



# 2024-2028 Strategic Plan

# LGS FOUNDATION<sup>®</sup>

## LENNOX-GASTAUT SYNDROME



# Standing Together. Stronger Together.

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**Standing Together. Stronger Together.**

**LGS FOUNDATION**  
LENNOX GASTAUT SYNDROME  
[www.LGSFoundation.org](http://www.LGSFoundation.org)

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**Features of LGS**

- Seizure onset in childhood
- More than one type of seizure
- Developmental delay
- Characteristic EEG abnormalities



# 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.



# 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.*

# OUR TEAM

Learn more about Our Team on our website at [www.lgsfoundation.org/our-team](http://www.lgsfoundation.org/our-team).

**Board of Directors**

**Staff**

**Medical Science Advisory Council**

**Leadership Circle**

# About LGS & Our Community



# LGS PATIENT AND CAREGIVER UNMET NEEDS\*

## Seizures:

97% report refractory seizures

94% report cluster seizures

85% report >2 seizure types

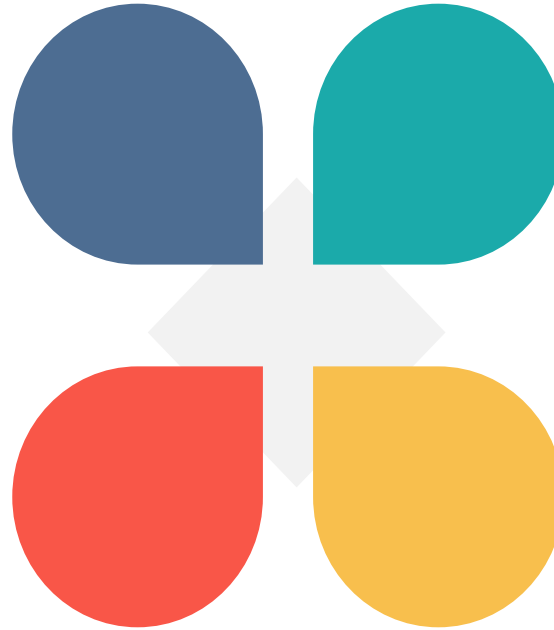
81% injured from seizures in the last year

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*



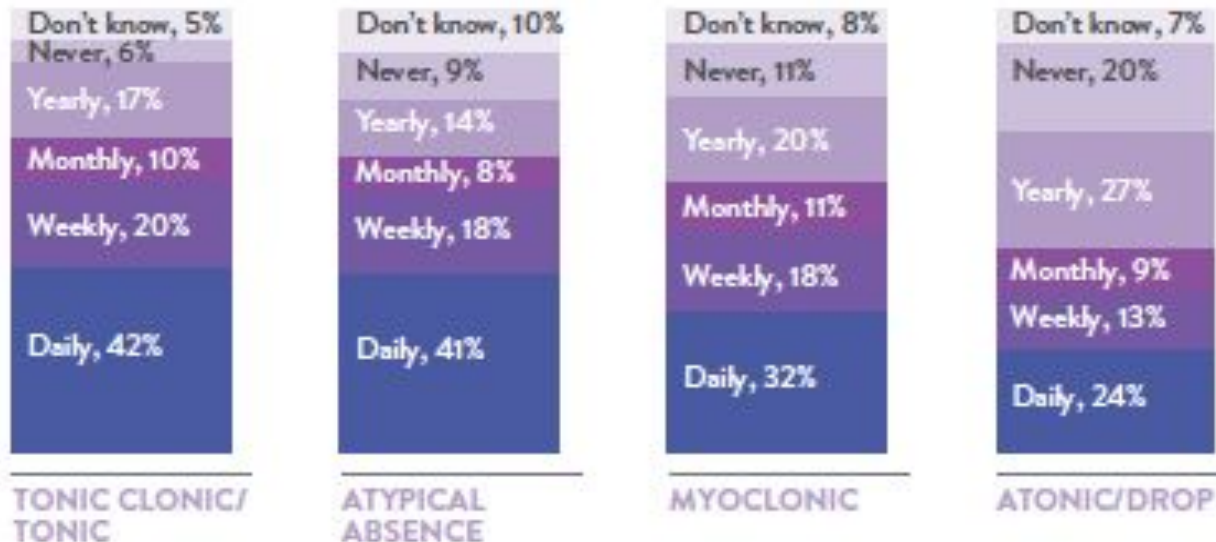
# PRIORITIZING UNMET NEEDS

## 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



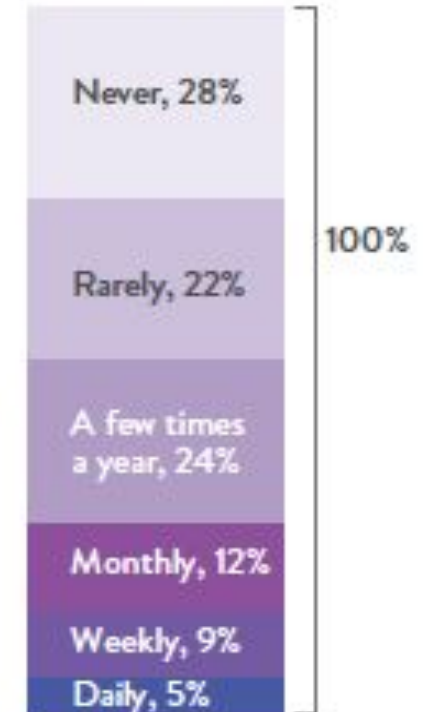
### Seizure Clusters and Status Epilepticus

- 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	%
<b>DEVELOPMENTAL</b>	
Severe Development Delay	80%
Moderate Delay	18%
Mild Delay	2%
<b>COMMUNICATION</b>	
Unable to read	72%
Unable to write	69%
Non-verbal	60%
<b>PSYCHIATRIC</b>	
Aggression	59%
Irritability/Agitation	41%
Impulsiveness	33%
<b>SLEEP</b>	
Sleep Disturbances	87%
Nocturnal Seizures	81%
Insomnia	58%
<b>AUTISTIC FEATURES</b>	
Diagnosed with Autism	26%
Repetitive body movements	39%
Tactile sensitivity or sensory issues	38%
<b>MOBILITY</b>	
Uses a wheelchair or adaptive stroller	73%
<b>FEEDING</b>	
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.**

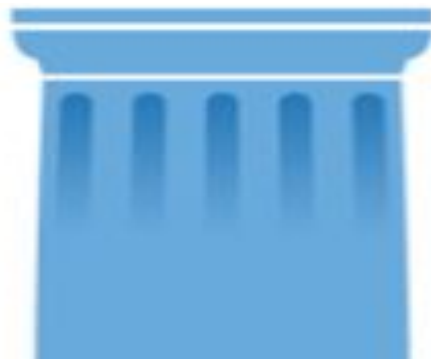
*\*2018 LGS Foundation Caregiver Concerns Survey*

# Our Theory of Change



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

**Support, Empower, Educate (SEE)**



**Accelerate Research (Rch)**



**Awareness and Community Building Events (ACB)**



**Build & Strengthen Organization (BSO)**



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

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

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

Increase investment in LGS.

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