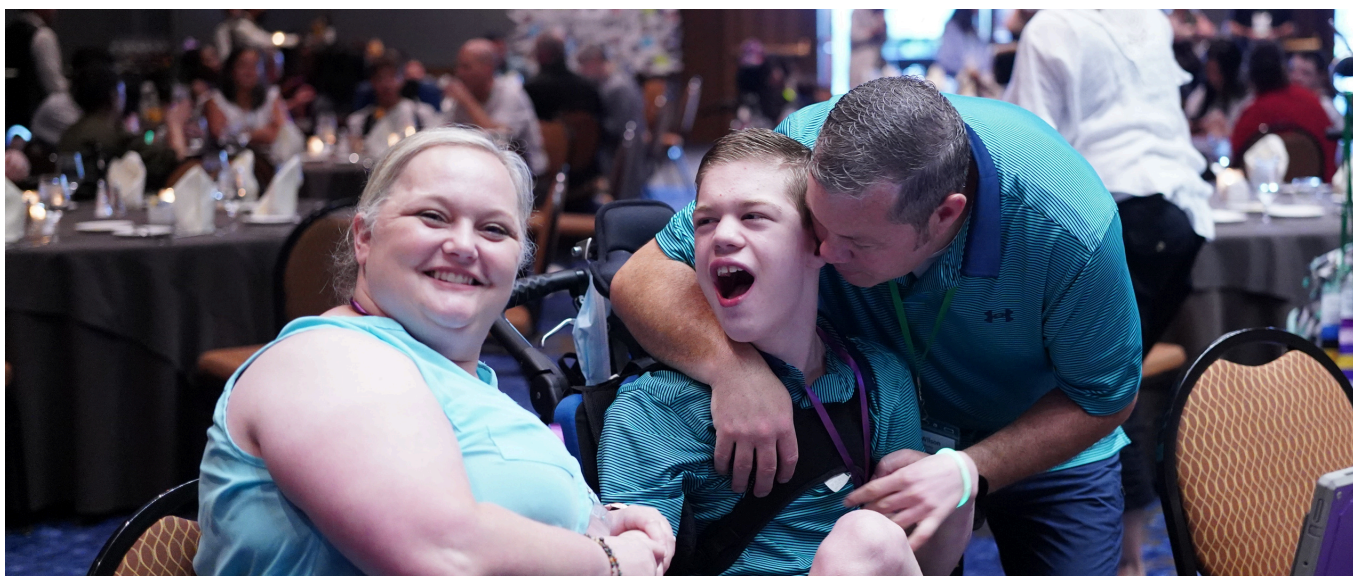


# Thursday

Thursday, July 11

3 pm PT	Registration & Exhibit Hall Open	Komatke Foyer
3 pm	LGS Community Corral <i>Stop by, kick up your feet and make new friends. Snacks and activities available.</i>	Coyote/Buzzard
4 - 5 pm	Yoga & Guided Meditation	Komatke C
5 - 6:30 pm	LGS 101 for Newly Diagnosed Families <i>Tracy Dixon-Salazar, PhD</i>	Komatke A
7 pm	Registration, Exhibit Hall, & Community Corral Closing	
7 - 8 pm	Yoga & Guided Meditation	Komatke C




**LGS FOUNDATION<sup>®</sup>**  
**LEARN FROM EVERY PATIENT DATABASE**  
*Your Voice is Key for the Future of LGS Treatments*

**Join Now!**




# Friday

## Friday, July 12

7-8:30 am **Breakfast** Pipai Kave

7:30 am **Exhibit Hall & Resource Center Opens** Komatke Foyer

### Ask an LGS Expert

*Grab your breakfast & Join us for an open forum discussion with an LGS expert*

<p><b>Ask a LGS Specialist</b> Scott Perry, MD</p> <p style="text-align: right;"><i>Buzzard</i></p>	<p><b>Ask a Genetic Counselor</b> Beth Rosen Sheidley, MS</p> <p style="text-align: right;"><i>Gila Monster</i></p>
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8 am **Registration Opens** Akimel Foyer

8:30 am **Sibs Adventure Camp Program - Drop-Off** 1st Floor - Pima Wing

## Sessions Begin

8:45 am **Welcome/Opening Remarks** Komatke Ballroom  
Karen Groff, M ED

9:15 am **Understanding the Emotional Journey of Families**  
Dr. Julie Lazzara, PhD

9:35 am **What do we know about LGS today?**  
Dr. Elaine Wirrel, MD

9:50 am **Exciting New Directions in LGS**  
Tracy Dixon-Salazar, PhD

## Break & Transition to Workshops

10:30 am **LGS Workshop 1**

<p><b>Seizure Types, Seizure Action Plans, &amp; Using Technology Devices</b> Rob Moss &amp; Tom Stanton</p> <p style="text-align: right;"><i>Komatke A</i></p>	<p><b>Non-Surgical Treatment Options &amp; Clinical Trials</b> Elaine Wirrell, MD</p> <p style="text-align: right;"><i>Komatke B</i></p>	<p><b>Managing Challenging Behaviors</b> *Pre-Register to Attend Eileen Devine, LCSW</p> <p>Sponsored by:  <b>Jazz Pharmaceuticals</b></p> <p style="text-align: right;"><i>Komatke C</i></p>
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## Lunch Break

12:30 - 1 pm **Yoga & Guided Meditation** Pipai Kave  
Komatke C

1 pm **LGS Workshop 2**

<p><b>Surgical Approaches &amp; Assessments for LGS</b> Scott Perry, MD</p> <p style="text-align: right;"><i>Komatke A</i></p>	<p><b>Genetics Made Simple</b> Beth Rosen Sheidley, MS</p> <p style="text-align: right;"><i>Komatke B</i></p>	<p><b>Managing Challenging Behaviors</b> *Pre-Register to Attend Eileen Devine, LCSW</p> <p style="text-align: right;"><i>Komatke C</i></p>
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## Break

3 pm **LGS Workshop 3**

<p><b>The Early Years: Navigating the medical system, school, &amp; therapies</b> Recommended for ages 0-11 Jennifer Griffin, LGS Foundation Diana Smaglick <i>Komatke Ballroom</i></p>	<p><b>Preparing for Transition of Medical Care</b> Recommended for ages 12-17 Jamie Twanow, MD <i>Komatke A</i></p>	<p><b>Understanding the Unique Needs of Adults with LGS</b> Recommended for ages 17+ Laurie Bailey, UCB Sponsored by:  <b>UCB</b> Inspired by patients. Driven by science. <i>Komatke B</i></p>	<p><b>Managing Challenging Behaviors</b> *Pre-Register to Attend Eileen Devine, LCSW <i>Komatke C</i></p>
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## Break

4:45 pm **Workshop Takeaways** Komatke Ballroom  
Moderated by: Tracy Dixon-Salazar, PhD

5:30 pm **Camper Pick-Up** 1st Floor - Pima Wing

5:40 pm **Group Photo** Atrium Stairs

6 - 8:30 pm **Opening Reception** Pipai Kave Foyer  
*Join us for an evening of community and fun. Dinner will be served.*

8 - 8:30 pm **Yoga & Guided Meditation** Komatke C

# Saturday

## Saturday, July 13

7 - 8:30 am **Breakfast** Pipai Kave

7:30 am **Exhibit Hall & Resource Center Opens**

7:30 - 8:30 am **LGS Research Poster Display**  
*Learn about the latest in LGS research and ask the experts questions.*

**Ask an LGS Expert**

*Grab your breakfast & Join us for an open forum discussion with an LGS expert*

**Ask a Genetic Counselor**

*Beth Rosen Sheidley, MS*

*Gila Monster*

**Managing Challenging Behaviors**

*Eileen Devine, LCSW*

*Buzzard*

8:00 am **Registration Opens**

8:30 am **Sibs Adventure Camp Program - Drop-Off** 1st Floor - Pima Wing

## Sessions Begin

8:45 am **Welcome/Opening Remarks** Komatke Ballroom  
*Karen Groff, MEd*

9 am **Celebrate the Struggle to Find Joy in the Journey**  
*Ami Waggoner, LGS Caregiver Expert, Neurelis Ambassador*

9:15 am **Learn More About FINTEPLA Clinical Trial Experience**  
*Beck Reyes, NP, MSN, CPNP, CNRN*

9:30 am **Treatment Updates from Jazz**  
*Speaker TBD*

9:45 am **Takeda**  
*Anthony Frangie*

10 am **Treatment Updates from Longboard**  
*Randall Kay, MD*

## Break

10:30 am **Updates on RNS Research**  
*Martha Morrell*

10:45 am **Updates on Deep Brain Stimulation (DBS)**  
*Charuta N Joshi, MBBS, FAES, CSCN (EEG)*

11 am **LGS Research Updates: Surgery or Medications for LGS**  
*Sandi Lam, MD, MBA*

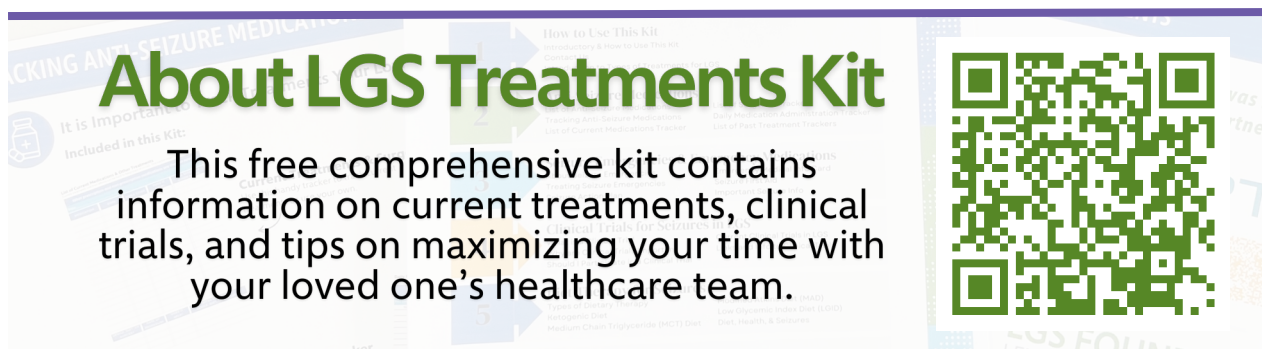
11:15 am **LGS Learn from Every Patient Database: Phase 1**  
*Nasha Fitter*

11:30 am **LGS Research Updates: IESS Work**  
*Juliet Knowles, MD, PhD*

11:45 am **LGS Research Updates: Sleep Network**  
*Aaron Warren, PhD*


12:00 pm **LGS Research Updates: Sleep Research**  
*Renee Shellhaas, MD, MS*

## Lunch Break




About LGS Treatments Kit

This free comprehensive kit contains information on current treatments, clinical trials, and tips on maximizing your time with your loved one's healthcare team.





## Saturday


1:15 pm	LGS Learn from Every Patient Database: Phase 2 <i>Tracy Dixon-Salazar, PhD</i>		
1:30 pm	Advocating for the Best Care <i>Jennifer Griffin, LGS Foundation</i>		
2:00 pm	LGS Workshop 4		
	Accessing Managed & Palliative Care <i>Ashley Ponders, MSN, FNP-C</i>  Komatke A	Mortality & SUDEP in LGS <i>Erin Fecske, DNP, APRN, CNRN, CPNP-PC, FAES</i> <i>Jeff Buchhalter</i>  Komatke B	Advocating for a Better Future for Your Loved One <i>Jennifer Griffin, LGS Foundation</i>  Sponsored by:  Komatke C

### Break

4:15 pm	Recap: What We Learned <i>Moderated by: Karen Groff, M ED</i>	
5:30 pm	Camper Pick-Up	
6 - 6:30 pm	Memorial Celebration of Life Butterfly Release <i>Release a butterfly as we remember</i>	Komatke Foyer
6:30 pm	LGS Foundation Dinner & Dance Party <i>Put on your dancing shoes and get ready for a fun evening.</i>	Pipai Kave

## Sunday

### Sunday, July 14

7 - 8:30 am	Breakfast	Pipai Kave
9 - 10:30 am	Share Your Voice <i>Continue the conversations. Join us for LGS focus groups with the experts. More information coming soon.</i>	Location TBD
9 am	Butterfly Wonderland - Family Field Trip <i>*Pre-Register to Attend</i> <i>Free to all conference attendees. Space is limited, please pre-register to attend.</i>	Sponsored by: 

Bridging the gap between patient families and researchers.

# LGS FOUNDATION COLLABORATIVE RESEARCH NETWORK



Join Us 

There is an urgent need to advance research and improve patient care for those living with LGS, especially adults. We need LGS families and world-class researchers to tackle this major challenge. Our plan is to identify the most promising patient-centered research questions and recruit world-class researchers to answer them. Join us today to learn more about how we can advance patient-partnered research.