




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>A relaxed, drop-in space to ask questions, share experiences, and connect directly with experts to discuss LGS Foundation resources, family support, and advocacy opportunities.</i>	-Jennifer Griffin, Director of Family Support, LGS Foundation

LGS Today: Where We Stand

Time (ET)	Session	Presenter(s)
8:00 - 8:10 am	Welcome <i>Opening remarks and what to expect throughout the conference.</i>	-Tracy Dixon-Salazar, PhD, Executive Director, LGS Foundation

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8:10 - 8:25 am	Keynote: What I Learned in 42 Years of Living with LGS <i>A personal reflection on lived experience, progress, and the power of community over time.</i>	-Fred Roedl, MBA, Board Chair, LGS Foundation
8:25 - 8:40 am	Where Are We In LGS Diagnosis, Treatment, and Care, and What You Can Do Now to Help Your Loved One? <i>An overview of today's care landscape and practical ways families can take action now.</i>	-Tracy Dixon-Salazar, PhD, Executive Director, LGS Foundation
8:40 - 8:55 am	Epidemiology & Standard of Care <i>A clear look at how LGS is defined, diagnosed, and treated based on current evidence.</i>	-Scott Perry, MD
8:55 - 9:10 am	How Can We Treat Seizures Based On Your Loved One's Seizure Patterns and The Time of Day They Occur? <i>Exploring how timing, patterns, and individual differences shape treatment decisions.</i>	-David F Clarke, MBBS, ABPN, ABCN
9:10 - 9:15 am	Lived Experience: What Is It Like to Consider Surgery and Navigate All the Information <i>A caregiver perspective on decision-making, uncertainty, and navigating options.</i>	-Tiffany Johnson, LGS Caregiver Expert
9:15 - 9:20 am	Lived Experience: LGS Sibling Perspective <i>A sibling's view on growing up alongside LGS.</i>	-Shay McLeod, LGS Sibling
9:20 - 10:00 am	Bringing It All Together: Families and Professionals in Conversation <i>An interactive panel bringing together clinical insight and real-world experience, with audience Q&A.</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	Where Is LGS Care Strong? Where Are the Gaps?	-Renee Shellhaas, MD, MS

	<i>Identifying progress in care and the areas where innovation is still needed.</i>	
10:45-11:00 am	What Does Optimal Care Include; How Do You Know You're Getting It? <i>Defining what high-quality, coordinated LGS care should look like across settings.</i>	-Babitha Haridas, MD
11:00-11:05 am	Caregiver Perspective: Pediatric Care <i>Insights from a caregiver navigating care in early childhood.</i>	-Jordan Bradley, LGS Caregiver Expert
11:05-11:10 am	Caregiver Perspective: Transition of Care <i>Experiences and challenges during the shift from pediatric to adult care.</i>	-Jamie Riley, LGS Caregiver Expert
11:10-11:15 am	Caregiver Perspective: Adult Care <i>Perspectives on long-term care and adult support needs.</i>	-Stephen Feather, LGS Caregiver Expert
11:15-12:00 pm	Bringing It All Together: Families and Professionals in Conversation <i>A panel discussion focused on improving care systems, research priorities, and real-world impact.</i>	-Featured Speakers & Caregiver Experts
12:00-1:15 pm	Lunch & Family Mingle <i>Enjoy lunch while connecting with others or joining optional discussion tables.</i>	

Workshop Block 1:1 (Concurrent)

Time (ET)	Session	Presenter(s)
1:15-2:45 pm	A: What Is Your Loved One's Precise Diagnosis: Learn About LGS Signatures and How Each Signature Is Treated <i>Understand seizure types, genetic factors, and comorbidities to better define your loved one's diagnosis and care needs.</i> <i>Sponsored by GeneDX</i>	-Tracy Dixon-Salazar, PhD, Executive Director, LGS Foundation -Renee Shellhaas, MD, MS
1:15-2:45 pm	B: Rethinking Challenging Behavior (Brain-First Parenting Framework)	-Eileen Devine, LCSW, Brain First Parenting

	<i>Learn how brain-based approaches can shift how we understand and respond to behavior.</i>	-Tiffany Johnson, LGS Caregiver Expert
1:15-2:45 pm	C: Mapping Your LGS Care Roadmap: From Diagnosis to Adulthood <i>Explore what care looks like at each stage and how to build the right team over time.</i>	-Dave F. Clarke, MBBS, ABPN -Dave Burdette, MD -Jamie Riley, LGS Caregiver Expert
2:45-3:15 pm	Refreshment Break	

Workshop Block 1:2 (Concurrent)

Time (ET)	Session	Presenter(s)
3:15-4:45 pm	D: Is LGS Surgery and/or Neuromodulation Right for My Loved One? <i>Review surgical and device-based options and how families approach these decisions.</i>	-Scott Perry, MD LGS Caregiver Experts: -Jamie Riley -Diana Smaglik -Brandi Fincher
3:15-4:45 pm	E: Devices to Make Life Easier in LGS <i>An overview of tools and technologies that support monitoring, safety, and daily living.</i>	-Greg Worrell, MD, PhD -Gita Gupta, MD -Jeannie Schnur, LGS Caregiver Expert
3:15-4:45 pm	F: Building Your LGS Care Team and Care Plan <i>Map your current care team, identify gaps, and begin building a plan that fits your needs.</i>	-Fabio Nascimento, MD -Cynthia Keator, MD -Tricia Proefrock, LGS Caregiver Expert
4:45-5:00 pm	Evening Break	

Camp Small Steps

Time (ET)	Session	Presenter(s)
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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>	
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17th July Saturday – JULY 11, 2026

Time (ET)	Session	Presenter(s)
7:00 - 8:00 am	Breakfast & Open Care Conversations <i>Another opportunity to connect informally with experts and other families.</i>	-Eileen Devine, LCSW, Brain First Parenting -Scott Perry, MD -Jennifer Griffin, Director of Family Support, LGS Foundation

Accelerating Research & Cures

Time (ET)	Session	Presenter(s)
8:00 - 8:05 am	Welcome Back Day 2 <i>A brief kickoff to the day's research-focused sessions.</i>	-Fred Roedl, MBA, Board Chair, LGS Foundation
8:05 - 8:20 am	Research Pipeline Overview <i>A look at current and emerging research efforts shaping the future of LGS care.</i>	-Tracy Dixon-Salazar, PhD, Executive Director, LGS Foundation



8:20 - 8:30 am	LGS-CORE Study <i>How shared family data is helping drive research, improve care, and accelerate discovery.</i>	-Helen Chen, PhD, Research Director, LGS Foundation
8:30 - 8:40 am	Becoming a Research Partner: Understanding Clinical Trial Participation <i>What it means to participate in research and how families play a role.</i>	-Helen Chen, PhD, Research Director, LGS Foundation
8:40 - 9:00 am	Panel Discussion + Interactive Q&A	All speakers
9:00 - 10:10 am	Research & Industry Partner Updates <i>Updates from partners advancing treatments, clinical trials, and innovation.</i>	
10:10-10:30 am	Refreshment Break	

LGS Associated Disorders

Time (ET)	Session	Presenter(s)
10:40-10:50 am	Introduction to LGS Associated Disorders <i>An overview of common comorbidities and how they impact care.</i>	-Tracy Dixon-Salazar, PhD, Executive Director, LGS Foundation
10:50-11:05 am	Seizure Management <i>Strategies for managing seizures, clusters, and safety in daily life.</i>	-Babitha Haridas, MD
11:05-11:25 am	Pulmonary Risks <i>Understanding respiratory risks and monitoring needs in LGS.</i>	-Michael Schechter, MD, MPH
11:25-11:40 am	Sleep in LGS <i>Addressing sleep challenges and their impact on health and quality of life.</i>	-Gita Gupta, MD
11:40-11:45	Caregiver Perspective: High-Risk & Medically Complex Care <i>A real-world perspective on managing complex care needs, including seizure management, sleep challenges, and pulmonary considerations, and how participation in research helps advance care.</i>	Kurt Oberhausen, LGS Caregiver Expert



11:45-12:00 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: Seizures, Hospitalizations, and Emergencies <i>Learn how to prepare for emergencies and communicate effectively with care teams.</i> <i>Sponsored by Neurelis</i>	-Janna Moore, MPA Executive Director, Epilepsy Support Network of Orange County
1:15-2:45 pm	H: Building Frustration Tolerance: A Brain-First Approach to Growing Your Child's Resilience <i>Explore strategies to support emotional regulation and resilience in daily life.</i>	-Eileen Devine, LCSW, Brain First Parenting -Tiffany Johnson, LGS Caregiver Expert
1:15-2:45 pm	I: Caring for the Whole Family: Reset, Redefine, Rebuild <i>Focus on family connection, caregiver support, and building resilience together.</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>An interactive closing session reflecting on key takeaways and how to move forward as a community.</i>	
4:45-4:50 pm	Closing Remarks	

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5:00 pm	Celebration of Life & Butterfly Release <i>A meaningful ceremony honoring loved ones, followed by a closing reception.</i>	
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