

Our Mission:

To improve the lives of individuals impacted by LGS through advancing research, awareness, education, and family support.

2024-2028 Strategic Plan

LGS FOUNDATION[®]
LENNOX-GASTAUT SYNDROME



Standing Together. Stronger Together.

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About the LGS Foundation



OUR VISION AND MISSION

VISION: To end the suffering and devastation caused by LGS.

MISSION: The Lennox-Gastaut Syndrome (LGS) Foundation is a nonprofit organization dedicated to improving the lives of individuals impacted by LGS through advancing research, awareness, education, and family support.

LGS FOUNDATION[®]
LENNOX-GASTAUT SYNDROME



OUR GUIDING PRINCIPLES



CORE VALUES & GUIDING PRINCIPLES:

Families First – We put families first in everything we do.

We are one LGS community and patient-family priorities drive all we do.

Community – We're all in this together.

*We seek to build a community of support and collaboration that will have a felt impact.
Nobody walks this journey alone.*

Tirelessness – We will never give up.

We believe in tirelessly searching for the cures.

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About LGS & Our Community



LGS PATIENT AND CAREGIVER UNMET NEEDS*

Seizures:

97% report refractory seizures

94% report cluster seizures

85% report >2 seizure types

81% injured from seizures in the last year

75% are on >3 therapies

66% report seizures longer than 5 minutes

50% hospitalized in the last year from seizures

Most problematic seizures are tonic clonic, tonic, atonic

Beyond the Seizures:

96% intellectually disabled

87% report sleep issues

83% report autistic features

76% behaviorally challenged

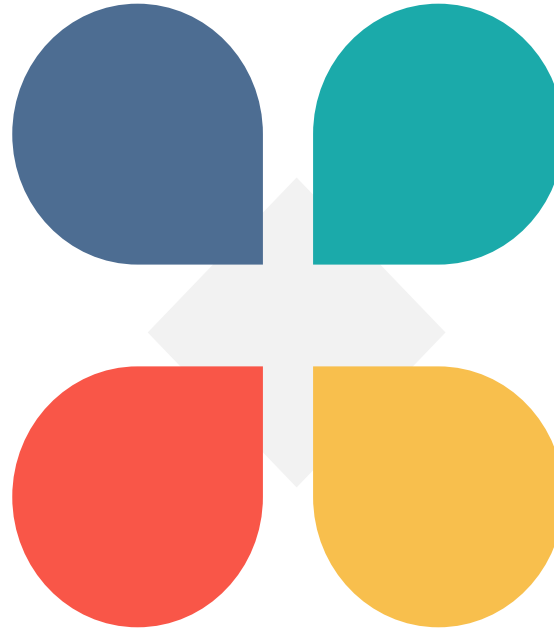
73% use a wheelchair

72% cannot read

69% cannot write

60% are nonverbal

27% are tube fed



**2018 LGS Foundation Caregiver Concerns Survey*

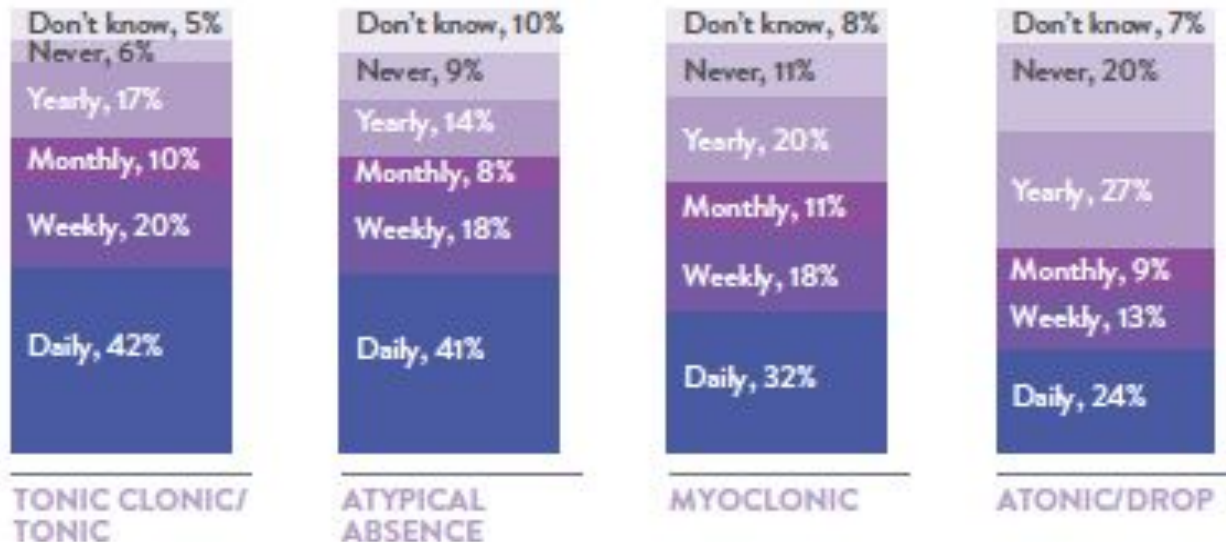
PRIORITIZING UNMET NEEDS

1. Seizures, clusters, status, and safety are major issues.

Current Seizure Frequency

55% of respondents said the person with LGS was currently having 4 or more types of seizures. 42% said the person with LGS was having 1-3 types of seizures. Only 3% reported seizure freedom. The most problematic seizure types currently present were 1) Tonic Clonic, 2) Tonic, 3) Atonic, 4) Myoclonic, 5) Atypical Absence.

TYPE AND FREQUENCY OF CURRENT, MOST PROBLEMATIC SEIZURES



Seizure Clusters and Status Epilepticus

- 94% have experienced seizure clusters
- 65% have had seizures lasting longer than 5 minutes
- 63% report using at home rescue medicines in the last 12 months

Seizure Injuries

81% report ever having a seizure-related head injury. Frequency of injuries in the last 12 months are listed below.

HEAD INJURIES IN THE LAST 12 MONTHS



PRIORITIZING UNMET NEEDS

2. Symptoms other than seizures are prevalent.

Symptoms Other than Seizures	
LGS has far reaching effects beyond just seizures. Issues with development, communication, psychiatric symptoms, sleep, behavior, and mobility are common. The frequency of the most commonly reported issues in these domains are shown below.	
ISSUE	%
DEVELOPMENTAL	
Severe Development Delay	80%
Moderate Delay	18%
Mild Delay	2%
COMMUNICATION	
Unable to read	72%
Unable to write	69%
Non-verbal	60%
PSYCHIATRIC	
Aggression	59%
Irritability/Agitation	41%
Impulsiveness	33%
SLEEP	
Sleep Disturbances	87%
Nocturnal Seizures	81%
Insomnia	58%
AUTISTIC FEATURES	
Diagnosed with Autism	26%
Repetitive body movements	39%
Tactile sensitivity or sensory issues	38%
MOBILITY	
Uses a wheelchair or adaptive stroller	73%
FEEDING	
Tube fed	27%

3. Rank order of issues by caregivers.

Most common respondent concerns in the open response section:
1. Seizures & safety
2. Developmental delay, especially communication
3. Behaviors, especially aggression
4. Mobility & physical care issues
5. Sleep disturbances
6. Medical costs & access to care
7. Social isolation

THE LGS FOUNDATION WILL PRIORITIZE ISSUES THAT FAMILIES HAVE SAID ARE MOST PRESSING.

**2018 LGS Foundation Caregiver Concerns Survey*

Our Theory of Change



OUR 4 PILLARS: HOW WILL WE IMPROVE LIVES OF THOSE IMPACTED BY LGS

Support, Empower, Educate (SEE)



Develop sustainable programs that support, educate, empower LGS families

- Build and grow volunteers
- Share quality education and resources
- Empower families to seek the best care

Accelerate Research (Rch)



Distribute research funding to advance LGS basic, clinical, and translational research and build the next generation of researchers

- Ensure the LGS patient voice is heard
- Convene, build consortia, drive research

Awareness and Community Building Events (ACB)



Raise awareness of LGS globally and grow the patient, family, & research community.

Increase investment in LGS.

Build & Strengthen Organization (BSO)



Grow and improve upon systems and processes that encourage efficient and effective operations.

Invest in staff, leadership, and skill development.

OUR 4 PILLARS AT WORK THROUGH OUR PROGRAMS & OUR CAPACITY

Our Theory of Change:

If we raise awareness and build community, support, empower, educate that community, and if we fund the best patient-driven research it will improve the lives of those impacted by LGS.

OUR IMPACT:
IMPROVED LIVES



Support, Empower, Educate

Families First Programs:

- Ambassadors/Navigators
- Bereaved
- Advocacy
- Patient Assistance Program
- Monthly Support Group
- Online Support Groups
- Volunteers

Resources & Educational Programs:

- New Family Onboarding
- Family Materials & Kits Programs
- Resources & Referral (online/intake)
- LGS Learning and Resource Center

Accelerate Research

Finding a Cure, Together Programs:

- Community Voice & Surveys
- Cure LGS 365 Program
- Learn from Every Patient Database
- Research Collaborations
- Meeting of the Minds

Awareness and Community Building

Awareness and Community Events

- Family and Professional Conference
- Int'l LGS Awareness Day (IAD)
- LGS Walk n' Wheel
- Swing FORE a Cure



2024-2028 Strategic Plan OGSM



APPROVED BY BOARD OF DIRECTORS 12/13/23

5 Year (2024-2028) Strategic Objectives & Goals

Strategic Objective: To end the devastation and suffering caused by LGS while improving the lives of individuals impacted by LGS through advancing research, awareness, education, and family support.

- **Goal 1:** Support, empower, and educate LGS families
- **Goal 2:** Raise awareness and build community
- **Goal 3:** Accelerate research
- **Goal 4:** Build and strengthen the organization

Strategies and Measures

See the OGSM Public Copy:

<https://docs.google.com/spreadsheets/d/1EkHFjBSiRQHAHmxW6wxFOfA-ngYf25V2/edit#gid=388240778>

PDF this to post on website