The challenges are tough. So are we.
Welcome to the LGS Foundation. You are not alone. No matter where you are in your journey with LGS, we are here to support you.

Over twenty-five years ago, our healthy, typically developing two-year-old daughter, Savannah, had her first seizure. More than 40,000 seizures would follow over the next 16 years. Our family sat by helplessly as we watched the seizures evolve into LGS and cause more and more brain damage in our little girl. We felt so isolated and alone. In 2008, the LGS Foundation was founded. It was created so families like mine would not be alone. Our family was so happy to finally find our LGS community of support.

Like many families living with LGS, medically there was nothing we didn’t try to stop our daughter's seizures. There was no stone we left unturned. Sadly, science and medicine simply could not help her. For twelve years I studied in college looking for answers to what could cause epilepsy, ultimately getting my Ph.D. in Neuroscience. Then one day, the answers came. We found the cause of Savannah's seizures, which led to her LGS, and that led us to a precision therapy that changed our lives. The seizures dramatically decreased with this new treatment, and Savannah began to learn and develop again.

While Savannah is doing better today, every day I hear more stories of the devastation caused by LGS. It’s time to change that!

At the LGS Foundation, every day we work to find new treatments and cures for LGS. We work towards the best medical care. And we build a strong community of support that provides impactful programs to our families. It’s time to end the widespread suffering and devastation caused by LGS. Welcome to our community.

With hope,

Tracy Dixon-Salazar, PhD
Mom of Savannah, an adult living with LGS
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NEW FAMILY WELCOME KITS
New Family Welcome Kits are for families new to LGS and the LGS Foundation. Each kit provides educational materials and info on where to find help.
www.lgsfoundation.org/newly-diagnosed

LGS LEARNING & RESOURCE CENTER
Check out the LGS Learning and Resource Center on the LGS Foundation Website. This great tool has tons of info on topics related to LGS.
www.lgsfoundation.org/category/learning-resource-center

NAVIGATING LGS VIDEO SERIES
The LGS Foundation is at the forefront of LGS education. Videos by experts from all around the world will help as you navigate the LGS maze.
www.lgsfoundation.org/navigating-lgs-video-series

ADVOCATES FOR LGS
Advocates for LGS bring the patient-family voice to members of the federal and state government and advocate for better research and care for LGS.
www.lgsfoundation.org/advocates-for-lgs
FAMILY SUPPORT

LGS ONLINE SUPPORT GROUPS

Get the emotional support you need from others in similar circumstances and gain practical advice on managing LGS in this judgment-free space.

www.lgsfoundation.org/get-connected-and-supported/online-communities

IN-PERSON MEET UPS

In-person meetings allow families to truly connect, make real friendships, and share the daily ups and downs with other LGS families.

www.lgsfoundation.org/get-connected-and-supported/attend-an-lgs-meetup

ELEVATE PATIENT ASSISTANCE PROGRAM

This program provides financial assistance to individuals with LGS to help pay for durable medical equipment not covered by insurance.

www.lgsfoundation.org/get-connected-and-supported/apply-for-our-elevate-patient-assistance-program

LGS NAVIGATORS & AMBASSADORS

Connect with an LGS Navigator and Ambassador today. These volunteer caregivers share their knowledge about managing LGS with others.

https://www.lgsfoundation.org/get-connected-and-supported/connect-with-an-ambassador/

www.LGSFoundation.org
CURE LGS 365 RESEARCH GRANTS
Scientists can apply for research grants 365 days a year as we seek better treatments and cures for LGS. Projects may be funded from $25,000-$75,000.
www.lgsfoundation.org/365-research-grants

LGS RESEARCH MEETING OF THE MINDS
This biennial conference brings together our LGS Research Network of scientific, medical, and family experts to discuss how to advance research in LGS.
www.lgsfoundation.org/lgs-research-meeting-of-the-minds

LGS FOUNDATION SEMINAR SERIES
These seminars are designed to present the latest in LGS research and lead to open discussions about how to advance our understanding of LGS.
www.lgsfoundation.org/lgs-meeting-of-the-minds-seminar-series

LGS RESEARCH ROUNDTABLE AT AES
This annual meeting held at the American Epilepsy Society (AES) Meeting highlights the research funded by the LGS Foundation.
lgsfoundation.org/lgs-foundation-2021-research-roundtable-live-stream

www.LGSFoundation.org
AWARENESS & EDUCATION

PROFESSIONAL & FAMILY CONFERENCE

This biennial, comprehensive, three-day educational meeting brings together more than 300 attendees and epilepsy professionals. This meeting is a highlight for our community.

www.lgsfoundation.org/lgs-conference

WALK 'N' WHEEL FOR LGS

Join our families as we Step Towards the Cures, Together. Hundreds of families join this annual walk to raise money to find the cures for LGS.

www.lgsfoundation.org/walk-n-wheel-for-lgs

INTERNATIONAL LGS AWARENESS DAY®

November 1st is annual International LGS Awareness Day. Each year the LGS Foundation organizes in-person and online events worldwide.

www.lgsfoundation.org/lgs-awareness-day-event

When Kai was first diagnosed there wasn't much information or community until I found Lennox Gastaut Syndrome Foundation during an internet search. Within a few months I was at my first conference with families across the world learning about our community. It was amazing and I knew I wanted to be a part of the organization. As it’s grown over the years we have gained unbreakable relationships with amazing families.

-Darla, Mother of Son with LGS

- Kimberley, Mother of a Daughter with LGS

“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.”

www.LGSFoundation.org
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.

Check Out the LGS Foundation Website

LGS is tough. Finding resources and information should not be.

While there is no cure for LGS, there is a hopeful path forward. On our website, you will find useful information and resources – and most importantly, a community of support.

www.LGSFoundation.org

Sign Up for our Newsletter

lgsfoundation.salsalabs.org/eNewsSignUp

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