

Navigating the LGS Maze

Community Newsletter

LGS FOUNDATION
LEARN FROM EVERY PATIENT DATABASE



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

Your Medical Records Tell A Story, One That Can Help Shape Future LGS Treatments

We're still enrolling for Phase 1 - Own Your Medical Records - of the LGS Foundation's Learn from Every Patient Database. We've partnered with Citizzen - 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**. You can also share the information with researchers to advance research in LGS, if you choose. *U.S. Patients only.*

If you haven't signed up yet, [Join now!](#)

[Learn More](#)



Save the Date for International LGS Awareness Day!

This November, we'll kick off Epilepsy Awareness Month with International LGS Awareness Day on November 1st! As awareness spreads, more people choose to stand with us. Together, we get closer to fulfilling the hope of ending the suffering and devastation experienced by those impacted by LGS.

- November 1: International LGS Awareness Day & Illuminate for LGS
- November 2: Awareness Dinner in San Diego
- November 1-30: Epilepsy Awareness Month

[Learn More](#)



RaiseRight for LGS!

With RaiseRight, it's never been easier to support the LGS Foundation!

Buy gift cards from your favorite brands to earn on your purchases. No extra money spent. No extra time wasted.

Birthday, graduation, or special occasion coming up? With gift cards from RaiseRight, you automatically earn 2-20% back for the LGS Foundation. Grab a gift card today and start fundraising immediately!

[Learn More](#)



Our Community: Meet Olivia

We love sharing stories and getting to know one another, so each month we will feature a member of our amazing community. This month, we would like you to meet Olivia.

Olivia started experiencing seizures just before her second birthday. Then, at the age of 18, Olivia was diagnosed with LGS. Olivia underwent Deep Brain Stimulation (DBS) surgery.

Her Mom shares, "Olivia has had a 60% reduction in seizures and we have been able to reduce several of her medications. Olivia's cognitive abilities have improved, she is more alert, and happy."

[Learn More about Olivia](#)

May is Mental Health Awareness Month

May is Mental Health Awareness Month, shining a light on the significance of caring for our psychological well-being. Being a caregiver for a loved one with LGS demands boundless energy, empathy, and patience, presenting unique challenges. Caregiving can impose emotional and physical strains.

This month, we wanted to take a moment to highlight some of the resources available on our website and through RareMinds, an organization dedicated to supporting the rare disease community.

[Caring for the Caregiver](#)

LGS RESOURCE CORNER



Financial Resources

Looking for financial resources?

Check out our extensive list of resources to assist LGS families.

Resources include: Financial Planning, Medical Financial Assistance, Financial Resources for Equipment, and More!

[Learn More](#)



Seizure Types

We believe it's important for families living with LGS to be able to recognize different seizure types. Unfortunately, there is a lack of detailed, accurate information on the internet as to what seizure types may look like. So we created this video library of what seizures may look like.

[Learn More](#)



LGS Research Study

The Picozolo Study is investigating the safety and effectiveness of cannabidiol in infants (2 years old and younger) with Tuberous Sclerosis Complex (TSC), Lennox-Gastaut Syndrome (LGS) or Dravet Syndrome (DS) who experience inadequately controlled seizures.

[Learn More](#)



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