

LGS FOUNDATION  
LENNOX-GASTAUT SYNDROME

# Navigating THE LGS MAZE



## We stepped towards Finding the Cures, Together at the 8th Annual Walk 'n' Wheel for LGS Research!

Nearly 300 families, friends, and community members came together this month to support the LGS Foundation's Finding the Cures, Together Research Program at the 8th Annual Walk 'n' Wheel. Thanks to you and this amazing community, we've raised over \$44,000 for groundbreaking patient-led research in LGS, putting us at 73% of our goal. Wow, that's impressive!

And we aren't stopping there... we're determined to reach our \$60,000 goal by May 31st!



**"We are confident that advances in LGS Research will give children like Amarae a better chance. By funding precision therapies we can target the root cause of LGS and improve the quality of life for those living with this horrible disorder."**

- Amarae's Mom

[Give Now to Support LGS Research](#)

**Help us get one step closer to better treatments**

**Own Your LGS Loved One's Medical Records, at No Cost!**

We recently launched Phase 1 - Own Your Medical Records of the LGS Foundation's team from Every Patient Database. Our goal is to enroll 250 families by June!

We've partnered with InVivo's Citizen platform - a secure digital platform for storing all of your existing medical records, **controlled by you!**

It only takes about 15 minutes to sign up, and you will be able to access all your medical records in one place at no cost.

If you haven't signed up yet, join now! U.S. Patients only.

[Join Now](#) [Learn More](#)

**Get Your About LGS Treatments Kit!**

About LGS Treatments Kits are for families who are considering 'what's next' in treatment.

This comprehensive kit contains information on:

- Anti-Seizure Medications
- Seizure Emergencies & Emergency Medications
- Clinical Trials for Seizures in LGS
- Diet Therapy for Seizures
- Neurostimulation for Seizures
- Epilepsy Surgery
- Complementary & Alternative Therapy
- Genetics & LGS
- How to Talk to Your Doctor
- ... And More!

[Request Your Kit Now](#)

**Rare Patient Voice - Helping Patients & Caregivers Share Their Voice**

Rare Patient Voice provides opportunities to voice your opinions on medical products and services all while getting paid for your time.

Make your voice heard by participating in paid surveys, interviews and online communities.

Sign up today and start earning up to \$120 an hour.

In addition to you getting paid for your time, the LGS Foundation receives a \$10 donation for each enrollment.

[Learn More About Rare Patient Voice](#)

**15th Anniversary - Fun Fact!**

**Did You Know?**

**Our Family Ambassador Program Launched in 2015!**

In 2015, the LGS Family Ambassador Program was established to help support and mentor LGS caregivers and families. In 2022, the program grew to include LGS Patient Navigators, for families seeking specific medical solutions with others who have been through it already.

The LGS Foundation is firmly grounded in the belief that everyone living with LGS should have access to the information, resources, and support they deserve, including a connection with others.

[Learn More](#)

**About the LGS Community of Support**

The LGS Foundation has grown exponentially in the last 15 years, so we're taking some time to reintroduce you to our amazing community of support. Each month we will 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 Jackie Villatoro**

Jackie, her husband Edwin, and their two children live in West Babylon, NY. The family of four is passionate about supporting the LGS Foundation's mission and recently participated in the 8th Annual Walk 'n' Wheel.

Jackie shares, "My family and I are passionate about the LGS Foundation because of their mission to improve the lives of individuals impacted by LGS through advancing research, awareness, education, and family support. We need to accelerate research into better treatments for our children's complex seizure disorders. Many of the families, including ours, have children on more than three seizure medications with little to no seizure control and dealing with side effects such as loss of appetite, drowsiness, or behaviors. I am hopeful that better treatment therapies are out there just waiting to be discovered."

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

## LGS RESOURCE CORNER

**Get Assistance**

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.

[Request Assistance Today](#)

**Upcoming LGS Events**

We have such an exciting year ahead of us, with several opportunities to connect in-person and online.

We hope you'll join us at one of our many upcoming LGS events or support groups.

[View Calendar of Events](#)

**Clinical Trials for LGS**

Clinical trials are part of clinical research and at the heart of all medical advances. Without volunteers, clinical trials cannot exist and we wouldn't be able to find new treatments for LGS and seizures.

[LGS Clinical Trials](#)

## Follow the LGS Foundation on Social Media



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Thank you for your support!  
The LGS Foundation recently changed systems. If you had previously unsubscribed, we recognize that you're receiving this email. Please unsubscribe or manage your email preferences again, using the link below.

[Unsubscribe or Manage Your Preferences](#)