

START TIME	END TIME	SESSION TITLE	SPEAKER(S)
CONF DAY 1 – Thursday, July 9, 2026			
1:00 PM	6:30 PM	Sunshine Social: The Fun Starts Here	Fred Roedl, MBA Tracy Dixon-Salazar, PhD
DAY 2 – Friday, July 10, 2026			
7:00 AM	8:00 AM	Breakfast & Family Mingle	
8:00 AM	8:10 AM	Welcome to Day 1!	Tracy Dixon-Salazar, PhD
8:10 AM	8:25 AM	What I Learned in 42 Years of Living with LGS – Keynote Address	Fred Roedl, MBA
8:30 AM	8:35 AM	Lived Experience: What Is It Like to Consider Surgery and Navigate All the Information	Tiffany Johnson
8:35 AM	8:40 AM	Lived Experience: LGS Sibling Perspective	Shay McLeod
8:40 AM	8:55 AM	How Far We've Come, How Far We Have to Go	Tracy Dixon-Salazar, PhD
8:55 AM	9:10 AM	LGS Today: Diagnosis, Comorbidities, and Today's Standard of Care	Scott Perry, MD
9:10 AM	9:25 AM	Right Drug, Right Time: Treating Seizures by Pattern and Clock	David F. Clarke, MBBS, ABPN, ABCN
9:25 AM	10:00 AM	Bringing It All Together: Families & Professionals in Conversation • All Speaker Panel	Moderated by: Scott Perry, MD Panel: David F Clarke, MBBS, Tiffany Johnson, Shay McLeod, Tracy Dixon-Salazar, PhD, Fred Roedl, MBA
10:05 AM	10:15 AM	Group Photo	All Attendees
10:15 AM	10:30 AM	Morning/Refreshment Break	
10:35 AM	10:40 AM	Caregiver Perspective: Pediatric Care – Navigating care in early childhood	Jordan Bradley
10:40 AM	10:45 AM	Caregiver Perspective: Transition of Care – Shift from pediatric to adult care	Jamie Riley
10:45 AM	10:50 AM	Caregiver Perspective: Adult Care – Long-term care and adult support needs	Jennifer Griffin
10:50 AM	11:05 AM	Where Is LGS Care Strong? Where Are the Gaps?	Renee Shellhaas, MD, MS
11:05 AM	11:20 AM	What Does Optimal Care Include; How Do You Know You're Getting It?	Babitha Haridas, MBBS
11:20 AM	11:55 AM	Bringing It All Together: Families & Professionals in Conversation • All Speaker Panel	Moderated by: Renee Shellhaas, MD Panel: Babitha Haridas, MBBS, Jordan Bradley, Jamie Riley, Jennifer Griffin, Helen Chen, PhD

12:00 PM	1:15 PM	Lunch & Family Mingle	
1:15 PM	2:45 PM	WORKSHOP A: What Is Your Loved One's Precise Diagnosis? LGS Signatures, seizure types, genetic factors, comorbidities, DEE-SIGNS acronym Sponsored by GeneDX	Tracy Dixon-Salazar, PhD and Renee Shellhaas, MD
1:15 PM	2:45 PM	WORKSHOP B: Rethinking Challenging Behavior (Brain-First Parenting Framework) Brain-based approaches to understanding and responding to behavior Day one of Two day Workshop Sponsored by Jazz	Eileen Devine, LCSW
1:15 PM	2:45 PM	WORKSHOP C: Mapping Your LGS Care Roadmap: From Diagnosis to Adulthood Care at each stage; TOC, pediatric, adult, palliative care; finding a doctor; multidisciplinary teams; what is optimal care	David F Clarke, MBBS and Dave Burdette, MD
2:45 PM	3:15 PM	Afternoon/Refreshment Break	
3:15 PM	4:45 PM	WORKSHOP D: Is LGS Surgery and/or Neuromodulation Right for My Loved One? Surgical and device-based options; family decision-making	Scott Perry, MD
3:15 PM	4:45 PM	WORKSHOP E: Devices to Make Life Easier in LGS Seizure monitoring, sleep monitoring, vital signs, apps, daily safety & support	Greg Worrell, MD, PhD and Gita Gupta, MD
3:15 PM	4:45 PM	WORKSHOP F: Building Your LGS Care Team and Care Plan	Fabio Nascimento, MD Cynthia Keator, MD
4:50 PM	5:15 PM	Lights Down on Day 1, Spotlight on Our Leaders in LGS!	Tracy Dixon-Salazar, PhD
5:30 PM	9:30 PM	Camp Small Steps Join us for a night of camping fun complete with songs around the campfire!	
DAY 3 – Saturday, July 11, 2026			
7:00 AM	8:00 AM	Open Care Conversations (Drop-In)	Scott Perry, MD Eileen Devine, LCSW Jennifer Griffin

7:00 AM	8:00 AM	Breakfast & Family Mingle	
8:00 AM	8:05 AM	Welcome to Day 2	Fred Roedl, MBA
8:05 AM	8:10 AM	Why I Said Yes to Research: Addison's Story	Kurt Oberhausen
8:10 AM	8:25 AM	From Question to Cure: The LGS Research Pipeline in 2026 Overview of current and emerging LGS research initiatives	Tracy Dixon-Salazar, PhD
8:25 AM	8:35 AM	Our Stories, Our Data: Inside the LGS-CORE Registry Overview of LGS-CORE Registry and how family experiences drive research and accelerate treatment discoveries	Helen Chen, PhD
8:35 AM	8:45 AM	Could a Study or Trial Be Right for Us? A Family Guide to Clinical Research	Helen Chen, PhD
8:45 AM	8:55 AM	Merging Research and Families	Moderated by: Tracy Dixon Salazar, PhD Panel: Helen Chen, PhD Kurt Oberhausen
9:00 AM	9:15 AM	IP Talk - Neurelis	Ami Waggoner
9:15 AM	9:28 AM	IP Talk – UCB	Marytery Fajardo, MD
9:30 AM	9:40 AM	IP Talk – Harmony	TBD
9:40 AM	9:50 AM	IP Talk – Jazz	TBD
9:50 AM	10:00 AM	IP Talk – SK Life	TBD
10:00 AM	10:10 AM	IP Talk - Lundbeck	TBD
10:10 AM	10:20 AM	SOM-L Updates	Sandi Lam, MD, MBA
10:20 AM	10:35 AM	Morning/Refreshment Break	
10:40 AM	10:45 AM	Caregiver Perspective: High-Risk & Medically Complex Care Managing complex care, seizure management, sleep challenges, pulmonary, research participation	Stephen Feather
10:45 AM	10:55 AM	Introduction to LGS Associated Disorders – Common comorbidities and their impact on care	Tracy Dixon-Salazar, PhD
10:55 AM	11:10 AM	The 24-Hour View: Managing Seizures, Clusters, and Status Strategies for managing seizures, clusters, and safety in daily life	Babitha Haridas, MBBS
11:10 AM	11:30 AM	Breathing Easier: Pneumonia, Aspiration, and Pulmonary Risk in LGS Understanding respiratory risks and monitoring needs in LGS.	Michael Schechter, MD
11:30 AM	11:45 AM	The Other 8 Hours: Sleep in LGS and Why It Matters Addressing sleep challenges and their impact on health and quality of life	Gita Gupta, MD

11:45 AM	12:05 PM	Bringing It All Together: Families & Professionals in Conversation All speaker Panel	Moderated by: Tracy Dixon Salazar, PhD Panel: Helen Chen, PhD, Michael Schechter, MD, Gita Gupta, MD, Babitha Haridas, MD, Stephen Feather, Kurt Oberhausen
12:10 PM	1:15 PM	Lunch & Family Mingle	
1:15 PM	2:45 PM	WORKSHOP G: Crisis Planning: Seizures, Hospitalizations, and Emergencies Sponsored by Neurelis	Janna Moore, MPA
1:15 PM	2:45 PM	WORKSHOP H: Building Frustration Tolerance: A Brain-First Approach to Growing Your Child's Resilience Sponsored by Jazz	Eileen Devine, LCSW
1:15 PM	2:45 PM	WORKSHOP I: Caring for the Whole Family – Reset, Redefine, Rebuild	Maggie Kang, MD
2:45 PM	3:15 PM	Afternoon/Refreshment Break – Return to Main Ballroom	
3:15 PM	4:45 PM	Hope in Action: From Awareness to Change	Moderated by: Tracy Dixon-Salazar, PhD
4:45 PM	4:50 PM	Closing Remarks	Tracy Dixon-Salazar, PhD
5:00 PM	5:30 PM	Celebration of Life – Butterfly Release	Kathy Leavens
6:00 PM	8:00 PM	Focus Group – Jazz Caregiver Advisory Panel	Jazz