overview of seizure monitoring, sleep devices, and wearable technologies.</i>	-Greg Worrell, MD, PhD -Gita Gupta, MD

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3:15-4:45 pm	F: Building Your LGS Care Team & Plan <i>Creating a coordinated care team and emergency-ready summary document.</i>	-Fabio Nascimento, MD -Cythnia Keater, MD -Natalie Gilmore, LGS Caregiver Expert -Helen Chen, PhD, Research Director, LGS Foundation
4:45-5:00 pm	Evening Break	

Camp Small Steps

Time (ET)	Session	Presenter(s)
5:30-9:30 pm	Camp Small Steps <i>Evening family event with dinner, creative activities, music, and informal connection in a relaxed setting.</i>	

July 17 **Saturday – JULY 11, 2026**

Time (ET)	Session	Presenter(s)
7:00 - 8:00 am	Breakfast & Open Care Conversations <i>Informal Q&A with neurology, behavioral, and resilience experts.</i>	-Eileen Devine, LCSW, Brain First Parenting

Accelerating Research & Cures

Time (ET)	Session	Presenter(s)
8:00 - 8:05 am	Welcome Back Day 2	-Fred Roeld, MBA, Board Chair, LGS Foundation
8:05 - 8:20 am	Research Pipeline Overview <i>Overview of current and emerging LGS research initiatives.</i>	-Tracy Dixon-Salazar, PhD, Executive Director, LGS Foundation

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8:20 - 8:30 am	LGS-CORE Study <i>An overview of the LGS-CORE Registry and how shared family experiences help drive research, improve care, and accelerate new treatment discoveries.</i>	-Helen Chen, PhD, Research Director, LGS Foundation
8:30 - 8:40 am	Becoming a Research Partner: Understanding Clinical Trial Participation <i>Understanding clinical trials and the role families play in advancing LGS research.</i>	-Helen Chen, PhD, Research Director, LGS Foundation
8:40 - 9:55 am	Research & Industry Partner Updates <i>Updates on clinical trials, patient-driven research, and therapeutic innovation.</i>	
9:55 - 10:05 am	Panel Discussion + Interactive Q&A	
10:05-10:30 am	Refreshment Break	

LGS Associated Disorders

Time (ET)	Session	Presenter(s)
10:40-10:50 am	Introduction to LGS Associated Disorders <i>Overview of common comorbidities in LGS.</i>	-Tracy Dixon-Salazar, PhD, Executive Director, LGS Foundation
10:50-11:05 am	Seizure Management <i>Strategies for managing status, clusters, and safety.</i>	-Babitha Haridas, MD -Aditi Trivedi, MD
11:05-11:25 am	Pulmonary Risks <i>Understanding pneumonia/aspiration risk and respiratory monitoring.</i>	-Michael Schechter, MD, MPH
11:25-11:40 am	Sleep in LGS <i>Addressing sleep disruption and monitoring.</i>	-Gita Gupta, MD
11:40-12:00 pm	Bringing It All Together: Families and Professionals in Conversation <i>Panel Discussion + Interactive Q&A</i>	-Featured Speakers & Caregiver Experts
12:00-1:15 pm	Lunch Break	



Workshop Block 2:1 (Concurrent)

Time (ET)	Session	Presenter(s)
1:15-2:45 pm	G: Crisis Planning <i>Building seizure action plans and emergency preparedness tools.</i>	-Janna Moore, MPA Executive Director, Epilepsy Support Network of Orange County
1:15-2:45 pm	H: Building Frustration Tolerance <i>Brain-based resilience strategies for children and caregivers.</i>	-Eileen Devine, LCSW, Brain First Parenting
1:15-2:45 pm	I: Caring for the Whole Family <i>Practical tools for family regulation, connection, and emotional support.</i>	-Maggie Kang, MD
2:45-3:15 pm	Refreshment Break	

From Insight to Impact

Time (ET)	Session	Presenter(s)
3:15-4:45 pm	Hope in Action: From Awareness to Change <i>Interactive closing session reflecting on key insights and next steps.</i>	
5:00 pm	Celebration of Life & Butterfly Release <i>Ceremony honoring loved ones, followed by reception.</i>	