

# Navigating the LGS Maze

## Community Newsletter

LGS FOUNDATION  
LIVING BETTER. GIVING MORE.



INTERNATIONAL  
**LGS FOUNDATION**  
FAMILY & PROFESSIONAL CONFERENCE

Early Bird Pricing Ends May 1st

### Register Now to get Conference Early Bird Pricing!

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 workshop opportunities with subjects ranging from challenging behaviors and genetics to advocacy and adults with LGS. [View the agenda for more information.](#)


*"Attending the LGS Conference is good for the mind, body, spirit and soul."*

- LGS Caregiver, Attended the 2022 Conference


You don't want to miss it!

Register Now

#### 2024 Research Grantees



DR. JULIET KNOWLES, MD, PHD



DR. ZACH GRINSPAN, MD, MS

#### New Cure LGS 365 Grant Awarded!

Because of the funds you raise, we are able to fund patient-led research.


The LGS Foundation recently funded an **exciting new research study** that will identify risk factors and predict the progression of LGS in children. If we can predict who will get LGS, perhaps one day we can prevent it!

This work is being conducted by Dr. Juliet Knowles of Stanford University School of Medicine and Dr. Zach Grinspan of Weill Cornell School of Medicine.

Learn More

#### QUALITY OF LIFE IMPACTS OF RARE EPILEPSY AFFECTING PATIENT AND FAMILY LIFE

Click QR code to launch survey



Each rare epilepsy family's situation and experiences of living with a rare epilepsy are unique, that's why we want to hear from YOU!

Make sure your voice is heard!

Praxel Syndrome Foundation | LGS FOUNDATION | Funded by patients, driven to science.

#### Make Your Voice Heard!

Each LGS family's situation and experiences are unique. The goal of this survey is to define what 'normal' and 'disruptive' mean to you and your loved ones' quality of life.

The survey will ask about activities of daily living, communication, behavior(s), sleep, and seizures.

Take the survey today to have your voice heard!

Take the Survey Now



#### Our Community: Meet Cash


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 Cash.

Cash started having seizures when he was 3 weeks old. These were easily controlled with medications. Then, shortly after Cash's first birthday, the seizures returned!

His Mom shares, *"My advice for other LGS caregivers is to make the most of every moment, hang on to the good times to help get you through the hard times, and NEVER LOSE HOPE!"*

Learn More about Cash


### LGS RESOURCE CORNER



#### Learn About Clinical Trials

Clinical trials and research studies are done to scientifically evaluate a medical or surgical intervention. They are the primary way that researchers find out if a new treatment is safe and effective in reducing seizures in those with LGS.


Learn More



#### Check Out the Calendar of Events

Get connected and supported at an online support group or an in person event when you can join us in raising awareness and increasing education at one of our many Community Awareness Events.

Learn More



#### Apply for Patient Assistance

The 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.

Learn More



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Standing Together. Stronger Together.

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