

NEW FAMILY WELCOME KIT

*Your Guide to Understanding LGS,
Finding Support, and Finding Hope*



Information



Resources



Community



Hope



You are not alone.
We're here for you.

Welcome to the LGS Family

Every family's journey is different. Use this guide in the way that works best for you.

Dear Friend,

My name is Tracy, and I am the President & CEO of the LGS Foundation—and the mom of a daughter who had LGS. I share that with you because this work is deeply personal for me. When I say we understand what you are going through, I mean it with every part of my being.

Receiving an LGS diagnosis is overwhelming. The questions come fast, and the answers come slowly. You may feel alone in a way that is hard to describe to people who haven't lived it.

We have lived it. And you have found your community.

The LGS Foundation was built by families like yours, with individuals with LGS and their families at the center of everything we do. Inside this New Family Welcome Kit, you'll find information and resources carefully chosen to help you understand LGS, know what to ask your doctors, find support, and take the next steps that are right for your family.

But these resources are only the beginning.

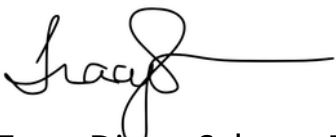
We are committed to ending the suffering caused by LGS. Our work is organized around 3 Grand Challenges: achieving comprehensive diagnoses, developing precision treatments, and ensuring whole-life care for every person with LGS. These aren't distant aspirations. They guide the research we fund, the partnerships we build, and the programs we create.

Your family's voice and experience matter to this work.

The urgency you feel is the urgency that drives us. Wherever you are in the LGS journey, please know that you do not have to navigate it alone.

We will walk it with you.

In hope,



Tracy Dixon-Salazar, PhD
President & CEO



Tracy and her daughter Savannah



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"The LGS Foundation is amazing. You become family instantly. Any questions or concerns you have, you can ask and will get responses." - LGS Mom

1 What Should We Do First?

You don't have to do everything today. Start with the steps that will help your family feel informed, prepared, and supported.



Learn about LGS

Start with the basics in this guide, then explore the LGS Learning & Resource Center when you're ready to learn more.



Find the right care

LGS is complex. We recommend seeing an Epileptologist, which is a Neurologist who specializes in epilepsy. Use our Find a Doctor or Comprehensive Care Center resource to help locate specialized care near you.



Make a Seizure Action Plan

Work with your healthcare provider to create a plan that explains what to do when a seizure happens, including when and how to use rescue medication.



Start tracking seizures

Keeping a seizure diary can help you and your healthcare team identify changes, patterns, and questions to discuss at appointments.



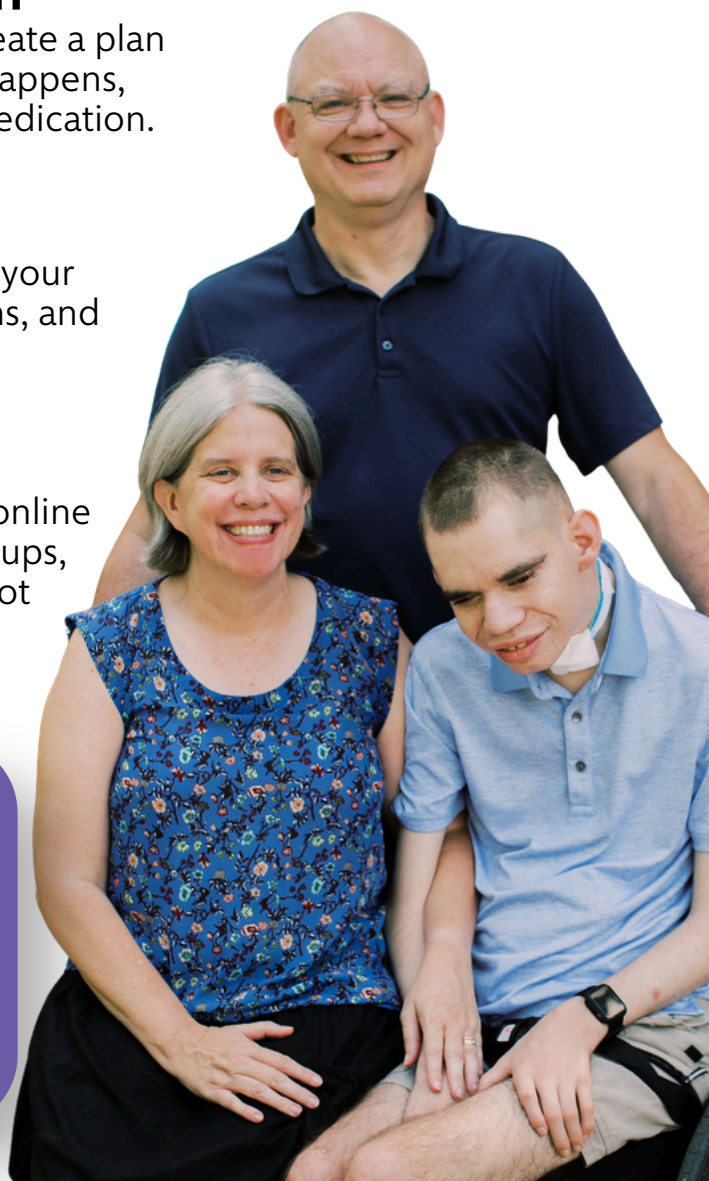
Find your people

Connect with other families through our online support community, monthly support groups, Family Ambassadors, and more. You do not have to navigate LGS alone.

Not Sure Where to Start?

You don't have to know which program or resource you need. Reach out to the LGS Foundation, and we'll help you find your next step.

FamilySupport@lgsfoundation.org



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Understanding LGS

What is LGS?

Lennox-Gastaut Syndrome (LGS) is a severe epilepsy syndrome that begins in childhood and often leads to lifelong challenges.

It develops over time.

What causes LGS?

In most cases, the cause is unknown. Possible causes include:



Brain injury in early life



Genetic factors



Brain infections



Metabolic disorders



Immune disorders



Unknown (in many cases)

4 Core Features



Seizure onset in childhood



More than one type of seizure



Developmental delay*



Slow Spike and Wave & GPFA** on EEG

*Many children are developing at appropriate levels at seizure onset but development may slow or pause when LGS begins.

**GPFA = Generalized paroxysmal fast activity.

How does LGS change over time?

LGS is a lifelong condition that can change over time.

Seizure types, EEG patterns, development, behavior, and support needs may change as a person with LGS grows.

Every child is unique. Early recognition and targeted treatment can make a big difference.

Want to Learn More?

Explore the LGS Learning & Resource Center for more information about diagnosis, seizures, treatments, research, and living with LGS.



Scan to Explore the
LGS Learning &
Resource Center



3

Keeping Your Loved One Safe

Seizure First Aid

- Stay with the person
- Keep them safe
- Turn them onto their side if they are not awake and aware
- Time the seizure
- Stay calm

Call 911 if...

- The seizure last longer than 5 minutes.
- The person has difficulty breathing.
- The person is injured, pregnant, or sick
- It is their first seizure
- Repeated seizures occur without recovery
- The seizure occurs in water

Do Not

- Restrain the person
- Put anything in their mouth



Scan to create a Seizure Action Plan



Create a Seizure Action Plan

A personalized Seizure Action Plan helps family members, teachers, caregivers, and healthcare providers respond consistently during an emergency.

4 Finding Your Community

No one understands the LGS journey quite like someone who has lived it.

Whether you're looking for someone to talk to, a place to ask questions, or simply the reassurance of knowing other families are out there, the LGS Foundation can help you find your community.



Connect One-to-One

LGS Family Ambassadors

Connect with someone who understands the LGS journey and can offer peer support, share resources, and help you feel less alone.



Scan to Connect
with a Family
Ambassador



Join a Support Group

Connect with other caregivers through our monthly virtual support groups, including spaces created for different members and stages of the LGS community.

- Standing Together. Stronger Together.
- Dad to Dad
- Grupo de Esperanza
- Caregivers of Adults with LGS



Scan to Explore
Upcoming Support
Groups



Connect Anytime

LGS Community Center

Join our online community to connect with other families, find resources, join conversations, and stay connected with the LGS Foundation.



Scan to Join the
LGS Community
Center



Private LGS Caregiver Support Community

Connect with LGS families in our private Facebook group for peer-to-peer conversation, questions, shared experiences, and support.



Scan to Join the
Caregiver Support
Community



Need Help Finding the Right Support?

FamilySupport@lgsfoundation.org | (718) 374-3800



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Living with LGS

LGS affects more than seizures. It can impact development, behavior, sleep, school, caregiving, and everyday family life. Needs may change over time, and you don't have to navigate every challenge at once.

Tools for Everyday Life

A few simple tools can make a big difference.

- ✓ **Keep a seizure diary**
Track seizures, treatments, changes, and questions for your healthcare team.
- ✓ **Keep Important Information Together**
Have your medication list, Seizure Action Plan, provider information, and important medical records easy to access.
- ✓ **Prepare for appointments**
Bring your questions, seizure information, and videos when helpful, and keep track of next steps.

Support for the Whole Family

LGS impacts the entire family. The LGS Foundation offers resources created to support caregivers and siblings along the journey.

VIP Sibling & Caregiver VIP Kits



Scan to Request
yours today!



About LGS Treatments Kit

This comprehensive kit contains information on current treatments, clinical trials, and tips on maximizing your time with your loved one's healthcare team.

Scan to Request
or Download





Caring for the Caregiver

Caring for someone with LGS is a commitment unlike any other. It can be deeply rewarding, and physically and emotionally demanding.

Whether your loved one was recently diagnosed, you're adapting as LGS changes, or you've been on this journey for years, support is here for you, too

Caregiving can be heavy, you deserve support

There is no single way to feel or adjust to life with LGS. Caregivers may experience shock, anger, stress, grief, fear, acceptance, adjustment, hope, and many emotions in between.

Support for Caregivers



Emotional Wellness

Resources for caregiver stress, adjustment, trauma, and emotional health.



Respite & Self-Care

Resources to help you find opportunities for rest, respite, and support.



Caregiver Connection

Connect with other LGS caregivers through our private community and support groups.



The Whole Family

Resources for navigating relationships, siblings, and the impact LGS can have across the family.

We're Here for You

Our Caring for the Caregiver resource hub brings together videos, caregiver stories, practical tools, respite resources, emotional wellness support, support groups, and additional resources for the different challenges caregiving can bring.

*Scan to Explore
Caring for the
Caregiver*



Need immediate emotional support?

Crisis-support counselors are available 24/7 via Raregivers™ - Text RARE to 741741



Research Gives Us Hope

Every family living with LGS has experiences that can help researchers better understand the disease, improve care, and accelerate the search for better treatments and cures. Your experience matters. Your story is the research.



Share Your Lived Experience.

➤ WHAT IS THE LGS-CORE STUDY?

A powerful and secure research study that collects data from the LGS patient-families to advance understanding of LGS, unmet needs, clinical care, and new therapies.

➤ HOW DOES JOINING HELP

Your family's story can help change what's next.

- Help researchers better understand living with LGS
- Help identify improved treatment options
- Connect your family to future research studies and clinical trials
- Make your family's experience part of LGS research.

➤ HOW TO JOIN?

- 1 Scan the QR code
- 2 Create a free account
- 3 Fill out short surveys at your own pace!



It only takes 5 minutes to register.

YOUR STORY *IS* THE RESEARCH.

Powering Breakthroughs for LGS

At the LGS Foundation, families come first, and researchers follow the family's lead. That is how we make sure the science answers what matters most to the people living with LGS. Learn more about our multi-year plan to find better treatments and cures for LGS.



8 Stay Connected

Your connection to the LGS Foundation doesn't end with this Welcome Kit.

Stay connected for new resources, research opportunities, community events, education, advocacy, and ways to make a difference.



Learn & Stay Informed

Access the latest news, resources, research updates, and opportunities.



Email Newsletter

Get LGS news, resources, and updates, delivered to your inbox.



Education

Learn from LGS experts and explore topics that matter to individuals and families.



Scan to Subscribe



Come Together

Join in-person and virtual events that bring our community together.



Family & Professional Conference

Connect with LGS families, clinicians, researchers, and more from across the globe.



Walk for LGS Research

Come together to raise awareness and support LGS research.



Scan to Learn About Upcoming Events



Get Involved

Help raise awareness, support research, and create lasting change.



International LGS Awareness Day™

Raise awareness and shine a light on LGS in your community.



Volunteer

Share your experience to help strengthen the LGS community and advance our mission.



Scan to Get Involved



Follow Along

Stay connected on our website and social channels for the latest news!



Scan to Explore the Website



Standing Together. Stronger Together.

About the LGS Foundation

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.

We're Here to Help

Not sure what you're looking for?
Reach out. We'll help you find it.



FamilySupport@LGSFoundation.org



(718) 374-3800



LGSFoundation.org

“My daughter and I are happy to feel like we are part of something where we can learn from and grow with. All the information we have received has made a difference for us. I am so grateful for you guys.”

— Lisa,
Mom to Grace



“There is hope. And there are so many people out there who are working through the same thing, who can identify with what you're going through, and who can offer support and encouragement to you. So just keep pressing on. You're doing great.”

— Darla,
Mom to Aaron

