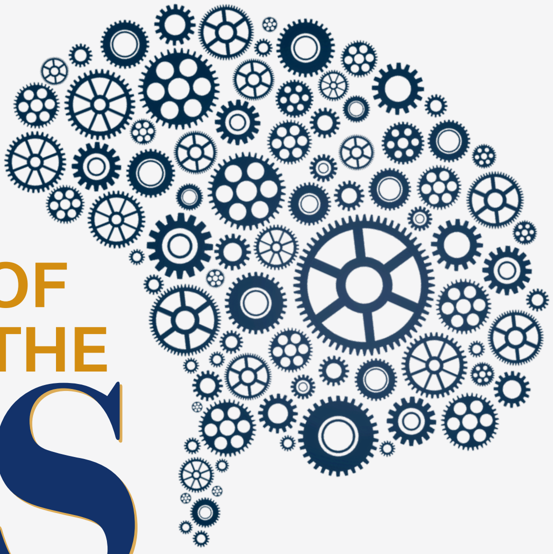

LGS RESEARCH MEETING OF THE MINDS

ADVANCING EVIDENCE-BASED LGS CARE ACROSS THE LIFESPAN

July 21 - 22, 2025

LGS FOUNDATION®
LENNOX-GASTAUT SYNDROME
www.LGSFoundation.org

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Meeting Goals and Objectives

Meeting Goals:

- Convene caregivers, health care providers, researchers, and industry partners to discuss how we advance evidence-based LGS care across the lifespan.
- Guide the LGS Foundation’s funding strategy in 2025 and beyond through information learned from this meeting.

Learning Objectives:

At the end of the meeting, the attendees should:

- Understand various stakeholder perspectives on evidence-based care in LGS.
- Evaluate the current methods for diagnosing and treating LGS across the lifespan and understand gaps in care.
- Learn about methods for conducting evidence-based research in LGS and associated DEEs.
- Analyze ongoing research efforts to create new evidence for LGS treatment.
- Discuss short-term and long-term efforts to improve evidence-based care in LGS and create clear next steps to work on.

Special Thanks to Our Organizers:

Elaine Wirrell, MD
Mayo Clinic, Rochester, MN

Scott Perry, MD
Cook Children’s Hospital, TX

Fabio Nascimento, MD
Washington University, MO

Renee Shellhaas, MD, MS
Washington University
School of Medicine

Elizabeth Gerard, MD
Northwestern Medicine

Jennifer Gelinas, MD, PhD
University of California Irvine

Pete Crino, MD, PhD
University of Maryland,
School of Medicine

Thank you to our amazing volunteers whose support helped this meeting run smoothly—your efforts mean the world!

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Research Conference Agenda

Monday, July 21st, 2025

7:00am	**BREAKFAST**	Stenton
SESSION 1:	**How do we currently manage LGS across the lifespan, where do we fall short, and what can we learn from other disease states?**	Main Ballroom
8:00am	Welcome & Opening Remarks *Fred Roedl, MBA, LGS Foundation Board Chair*	
8:05am	**Introduction:** What is evidence-based care and why do we want it? *Tracy Dixon-Salazar, PhD, LGS Foundation Executive Director*	
8:25am	What it is like caring for a child with LGS *Jennifer Fischer, Caregiver of a Child with LGS*	
8:30am	What it is like caring for an adult with LGS *Stephen Feather, Caregiver of an Adult with LGS*	
8:35am	How do we currently manage LGS in children? Where do we fall short? *Moderator: Elaine Wirrell, MD, Mayo Clinic*	
8:55am	How do we currently manage LGS in adults? Where do we fall short? *Moderator: Fabio Nascimento, MD, University of Washington*	
9:15am	Developing Evidence-Based Guidelines - The Cystic Fibrosis Experience *Michael Schechter, MD, MPH, Virginia Commonwealth University*	
9:45am	**BREAK**	
10:00am	How do we currently manage transition of care? Where do we fall short in the DEEs? *Ann Tilton, MD, Child Neurology Foundation*	Main Ballroom
10:30am	What can we learn from transition of care programs for congenital heart disease? *Emily Ruckdeschel, MD, Children's Hospital of Philadelphia*	
11:00am	Panel Discussion: How do we prioritize the gaps in evidence-based care in LGS? *Moderators:* *Renee Shellhaas, MD, MS, Washington University School of Medicine* *Scott Perry, MD, Cook Children's Hospital*	
12:00pm - 1:00pm	**LUNCH BREAK**	Stenton

Research Conference Agenda

Monday, July 21st, 2025

SESSION 2A: What methods can we use to advance evidence-based care across the LGS lifespan?

Main Ballroom

1:00pm Welcome Back
Fred Roedl, MBA, LGS Foundation Board Chair

1:05pm From Guessing to Knowing: Changing the Path for LGS Across the Lifespan
Kathy Leavens, LGS Foundation Senior Director of Programs

1:10pm **Introduction:**
What methods can we use to advance evidence-based care across the LGS lifespan?
Scott Perry, MD, Cook Children's Hospital

1:15pm Building a Team - Pediatric Epilepsy Research Consortium LGS Special Interest Group as an Example of Research Collaboration
Debopam Samanta, MD, University of Arkansas Medical Science

1:35pm Growing the Team - Training Adult Providers to Care for Rare Epilepsies
Elizabeth Gerard, MD, Northwestern Medicine

1:55pm Barriers to Multidisciplinary Complex Care in Adulthood
Alexa King, MD, Northwestern Medicine

2:15pm Building Consensus: Where are we now?
Juliet Knowles, MD, PhD, Stanford University

2:35pm **BREAK**

Main Ballroom

3:00pm Using the Electronic Health Records (EHR) to Generate Natural History
Jillian McKee, MD, PhD, Children's Hospital of Philadelphia

3:20pm Mining Big Data to Determine Evidence-Based Care
Zach Grinspan, MD, MS, Weill Cornell School of Medicine

3:40pm Acquiring Data from the Hospital IT's View - Barriers to Implementation
George Morris, MBA, VP Chief Data & Analytics Officer, Cook Children's Hospital

4:00pm Putting the Patient In Charge
Michael Hammer, PhD, University of Arizona

4:20pm Building the Best Note - Panel Discussion
Moderator; Scott Perry, MD, Cook Children's Hospital

Research Conference Agenda

Monday, July 21st, 2025

SESSION 2B: Industry Partner Perspectives

4:40pm	**Introduction:** Evidence-Based Care from Industry Partner Perspective *Tracy Dixon-Salazar, PhD, LGS Foundation Executive Director*	*Main Ballroom*
4:45pm	LGS Trials Past, Present, Future *Dennis Dlugos, MD, Lundbeck*	
4:55pm	One Syndrome, Many Causes: Understanding the diverse genetics of LGS *Karthik Rajasekaran, PhD, Jazz Pharmaceuticals*	
5:05pm	LGS & Fintepla: What's New, What's Next? *Amelie Lothe, PhD, UCB Pharmaceuticals*	
5:20pm	Novel Drug Formulations for Patients Suffering with DEEs *Howard Franklin, MD, Assertio Pharmaceuticals*	
5:30pm	Clemizole (EPX-100): A Novel Treatment in Development for LGS. *Anna Jeong, MD, Senior Medical Director, Harmony Biosciences*	
5:40pm	Wrap-Up *Tracy Dixon-Salazar, PhD, LGS Foundation Executive Director*	
6:00pm	**RECEPTION DINNER**	*Courtyard*

LGS FOUNDATION
LENNOX-GASTAUT SYNDROME

LGS PROFESSIONAL RESOURCES

- *Educational Resources (e.g. CMEs)*
- *Support for your Patients-Families*
- *Research Funding Opportunities*

What We Offer:

- 12,000+ community members in 23 countries
- Funding for cutting-edge LGS research
- Resources for LGS professionals including;
  - LGS ICD-10 Code Use for Research
  - PERC LGS Special Interest Group Info
  - Comprehensive Care Center Listings
  - LGS Collaborative Research Network

Scan to Learn More

Research Conference Agenda

Tuesday, July 22nd, 2025

7:00am	**BREAKFAST**	*Stenton*
SESSION 3:	**What do we need to do now to advance LGS evidence-based care across the lifespan?**	*Main Ballroom*
8:00am	Welcome Back *Tracy Dixon-Salazar, PhD, LGS Foundation Executive Director*	
8:05am	**Introduction:** What do we need to do now to advance evidence-based care across the lifespan? *Jennifer Gelinas, MD, PhD, University of California Irvine*	
8:15am	What evidence is needed now for children in order to make decisions? *Bertha Guillen, Caregiver of a Child with LGS*	
8:20am	What evidence is needed now for adults in order to make decisions? *Jamie Riley, Caregiver of an Adult with LGS*	
8:25am	Learning from Animal Models: Where Are We Limited? *Juliet Knowles, MD, PhD, Stanford University*	
8:45am	Identifying Genetic Markers of LGS and Associated DEEs in Children and Adults: Are All Genetic Conditions the Same? *Pete Crino, MD, PhD, University of Maryland*	
9:05am	Knowing the cause of your childs seizures: is it genetic? *Tracy Dixon-Salazar, PhD, LGS Foundation Executive Director* *Tiffany Johnson, MBA, LGS Foundation Director of Development* *Mary Freivogel, MS, CGC, GeneDx*	
9:25am	LGS Learn from Every Patient Database *Tracy Dixon-Salazar, PhD, LGS Foundation Executive Director*	
9:35am	Identifying EEG/Network Markers of DEEs and LGS in Children and Adults *Jennifer Gelinas, MD, PhD, University of California Irvine*	
9:55am	Identifying the Best Stimulation Approaches to Seizures *John Rolston, MD, PhD, Brigham & Women's Hospital, Harvard Medical School*	
10:15am	**BREAK**	
10:30am	Defining LGS in Undiagnosed Adults: How Do We Find Them? *Chris McGraw, MD, PhD, Northwestern Medicine*	*Main Ballroom*
10:50am	Measuring Cognition and Behavior in LGS *Kette Valente, MD, PhD, University of Sao Paulo*	
11:10am	Characterizing Sleep in LGS *Gita Gupta, MD, John Hopkins University*	

Research Conference Agenda

Tuesday, July 22nd,2025

11:30am	Developing Patient Centric Seizure Action Plans for DEEs - One size doesn't fit all *Eric Pina Garza, MD, FAES, Centennial Children's Hospital, Vanderbilt University*	*Main Ballroom*
11:50am	Wrap-Up *Jennifer Gelinas, MD, PhD, University of California Irvine*	
11:55am	Thinking Ahead to Session 4 *Tracy Dixon-Salazar, PhD, LGS Foundation Executive Director*	
12:00pm - 1:00pm	**LUNCH BREAK**	*Stenton*

SESSION 4: Where do we go from here?

1:00pm	Welcome Back/Introduction to Breakout Groups *Tracy Dixon-Salazar, PhD, LGS Foundation Executive Director*	*Main Ballroom*
1:15pm	Transition to Breakouts	
1:20pm	**Breakout Discussions** • Discussion Group 1 *-Main Ballroom* • Discussion Group 2 *-Foyer Meeting Area* • Discussion Group 3 *-Mount Vernon*	
2:20pm	Transition to Main Ballroom	*Main Ballroom*
2:25pm	Discussions - What did we learn and what do we do next? *Moderator: Scott Perry, MD, Cook Children's Hospital*	
3:25pm	Meeting Wrap-Up *Tracy Dixon-Salazar, PhD, LGS Foundation Executive Director*	
3:35pm	Closing Remarks *Fred Roedl, MBA, LGS Foundation Board Chair*	

> *“Because we commit our minds to science and our hearts to compassion, even the most complex challenges—like LGS—have become opportunities for hope and change.”*
>
> -Tracy Dixon-Salazar, PhD

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DEEpOCEAN

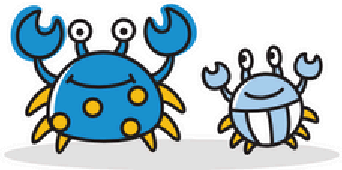
A NEW WAVE OF HOPE

Join Us in the Quest to Help Advance Treatment for Developmental and Epileptic Encephalopathies (DEE)

ABOUT THE DEEp OCEAN STUDY

The DEEp OCEAN clinical study is assessing the safety, efficacy, and tolerability of the investigational drug in the treatment of seizures in children and adults with DEE, a severe form of epilepsy that affects learning and development.

All study-related visits, tests, and medications will be provided at no cost. Where regulations allow, participants and caregivers will be fairly compensated for their travel, time, and effort for the duration of the clinical study.



WHY PARTICIPATE IN CLINICAL RESEARCH?

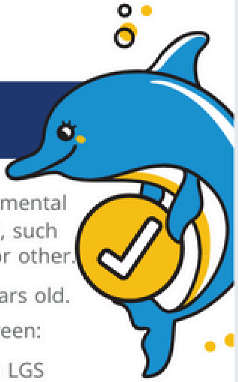
There's no guarantee that participants will get a health benefit from being in the study. You might have the opportunity to learn more about your loved one's condition and play a role in defining future treatment options for the DEE community. The decision to participate is completely voluntary and a personal choice.

Interested in Learning More?

Visit www.DEEpDEEstudy.com for more information about how to participate today!

For additional details please visit www.ClinicalTrials.gov using the study ID: NCT06719141

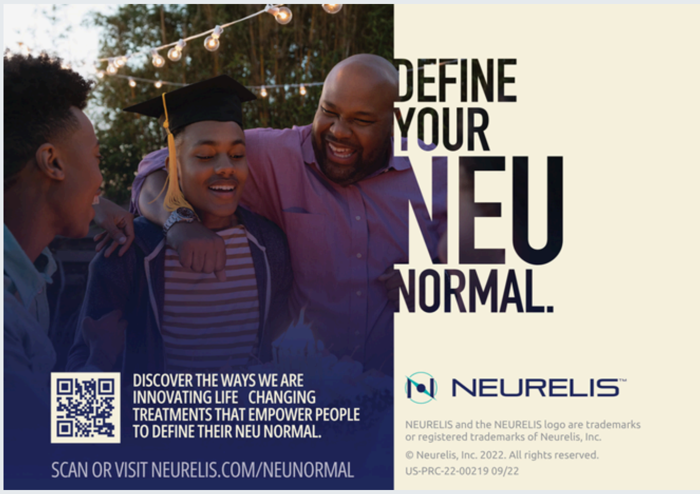
Qualified Participants:



- Have been diagnosed with a Developmental and Epileptic Encephalopathies (DEE), such as Lennox-Gastaut Syndrome (LGS) or other.
- Are between the ages of 2 and 65 years old.
- Have experienced seizure onset between:
  - Birth and 8 years old for people with LGS
  - Birth and 5 years old for people with DEE (other)
- Have an average of 4 seizures per month during the last 3 months.
- Are willing and able or have a caregiver who can maintain study diaries throughout the DEEp OCEAN study.

Additional study requirements to participate will apply. A study representative will discuss them with you.

SITE CONTACT INFORMATION:



Help Shape the Future of LGS Care — At No Cost to Your Patients

Support Better Outcomes Through:

🗂️ **Streamlined Medical Record Access**
Easily consolidate patient health data in a secure, digital account — empowering families and enhancing care coordination.

🧠 **Informed Clinical Decision-Making**
Support data-driven care by contributing to a centralized repository of real-world LGS insights.

🔬 **Collaborative Research**
Participate in a global effort to uncover LGS patterns, improve diagnostics, and accelerate therapeutic discoveries.

Scan to Learn How Your Patients Can Enroll →

LGS FOUNDATION
LEARN FROM EVERY PATIENT DATABASE
Your Voice is Key for the Future of LGS Treatments

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LIGHTHOUSE
LGS CLINICAL STUDY

You're focused on the moments that matter. *So are we.*

If you or someone you care about is living with Lennox-Gastaut syndrome (LGS), consider the Lighthouse clinical study.

About the Lighthouse Clinical Study

The purpose of the Lighthouse clinical study is to evaluate the safety and efficacy of the investigational medication, clemizole, as an additional therapy to potentially lower the number of seizures in children and adults living with Lennox-Gastaut syndrome (LGS). If someone you care about has frequent seizures from LGS, even when taking antiseizure medication(s), this clinical study may be an option.

The investigational medication, clemizole, is an oral solution that will be administered twice a day during the study. The study may last up to 3 1/2 years, including both clinic visits and phone calls.

HARMONY BIOSCIENCES

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Cure LGS Research Grants 365

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No Deadlines
Submit Anytime

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The LGS Foundation reviews unsolicited basic, translational, and clinical research proposals year round. Priority areas in 2025 are sleep, expressive communication, and EEG evolution in LGS.

- **Level 1: $25,000**
  May be paid over one year or two. Indirect costs are not permitted. International applicants are welcome to apply.
- **Level 2: $50,000**
  May be paid over one year or two. Indirect costs are not permitted. International applicants are welcome to apply.
- **Level 3: $75,000**
  May be paid over one year or two. Indirect costs are not permitted. International applicants are welcome to apply.

Scan to Learn More

LGS FOUNDATION®
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Our Vision:

To end the suffering and devastation caused by LGS.

Our Mission:

The Lennox-Gastaut Syndrome (LGS) Foundation is a nonprofit organization dedicated to improving the lives of individuals impacted by LGS through advancing research, awareness, education, and family support.

Our Pillars to Success:

To accomplish our mission we must:
Support, empower, and educate our community
Accelerate research
Raise awareness and build community
Build and strengthen our organization

Our Theory of Change:

If we create meaningful, impactful, patient-driven programs guided by our pillars, we will improve the lives of those impacted by LGS.

Get Involved: Volunteer Fundraise Donate

Visit Our Website

E-mail: info@LGSFoundation.org
Phone: 718-374-3800

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www.LGSFoundation.org