



# LGS FOUNDATION®

## GUIDE TO PROGRAMS



Research • Awareness  
Education • Support

*LGS is hard. Finding information doesn't need to be.*

## A MESSAGE FROM OUR EXECUTIVE DIRECTOR



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.

In 1995, 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, there was nothing we didn't try to stop our daughter's seizures. There was no stone we left unturned. Sadly, science and medicine 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 genetic cause of Savannah's seizures. This led us to try a medicine targeted toward her genetic mutations and this 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 and more stories of the devastation caused by LGS. It's time to change this!

At the LGS Foundation, we work every day 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.

With hope,

Tracy Dixon-Salazar, PhD

Mom to Savannah, an adult living with LGS





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# EDUCATION

SCAN WITH  
PHONE CAMERA  
TO LEARN MORE  
ABOUT EACH  
PROGRAM

## 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.



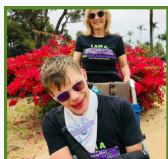
## LGS LEARNING & RESOURCE CENTER



Check out the LGS Learning and Resource Center on our website. This great tool has an abundance of info on topics related to LGS.



## NAVIGATING LGS VIDEO SERIES



The LGS Foundation is at the forefront of LGS education. Videos by experts from all around the world will help you navigate the LGS maze.



## ABOUT LGS TREATMENTS KITS



About LGS Treatments Kits are for families who are considering "what's next" in treatment. The kit is filled with current treatments, information on clinical trials, and tips on how to maximize your time with healthcare providers.



# FAMILY SUPPORT



**Learn more with QR Codes:**  
Open your phone camera, aim the camera at the QR code, & open the link in your web browser!

## LGS ONLINE SUPPORT



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



## UPCOMING EVENTS & ACTIVITIES



See our calendar and join us for one of our in-person events such as our annual walk, awareness dinner, or family conference. In-person events allow families to truly connect.



## ELEVATE PATIENT ASSISTANCE PROGRAM



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



## LGS PATIENT NAVIGATORS & FAMILY AMBASSADORS



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



# RESEARCH PROGRAMS



Scan me!

## 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.



## 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.



## LGS LEARN FROM EVERY PATIENT DATABASE



This critical database collects medical records and survey data to document the impact of LGS on a person's health over their lifetime. Share your data today so we can learn from all and change the future!



**OWN YOUR  
MEDICAL RECORDS**



**PHASE 1**

**ANSWER QUESTIONS  
ABOUT YOUR LGS JOURNEY**



**PHASE 2**

**SHARE RECORDS FROM  
YOUR DOCTOR VISITS**



**PHASE 3**

[www.LGSFoundation.org](http://www.LGSFoundation.org)

# AWARENESS & EDUCATION



Scan us for more info!



## FAMILY & PROFESSIONAL CONFERENCE



This biennial, comprehensive, three-day educational meeting brings together hundreds of attendees and epilepsy professionals. Meeting in-person is a highlight for our community!



## WALK 'N' WHEEL FOR LGS RESEARCH



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



## INTERNATIONAL LGS AWARENESS DAY®



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



## ADVOCATES FOR LGS



Advocates for LGS bring the patient-family voice to members of the federal & state governments & advocate for better research & care for those with LGS.



# LGS FOUNDATION®

## LENNOX-GASTAUT SYNDROME



### 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.

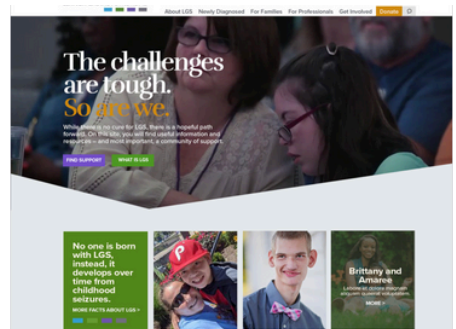


### Check Out the LGS Foundation Website

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](http://www.LGSFoundation.org)



Sign Up for our Newsletter



### Follow Us on Social Media



### Contact Us

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