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.

APPROVED BY BOARD OF DIRECTORS 12/13/23
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About the LGS Foundation
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.
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.

*2018 LGS Foundation Caregiver Concerns Survey*
PRIORITIZING UNMET NEEDS

2. Symptoms other than seizures are prevalent.

<table>
<thead>
<tr>
<th>ISSUE</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEVELOPMENTAL</td>
<td></td>
</tr>
<tr>
<td>Severe Development Delay</td>
<td>80%</td>
</tr>
<tr>
<td>Moderate Delay</td>
<td>18%</td>
</tr>
<tr>
<td>Mild Delay</td>
<td>2%</td>
</tr>
<tr>
<td>COMMUNICATION</td>
<td></td>
</tr>
<tr>
<td>Unable to read</td>
<td>72%</td>
</tr>
<tr>
<td>Unable to write</td>
<td>69%</td>
</tr>
<tr>
<td>Non-verbal</td>
<td>60%</td>
</tr>
<tr>
<td>PSYCHIATRIC</td>
<td></td>
</tr>
<tr>
<td>Aggression</td>
<td>59%</td>
</tr>
<tr>
<td>Irritability/Agitation</td>
<td>41%</td>
</tr>
<tr>
<td>Impulsiveness</td>
<td>33%</td>
</tr>
<tr>
<td>SLEEP</td>
<td></td>
</tr>
<tr>
<td>Sleep Disturbances</td>
<td>87%</td>
</tr>
<tr>
<td>Nocturnal Seizures</td>
<td>81%</td>
</tr>
<tr>
<td>Insomnia</td>
<td>58%</td>
</tr>
<tr>
<td>AUTISTIC FEATURES</td>
<td></td>
</tr>
<tr>
<td>Diagnosed with Autism</td>
<td>26%</td>
</tr>
<tr>
<td>Repetitive body movements</td>
<td>39%</td>
</tr>
<tr>
<td>Tactile sensitivity or sensory issues</td>
<td>38%</td>
</tr>
<tr>
<td>MOBILITY</td>
<td></td>
</tr>
<tr>
<td>Uses a wheelchair or adaptive stroller</td>
<td>73%</td>
</tr>
<tr>
<td>FEEDING</td>
<td></td>
</tr>
<tr>
<td>Tube fed</td>
<td>27%</td>
</tr>
</tbody>
</table>

3. Rank order of issues by caregivers.

- Seizures & safety
- Developmental delay, especially communication
- Behaviors, especially aggression
- Mobility & physical care issues
- Sleep disturbances
- Medical disturbances & access to care
- Social isolation

THE LGF 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 Programs

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

OUR IMPACT: IMPROVED LIVES

Build & Strengthen Organization

OUR CAPACITY
Management & Systems
Governance
Finances & Development
Communications
2024-2028
Strategic Plan OGSM

APPROVED BY BOARD OF DIRECTORS 12/13/23
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