

LGS FOUNDATION
LENNOX-GASTAUT SYNDROME

Navigating THE LGS MAZE



Discovering
Breakthroughs
and Innovations in
LGS Research

[Check Out the New Blog Post on Discovering Breakthroughs and Innovations in LGS Research](#)

Over the past five years, LGS research has experienced significant advancements, providing hope for individuals and families affected by this complex disorder. At the LGS Foundation, we know that patient-driven research plays a vital role in driving research on topics that matter most to patient families.

Our research efforts focus on four key areas:

1. Bringing the patient-family voice to LGS research. *Nothing about us, without us!*
2. Understanding and treating the evolution and underlying cause of LGS
3. Developing innovative treatments for seizures and LGS co-occurring conditions (e.g., communication, sleep, and behavior issues)
4. Establishing a Learn From Every Patient Database

[Read the Full Blog on LGS Research](#)

MEETING OF THE MINDS
SEPTEMBER 14-16, 2023
ADVANCING LGS CLINICAL RESEARCH

The LGS Foundation Meeting of the Minds is Happening Soon!

This September, the LGS Foundation is hosting its second Meeting of the Minds to discuss how we can **Advance Clinical Research** in LGS.

For this hybrid conference, we will bring together patients, families, doctors, researchers, and partners to understand how we can learn from every patient and brainstorm how to find the best treatments for LGS.

Be on the lookout for session recordings after the conference.

[Learn More About The Meeting of The Minds](#)

15th Anniversary Fun!
We're having a Virtual Dance Party on Saturday, August 12th!

The LGS Foundation is turning 15, and LGS Families are invited to the party! Put on your dancing shoes and kick things off with us at our **Virtual LGS Dance Party on Saturday, August 12th at 5pm PT / 4pm ET**, hosted by the one-and-only DJ Kara!

This family-friendly event is available to LGS Families who are members of the private LGS Foundation Online Caregiver Support Community.

[Learn More](#)

15 Years of Progress & Hope!

We are celebrating our 15th Anniversary of service to the LGS Community, and we recognize that our tremendous growth and impact have only been possible because of this amazing community!

Last year, we awarded over \$40,000 to LGS Families through our Elevate Patient Assistance Program and \$60,000 to fund cutting-edge Research through our Cure LGS 360 Grant Program.

In the spirit of **Standing Together, Stronger Together**, would you consider setting up a monthly recurring gift? Your continuous support will have a big impact!

When you set up a monthly recurring gift of at least \$15, you will receive a 15th Anniversary Commemorative Tote Bag (while supplies last).

[Give Now](#)

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 Family Ambassador Bertha Guillen

Bertha is a single mom to her LGS son Santi, who just turned 13. They reside in the suburbs of Kansas City. Santi enjoys music, bubbles, and spinning toys.

Santi's journey began when he was only five months old; he was misdiagnosed with gastrointestinal issues, and at eleven months old, he was diagnosed with Infantile Spasms. Unfortunately, after some decent seizure control, the seizures returned with a vengeance, and at eight years old, he was diagnosed with LGS. He is also autistic and non-speaking with global developmental delays.

Bertha shares, "I'm grateful to have the opportunity to be a Family Ambassador because no family should have to walk this path alone. No one truly understands the ups and downs of LGS except someone else who is living this marathon day in and day out. Sometimes all we need is someone to hear us out, and I'm glad to be able to be that for other families living this odyssey."

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

LGS RESOURCE CORNER

FINANCIAL ASSISTANCE FOR PATIENTS WITH LGS

Elevate Patient Assistance Program

The Elevate Patient Assistance Program provides financial assistance to individuals with LGS to help pay for durable medical equipment not typically covered through insurance or other programs.

Open to residents in the U.S.

[Apply Now](#)

RESOURCES FOR LGS CAREGIVERS

Looking for Information, and Materials on LGS?

The LGS Foundation is committed to providing a wealth of information for LGS caregivers, families, and professionals.

We believe that everyone should have access to the latest and best information available.

[Request Materials](#)

Stand Together Against Prolonged Seizures

STARS Research Study Clinical Trial

The STARS Research Study is a clinical trial for a drug called Alprazolam, which is sometimes used to treat seizures. This study is a phase 3 clinical trial and will determine if Alprazolam, administered via a Staccato Inhaler Device, will work to stop prolonged seizures that last more than 3 minutes.

[Learn More](#)

Follow the LGS Foundation on Social Media



[Check Out Our Calendar of Events](#)

Lennox-Gastaut Syndrome (LGS) Foundation
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[Give Now to Help Families Impacted by LGS](#)

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Please unsubscribe or manage your email preferences again, using the link below.

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