

Navigating THE LGS MAZE



The Meeting of the Minds Blew Our Minds!

Our 2nd Biennial LGS Research Meeting of the Minds was an Overwhelming Success!
Over 150 people attended this two-and-a-half-day hybrid research meeting in Baltimore, MD to discuss how we will advance clinical research in LGS.

Goals of the Meeting:

- To convene caregivers, healthcare providers, researchers, advocates, FDA officials, and industry partners to discuss how we measure seizure and non-seizure outcomes (like communications, behavior, sleep, and other key areas) in LGS research studies and clinical trials.
- To use our learnings from this meeting to guide the LGS Foundation's research funding strategy in 2024.

What We Learned:

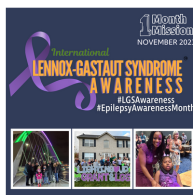
- We learned that each stakeholder has a unique perspective on measuring seizures and non-seizure outcomes in LGS, and that we must all work together to ensure we are using the best possible studies on the issues that matter most to patient families.
- We learned the current state of the art for measuring outcomes in LGS are seriously lacking, and many times, the tools used to measure progress are too advanced or too general for our LGS loved ones. We need better measures!
- We learned that there is a great deal of progress in measuring outcomes both inside the epilepsy community and externally in the fields of neurodevelopmental disorders, sleep, communications, and behavior. We must harness this progress to improve LGS research and clinical trials.
- We learned that improving LGS research studies is ripe for progress. Patient families, healthcare providers, researchers, advocates, FDA officials, and industry partners shared dozens of areas where the LGS Foundation can help to advance this work. It was incredible!

What's next?

- We are working hard to summarize all of the amazing insights that came from this meeting and prioritize, with our Patient Family Advisors, where we go next in funding LGS Research. Watch for new Cure LGS 365 Research Grant Request for Applications coming soon!

Thank you to all who attended and shared their voice!

[Watch Meeting of the Minds Recordings](#)



Raise LGS Awareness With Us!

International LGS Awareness Day and Epilepsy Awareness Month are right around the corner. We hope you'll join us as we raise awareness of LGS around the world!

There are many ways YOU can get involved:

- Help Support the LGS Foundation's Mission by Starting a Personal Fundraising Page
- Raise Awareness in Your Community by Ordering an LGS Awareness Box
- Raise Awareness on Social Media by Using the Tools in our Social Awareness Toolkit!

[Learn More](#)



Happy 15th Anniversary!

Standing Together. Stronger Together.

Formed in 2008, the LGS Foundation has grown into an internationally recognized nonprofit organization dedicated to improving the lives of those impacted by LGS through advancing research, awareness, education, and family support. The LGS Foundation brings together patients, families, healthcare providers, researchers, and other diverse stakeholders to better understand and treat LGS, and, one day, prevent, reverse, and cure this devastating disease.

Thank you for standing with us!

[Learn More](#)



About the LGS Community of Support

The LGS Foundation has grown expeditiously in the last 15 years, so we're taking some time to reintroduce you to our amazing community of support. Each month we feature someone who has made a significant impact on the lives of those affected by LGS.

This month we would like to you meet...

LGS Community Support Coordinator Jamie Riley

Jamie, her husband Allen, and three beautiful children live in North Haven, NH. Jamie and Allen's son, Andrew, has Lennox-Gastaut Syndrome. In addition to serving as a Community Support Coordinator, Jamie also serves as an Advocate for LGS.

"In the 16 years I have been Andrew's Mom, I have learned to be a strong persistent advocate for everything he needs. Recently, I have had the honor of attending the LGS Advisory Board with Jazz Pharmaceuticals. I was extremely excited to have the opportunity to be a voice for those with LGS. I was able to share the happiness and the more importantly the struggles, heartbreak and constant fights we go through to care for our loved ones. I am hoping my voice will have the opportunity to change the lives for those coming behind Andrew. There needs to be earlier diagnosis and a better job done with prompt effective treatment."

[Learn More about Advocates for LGS](#)

[Learn More about the Patient Navigator & Family Ambassador Program](#)

LGS RESOURCE CORNER



Upcoming Events

Looking to connect with others? Follow our calendar of events to stay up-to-date about the latest meetings and events.

[View Calendar](#)



What is Neuroremodulation?

Download our handy guide to understanding neuroremodulation to treat seizures associated with LGS.

[Download Materials](#)



Clinical Trials for LGS

Clinical trials are research studies performed in those with a medical condition like LGS. Learn more about clinical trials for LGS on our website.

[Learn More](#)



Support the LGS Foundation while shopping at Kroger!

Did you know that you can support the LGS Foundation while shopping at Kroger, with no cost to you!

A digital account is needed to participate in Kroger Community Rewards. If you already have a digital account, simply link your Shopper's Card to your account so that all transactions apply toward the LGS Foundation.

When prompted to enter the name or NPO number of the organization you wish to support, please use [Lennox-Gastaut Syndrome Foundation](#) or QV647.

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