

Thursday - July 9th, 2026

Arrival & Community Connection

1:00pm - 6:30pm **Registration & Help Desk Open**
Pick up your materials, get settled, and meet our team.
We're here to help you start the weekend with ease.

1:00pm - 6:30pm **Sunshine Social: The Fun Starts Here**
Kick off the conference in a relaxed, welcoming space designed for connection.

- **Enjoy:**
- Meet Me Stations (create and share your story)
 - Photo Experience Area
 - Live Caricature Artist
 - Exhibitor & Partner Tables
 - Special Guest Appearances




This afternoon is intentionally relaxed, come and go, meet others, and ease into the weekend. Light refreshments available during the Sunshine Social.



Friday - July 10th, 2026

LGS Today: Where We Stand

7:00am - 8:00am  **Breakfast & Open Care Conversation** (Caribbean IV & V)
A relaxed, drop-in hour to connect one-on-one with experts while enjoying breakfast.
Come with questions. Leave with clarity.

8:00am - 8:10am **Welcome to Day 1** (Caribbean VI & VII)

8:10am - 8:25am **Keynote: What I Learned in 42 Years of Living with LGS**
• *Fred Roedl, MBA*

8:30am - 8:35am **Lived Experience: What Is It Like to Consider Surgery and Navigate All the Information**
• *Tiffany Johnson, LGS Caregiver Expert*

8:35am - 8:40am **Lived Experience: What Is It Like to Grow Up in an LGS Family? LGS Sibling Perspective**
• *Shaye McLeod, LGS Caregiver Expert*

8:40am - 8:55am **How Far We've Come, How Far We Have to Go**
• *Tracy Dixon-Salazar, PhD*

8:55am - 9:10am **LGS Today: Diagnosis, Comorbidities, and Today's Standard of Care**
• *Scott Perry, MD*

9:10am - 9:25am **Right Treatment, Right Time: Treating Seizures by Pattern and Clock**
• *David F. Clarke, MBBS, ABPN, ABCN*

9:25am - 10:00am **Bringing It All Together: Families and Professionals in Conversation**

Moderated by:

- *Scott Perry, MD*

Panel:

- *David F. Clarke, MBBS, ABPN, ABCN*
 - *Tiffany Johnson, LGS Caregiver Expert*
 - *Shaye McLeod, LGS Caregiver Expert*
 - *Tracy Dixon-Salazar, PhD*
 - *Fred Roedl, MBA*
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10:05am - 10:15am **Group Photo**

10:15am - 10:30am **Morning Refreshment Break** 



Share the moments! #LGSconference2026

Friday - July 10th, 2026

Transforming LGS Care Today

(Caribbean VI & VII)

10:35am - 10:40am **Caregiver Perspective: Pediatric Care – Navigating Care in Early Childhood**

- *Jordan Bradley, LGS Caregiver Expert*

10:40am - 10:45am **Caregiver Perspective: Transition of Care – Shift from Pediatric to Adult Care**

- *Jamie Riley, LGS Caregiver Expert*

10:45am - 10:50am **Caregiver Perspective: Adult Care – Long-Term Care and Adult Support Needs**

- *Jennifer Griffin, LGS Caregiver Expert*

10:50am - 11:05am **Where Is LGS Care Strong? Where Are the Gaps?**

- *Renee Shellhaas, MD, MS*

11:05am - 11:20am **What Does Fundamental Care Include; How Do You Know You're Getting It?**

- *Babitha Haridas, MBBS*

11:20am - 11:55am **Bringing It All Together: Families and Professionals in Conversation**

Moderated by:

- *Renee Shellhaas, MD*

Panel:

- *Babitha Haridas, MBBS*
- *Jordan Bradley, LGS Caregiver Expert*
- *Jamie Riley, LGS Caregiver Expert*
- *Jennifer Griffin, LGS Caregiver Expert*
- *Helen Chen, PhD*

 12:00pm - 1:15pm **Lunch & Family Mingle**

Workshop Block 1:1 (concurrent)

1:15pm - 2:45pm

A

What Is Your Loved One's Precise Diagnosis?
LGS Signatures, seizure types, genetic factors, comorbidities, DEE-SIGNS

- *Tracy Dixon-Salazar, PhD*
- *Renee Shellhaas, MD*

Sponsored by: 

B

Rethinking Challenging Behavior:
Brain-based approaches to understanding and responding to behavior

Workshop 1 of 2

- *Eileen Devine, LCSW*

Sponsored by:  **Jazz Pharmaceuticals.**

C

Mapping Your LGS Care Roadmap: From Diagnosis to Adulthood - Helping families navigate care, connect with specialists, and manage transitions across every stage of life.

- *David F. Clarke, MBBS, ABPN, ABCN*
- *Dave Burdette, MD*

2:45pm - 3:15pm **Afternoon Refreshment Break**



Friday - July 10th, 2026

Workshop Block 1:2 (concurrent)

3:15pm - 4:45pm

D

Is LGS Surgery and/or Neuromodulation Right for My Loved One?
Surgical and Device-Based Options; Family Decision-Making

- Scott Perry, MD

E

Devices to Make Life Easier in LGS
Seizure Monitoring, Sleep Monitoring, Vital Signs, Apps, Daily Safety & Support

- Greg Worrell, MD, PhD
- Gita Gupta, MD
- Michael Schechter, MD

F

Building Your LGS Care Team and Care Plan - Map Your Current Care Team, Identify Gaps, and Begin Building a Plan That Fits Your Needs.

- Fabio Nascimento, MD
- Cynthia Keator, MD

4:50pm - 5:15pm

Lights Down on Day 1, Spotlight on Our Leaders in LGS

(Caribbean VI & VII)

- Tracy Dixon-Salazar, PhD
- Fred Roedl, MBA

5:30pm - 9:30pm **Camp Small Steps**

A sensory-aware camp experience created just for LGS families.

Enjoy dinner, hands-on activities, music, and time together in a space where everyone understands this journey.

Camp Small Steps is about joy in the midst of complexity, and remembering you're not walking this path alone.



Sponsored by:  Inspired by patients.
Driven by science.



Saturday - July 11th, 2026

Accelerating Research & Cures

- 7:00am - 8:00am  **Breakfast & Open Care Conversation** *(Caribbean IV-V & Boca)*
A relaxed, drop-in hour to connect one-on-one with experts while enjoying breakfast.
Come with questions. Leave with clarity.
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- 8:00am - 8:05am **Welcome to Day 2** *(Caribbean VI & VII)*
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- 8:05am - 8:10am **Why I Said Yes to Research: Addison's Story**
• *Kurt Oberhausen, LGS Caregiver Expert*
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- 8:10am - 8:25am **From Question to Cure: The LGS Research Pipeline in 2026**
• *Tracy Dixon-Salazar, PhD*
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- 8:25am - 8:35am **Our Stories, Our Data: Inside the LGS-CORE Registry**
• *Helen Chen, PhD*
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- 8:35am - 8:45am **Could a Study or Trial Be Right for Us?
A Family Guide to Clinical Research**
• *Helen Chen, PhD*
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- 8:50am - 9:05am **Finding Joy in the Journey**
• *Ami Waggoner, Patient Ambassador*
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- 9:05am - 9:18am **Making Informed Choices: FINTEPLA (fenfluramine) for
Your Loved One with Lennox-Gastaut Syndrome (LGS)**
• *Marytery Fajardo, MD*
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- 9:20am - 9:30am **Understanding the Behavioral Impact of LGS: A Collaboration
Between the LGS Foundation and Jazz Pharmaceuticals**
• *Tim Holick, MBA*
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- 9:30am - 9:40am **Partnering with the LGS Community: Listening, Learning, &
Advancing Research Together**
• *Sunita Misra, MD, PhD*
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- 9:40am - 9:50am **Bexicaserin: An Investigational Therapy for Developmental
and Epileptic Encephalopathies (DEEs)**
• *Ron Jordan, MD*
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- 9:50am - 10:00am **Sympazan (clobazam) Oral Film:
For Those Who Spit Out or Have Difficulty Swallowing
Their Medicine, SYMPAZAN[®] May Help**
• *Alain Dury, PhD*
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- 10:00am - 10:10am **LGS Voices Shaping Better Evidence: Updates from the
Surgery or Meds for LGS (SOM-L) Study - Treatments,
Outcomes, and Caregiver Burden**
• *Sandi Lam, MD, MBA*

Saturday - July 11th, 2026

LGS Associated Disorders (LAD)

10:10am - 10:30am **Morning Refreshment Break** ☕

10:35am - 10:40am **Caregiver Perspective: High-Risk & Medically Complex Care**

- *Stephen Feather, LGS Caregiver Expert*

10:40am - 10:50am **Introduction to LGS Associated Disorders – Common Comorbidities and Their Impact on Care**

- *Tracy Dixon-Salazar, PhD*

10:50am - 11:05am **The 24-Hour View: Managing Seizures, Clusters, and Status**

- *Babitha Haridas, MBBS*

11:05am - 11:25am **Breathing Easier: Pneumonia, Aspiration, and Pulmonary Risk in LGS**

- *Michael Schechter, MD*

11:25am - 11:40am **The Other 8 Hours: Sleep in LGS and Why It Matters**

- *Gita Gupta, MD*

11:40am - 12:05pm **Bringing It All Together: Families and Professionals in Conversation**

Moderated by:

- *Tracy Dixon-Salazar, PhD*

Panel:

- *Helen Chen, PhD*
- *Michael Schechter, MD*
- *Gita Gupta, MD*
- *Babitha Haridas, MBBS*
- *Stephen Feather, LGS Caregiver Expert*
- *Kurt Oberhausen, LGS Caregiver Expert*

🕒 12:10pm - 1:15pm **Lunch & Family Mingle**

Saturday - July 11th, 2026

Workshop Block 2:1 (concurrent) 1:15pm - 2:45pm

G

Crisis Planning: Seizures, Hospitalizations, and Emergencies - Building seizure action plans and emergency preparedness tools.

- Janna Moore, MPA

Sponsored by:  NEURELIS

H

Building Frustration Tolerance: A Brain-First Approach to Growing Your Child's Resilience

Workshop 2 of 2

- Eileen Devine, LCSW

Sponsored by:  Jazz Pharmaceuticals

I

Caring for the Whole Family: Reset, Redefine, Rebuild - Leave feeling less alone and more supported. Learn simple ways to calm the nervous system during stressful times.

- Maggie Kang, MD

2:45pm - 3:15pm **Afternoon Refreshment Break** 

3:15pm - 4:50pm **Hope in Action: From Awareness to Change**

Moderated by:

- Tracy Dixon Salazar, PhD



5:00pm - 5:30pm **Celebration of Life - Butterfly Release**

The Celebration of Life honors the impact and profound influence of those who have departed from our world. A special time dedicated to honoring our loved ones, who spirits guide us in our pursuit of cures for LGS.

