

LGS FOUNDATION
LENNOX-GASTAUT SYNDROME

Navigating THE LGS MAZE



Thank you for making Swing "FORE" a Cure 2022 a success!

The LGS Foundation's Inaugural Swing "FORE" A Cure Golf Outing was held last month in Dublin, Ohio. The event was designed to raise awareness about LGS in the greater Columbus community and to raise funds for the Foundation's research and family support programs. Fifty-six players enjoyed a round of golf, including special contests, a dinner, a raffle, and a silent auction. Over \$11,000 was raised through the combined efforts of golfers, volunteers, sponsors, and donors.

Karen and Jeff Groff, parents to Dan, who has LGS, and hosts of the outing, reported that six individuals with LGS were represented by golfers. "We were fortunate to connect with three more Ohio families that we did not previously know," they said. "The event was a lot of fun, and it helped create a community of support." "One of the golfers commented, "I had no idea about what those with LGS deal with on a daily basis."

The Groffs are active volunteers for the LGS Foundation, and they work every day to create hope and improve the lives of those impacted by LGS.

[Read More](#)

**The LGS Foundation
is committed to
accountability,
transparency,
and excellence.**



Did you know? The LGS Foundation Received the Platinum Seal of Transparency!

The LGS Foundation has been awarded the **Platinum Seal of Transparency** from *Candid* (formerly GuideStar), which is the world's largest source of information on individual nonprofits. **This Platinum rating, Candid's highest level of recognition, places the LGS Foundation among the top 0.1% of all national charities in terms of transparency.** This site ranking is reserved for nonprofits that share comprehensive financial and operational information, along with details regarding the impact of programs and services, through their *Candid* profile.

"Achieving *Candid's* **Platinum Seal of Transparency** is a tremendous milestone for the LGS Foundation," said Foundation Board President Natalie Gilman. "It's vitally important for our stakeholders to understand that our commitment to transparency ranks among our organization's highest priorities." The LGS Foundation's *Candid* profile provides donors and potential financial partners with in-depth information related to financial goals, strategies, capabilities, and progress. This knowledge assures a donor they can give with great confidence in supporting our efforts to end the devastation and suffering caused by LGS.

The LGS Foundation thanks each donor for their support, and we invite you to visit our updated *Candid* profile. Please note that to view, you'll need to register for a free account.



Shop for LGS Awareness

November 1st is International LGS Awareness Day! Want to help raise LGS awareness and look stylish while you do it? Visit our Awareness Pop-Up Shop today to shop our exclusive LGS Awareness Apparel. Available for a limited time only!

We have options for everyone - Our LGS Warriors, Moms, Dads, and all of your family and friends!

Proceeds help fund our mission to improve the lives of individuals impacted by LGS.

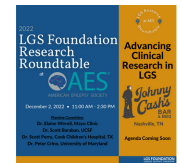
[Shop Now!](#)

International LGS Awareness Day is November 1st!

This year, we invite you to join the LGS Foundation for our Illuminate for LGS social media campaign, a Halloween Masquerade Ball at Epilepsy Awareness Day at Disneyland, and our Every Moment Matters LGS Dinner Event in San Diego, CA.

Help us lift our voices worldwide in recognition of LGS Awareness Day as we raise awareness and bring LGS families together.

[Learn More](#)



LGS Research Roundtable at AES

Join us on Friday, December 2nd at 11:00am EST for the LGS Foundation Research Roundtable at the American Epilepsy Society's (AES) Annual Meeting in Nashville, TN. Learn about how we are working to advance clinical research in LGS. There are both in-person and virtual opportunities to attend.

[Register to Attend In Person Now](#)

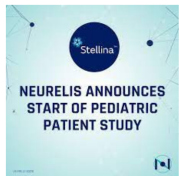
[Register to Attend Virtually Now](#)

Clinical Trial Opportunities

Did you know that most patient families living with LGS are never told about available clinical trials? That is why we share info on trials with the LGS community. There are currently several open clinical trials in LGS. The newest, the Stellina Study, is a Phase 1/2a clinical study evaluating a single dose of diazepam nasal spray (VALTOCO) as a rescue medication in children aged 2-5 who have been diagnosed with epilepsy.

[Learn More About the Stellina Study](#)

[Learn More About All LGS Clinical Trials](#)



Your voice is key in driving LGS research!

We are doing a research study funded by the Patient-Centered Outcomes Research Institute (PCORI) looking at treatments and their effect on children and adolescents with Lennox-Gastaut Syndrome (LGS).

[Learn More About this Study](#)

[Take the Survey \(English\)](#)

[Tomar la Encuesta \(Español\)](#)

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

Lennox-Gastaut Syndrome (LGS) Foundation
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Thank you for your support!

The LGS Foundation recently changed systems. If you had previously unsubscribed, we apologize that you're receiving this email. Please unsubscribe again, using the link in this email below.

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