

You Spoke, We Listened!

Families Want to Know More About LGS Research

We surveyed our LGS patient family community about life with LGS and needed resources. We heard many things from you, including:

We need research towards better treatments and cures!

We need more family support groups and patient assistance!

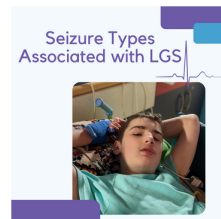
We need access to information on the best care for those with LGS!

We need more information on research opportunities, including clinical trials!

Slowly, but surely, the LGS Foundation has been tackling this list. In 2021 we held our LGS Research Meeting of the Minds and laid out a plan to accelerate research toward the cures. In 2021 and 2022, we expanded our Patient Support Programs. And earlier this year we launched our LGS Learning & Resource Center to educate about the latest in LGS care. We have now begun to add information about research.

In the survey, 80% of LGS families said they would consider participating in a clinical trial, but only 30% had ever considered one. 90% of families said they were never informed of trial options. We need to change that. Be sure to check out the new Clinical Trials in LGS page to learn more about the 3 fantastic trials that are going on in LGS today. And stay tuned for our new page on LGS Research Studies (coming soon)

[Read More About LGS Clinical Trials](#)



New Seizure Identification Resource

We at the LGS Foundation believe it is important for families living with LGS to be able to recognize different seizure types. However, there is a lack of detailed, accurate information on the internet as to what seizure types may look like. This is what brought us to create this video library of seizures associated with LGS.

Thank you to the families who shared these heartbreaking videos with us so we may educate others.

[View Seizure Type Videos](#)

Welcoming Cindy to the LGS Foundation Team

The LGS Foundation is proud to announce our newest addition to the team, Cindy Dawson, LGS Foundation Development Manager.

Cindy's family has not been impacted by LGS, but since joining the LGS Foundation team, her heart has been. She new journeys with our community, sharing stories that increase awareness and strengthen support for efforts to improve lives impacted by this heartbreaking disease.

[Meet Cindy](#)



2022 International LGS Foundation Family & Professional Conference

We are only 3 weeks away from our Family & Professional Conference in Dallas, Texas!

You can still register to join us in person for three days of education and fun activities for the entire family. However, please note that the group room rate at the Gaylord Texan Resort & Convention Center ended May 25th, meeting accommodations may or may not be available at the prevailing rate. Please check with the Gaylord or other nearby hotels to make sure a room is available prior to registering with us to attend in person.

Can't attend in person? No problem! The Conference will also be live-streamed. You must register by June 10th to attend virtually.

[Register Now](#)



New Clinical Trial Opportunity

The Skyway Study is a Phase 3 clinical research study of an investigational medication, Soticlestat, for children, teens, and adults diagnosed with LGS who are currently using anti-seizure medications to manage symptoms and are still experiencing seizures.

[Learn More](#)



International LGS Awareness Day

November 1st is annual International LGS Awareness Day. Each year, the LGS Foundation organizes a social media campaign and in-person events worldwide in recognition of LGS Day to raise awareness and bring LGS families together.

[Learn More](#)



Epilepsy Awareness Day at Disneyland California

The 10th Annual Epilepsy Awareness Day at Disneyland, including a packed Education Expo, is October 31 – November 1, 2022. The LGS Foundation is hosting the Halloween Masquerade Ball on Halloween evening!

[Register for the Expo](#)



Swing FORE a Cure for LGS - Golf Outing

Join us in Dublin, Ohio on Saturday, July 23, 2022 for an afternoon of fun as we Swing FORE A Cure for Lennox-Gastaut Syndrome (LGS). Each player will receive a golf gift kit. Space is limited, so register your team early!

[Register to Attend](#)

[Donate to Help Individuals and Families Impacted by LGS](#)

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