

LGS FOUNDATION  
LENNOX-GASTAUT SYNDROME



# Navigating THE LGS MAZE

## Walk 'n' Wheel FOR LGS Research LENNOX-GASTAUT SYNDROME



### Stepping Towards a Cure, Together

Join Us on Saturday, May 6th, 2023

We're committed to funding cutting-edge LGS Research!

What we've learned is that if families aren't funding research that matters to them, no one is. The only way we can fund patient-led research is by raising the funds ourselves, so that's what we're doing! We hope you'll join us as we Step Towards Finding the Cures, Together!



#### Ways to Get Involved:

- Attend the North Carolina or Florida Walk In-Person
- Create a Personal Fundraising Page
- Host a Local Walk in Your Community
- Use the Social Media Guide to Raise Awareness and Funds
- Personalize and Share your 'What is LGS' Info Cards

[Learn More about the Walk 'n' Wheel for LGS Research](#)



#### LGS Foundation attends Rare Disease Week on Capitol Hill

Every year, the EveryLife Foundation brings together the rare disease community for Rare Disease Week on Capitol Hill. This year, six LGS caregivers joined the efforts to share their voices with members of Congress, network with other rare disease patients and caregivers, and learn about current policy proposals impacting the rare community.

*"We had an audience with the lawmakers. Our voices do make a difference and we have to believe that change will not take place unless families like ours are willing and able to engage with the decision-makers. Remember, they work for us." - Jen Griffin, Director of Family Support*

[Read the Full Blog](#)

#### 15th Anniversary - Fun Fact!

##### Did You Know?

##### Our first Walk 'n' Wheel was in 2016!

All proceeds from the annual Walk 'n' Wheel for LGS Research go directly to support the LGS Foundation's "Finding the Cures, Together" Research Program.

This vital program drives cutting-edge research that leads to new therapies and treatments for those impacted by LGS! You can learn more about each of the 5 Steps to Finding the Cures, Together on our website.

[Learn More](#)



#### About the LGS Community of Support

The LGS Foundation has grown expeditiously in the last 15 years. We would like to take 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 Lesa McLeod

Lesa, her two daughters, and her son Deven live on the gulf coast of Florida. Deven is seventeen years old and diagnosed with LGS. Deven loves the outdoors and playing in the water. The family enjoys their free time soaking up the sun at Florida's beautiful beaches.

Lesa shares, "As a Community Support Coordinator, I enjoy supporting and encouraging other LGS families and community members. LGS is a difficult journey and no one should have to walk it alone."

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

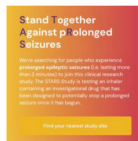
### LGS RESOURCE CORNER



#### Financial Resources

Looking for financial resources? Check out our extensive list of resources to assist LGS families.

[Learn More](#)



#### STARS Research Study

This study is a phase 3 clinical trial and will determine if Alprazolam, administered via a Staccato Inhaler Device, will work to stop prolonged seizures that last more than 3 minutes.

[Learn More](#)



#### Seizures & Safety

Visit the LGS Learning & Resource Center for information on seizures associated with LGS and resources to help keep your loved one safe.

[Learn More](#)

#### Follow the LGS Foundation on Social Media



[Give Now to Help Families Impacted by LGS](#)

Lennox-Gastaut Syndrome (LGS) Foundation  
6030 Santo Road, Suite 1 Unit 420878 | San Diego, California 92142  
719-374-3800

Thank you for your support!

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