



The Advocates for LGS Return to Washington, D.C.

Every year on the last day of February, the rare disease community unites as one to observe Rare Disease Day. Once again, as we did in 2023, Advocates from the LGS Foundation made their way to Washington, D.C. to participate in Rare Disease Week on Capitol Hill. It was here that we learned of current legislation aimed at supporting initiatives impacting the rare disease community, met with state legislators, and made our legislative asks.

"When Jennifer spoke of her inability to refill one of her son's brand name medications due to insurance insisting on a generic drug, Senator Klobuchar instructed her staff to look into this personally. Advocacy at its best!" - Jim Griffin, Director of Family Support

The truth is, the future is never going to be brighter if we don't raise our voices to make it that way. We need more Advocates from the LGS Community. We have training available and we will be offering an Advocacy Workshop at the upcoming International Family & Professional Conference. If you ever think of yourself as 'just one person who couldn't possibly make a difference', think again. Visit our website for more information about advocacy efforts or to join the Advocates for LGS team.

When we Unify & Amplify our voices, we are Stronger Than Ever!

[Read the Full Rare Disease Week Recap](#)



2024
Walk 'n' Wheel & Family Fun Day
Saturday, April 20th

- Kannapolis, NC
- Tampa, FL
- Virtually

Join Us Next Month for the Walk 'n' Wheel for LGS Research

Each year, hundreds of community members mobilize to raise funds for the LGS Foundation's "Finding the Cures, Together" Research Program, which drive cutting-edge research that leads to new therapies and treatments for those impacted by LGS!

We invite YOU to join us in Stepping Towards the Cures. Together by:

- Creating and sharing your personal fundraising page with your community
- Attending the Walk 'n' Wheel in North Carolina
- Attending the Walk 'n' Wheel in Florida

[Get Involved in the Walk 'n' Wheel](#)



2024 INTERNATIONAL LGS FOUNDATION FAMILY & PROFESSIONAL CONFERENCE
PHOENIX, AZ
JULY 12-14, 2024

REGISTRATION IS OPEN!

Register for the 9th International Family & Professional Conference

We hope you'll join us in Phoenix, AZ this July! Our comprehensive multi-day educational meeting brings together hundreds of LGS family members and epilepsy professionals from around the world to better understand the causes, treatments, and how to live with LGS.

Sessions cover topics like treatment options, improving quality of life, accessing resources, and much, much more. This year, we'll also have numerous breakout opportunities with subjects ranging from challenging behaviors and genetics to advocacy and adults with LGS. You don't want to miss it!

[Learn More About the Conference](#)



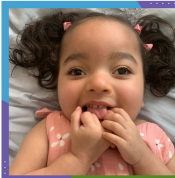
Meet Tiffany, the Newest Member of Our Board of Directors

Tiffany lives in Austin, Texas, with her husband, Greg, and 5-year-old LGS warrior, Greyson. Greyson was diagnosed with LGS at 4 years old, and the diagnosis was life-changing.

Tiffany has been a fundraiser for over 15 years, working in the non-profit and education sectors with an extensive background in major and principal gift acquisition and campaign strategy.

She is passionate about helping organizations close to her heart build partnerships and obtain funding so they may carry out their missions and make a difference. Please join us in welcoming her to the LGS Foundation's Board of Directors!

[Read Tiffany's Full Bio](#)



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 experienced a severe traumatic brain injury at birth resulting in seizures that evolved into infantile spasms all before her first birthday.

Her Mom shares, "While I am thankful for the treatments and community available, I know I am not the only one waiting for a cure and longevity of life. I have hope that one day we will be the ones posing a '100 Days Seizure Free' picture."

[Learn More About Olivia's Story](#)

NOW OPEN

Elevate Patient Assistance Program

The LGS Foundation's Elevate Patient Assistance Program provides financial assistance to individuals with LGS to help pay for durable medical equipment not typically covered through insurance or other programs.

This program is open to residents in the United States. The grant cycle opens in February and remains open until all funds are depleted. Families may submit an application for assistance once every five years, with the maximum allowance per family, per application, being \$1,500.

[Learn More & Apply Now](#)

LGS RESOURCE CORNER



Join a Monthly Virtual Support Group

The LGS Foundation co-hosts several online support groups, available only to LGS caregivers who are members of the Online Caregiver Support Community.

[Learn More](#)



Request Information and Materials

The LGS Foundation is committed to providing a wealth of information for LGS caregivers, families, and professionals. We believe that everyone should have access to the latest and best information available.

[Learn More](#)



View the LGS Learning and Resource Center

We're dedicated to providing a comprehensive LGS Learning and Resource Center so those impacted by LGS can find a doctor, learn about epilepsy surgery, understand seizure clusters, and more!

[Learn More](#)

