

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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Standing Together. Stronger Together.

LGS FOUNDATION
LENNOX GASTAUT SYNDROME
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.

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

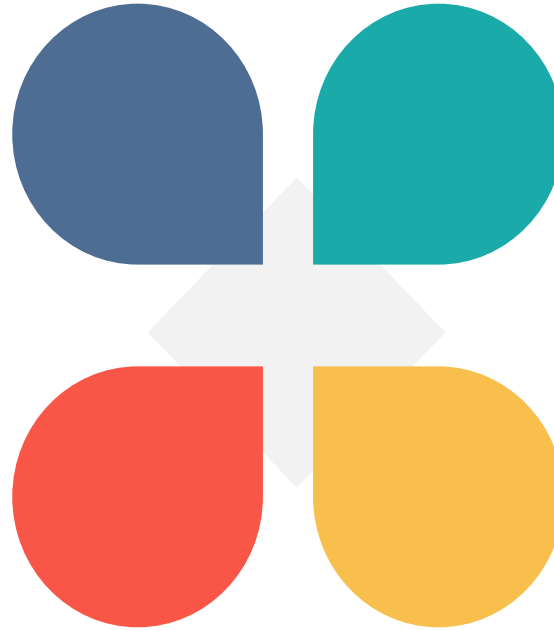
81% injured from seizures in the last year

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*

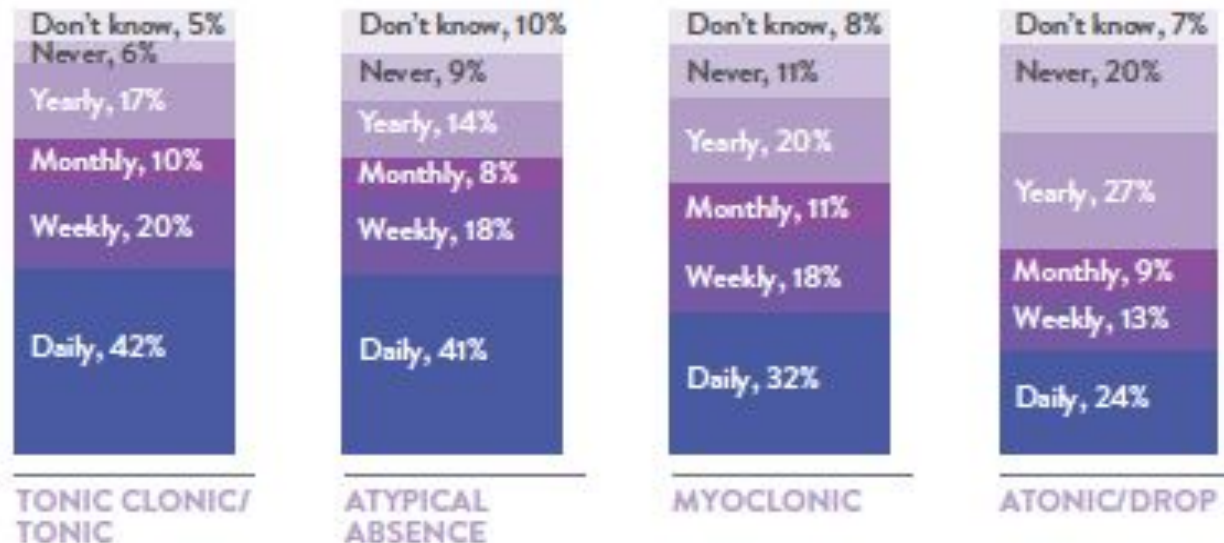
PRIORITIZING UNMET NEEDS

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



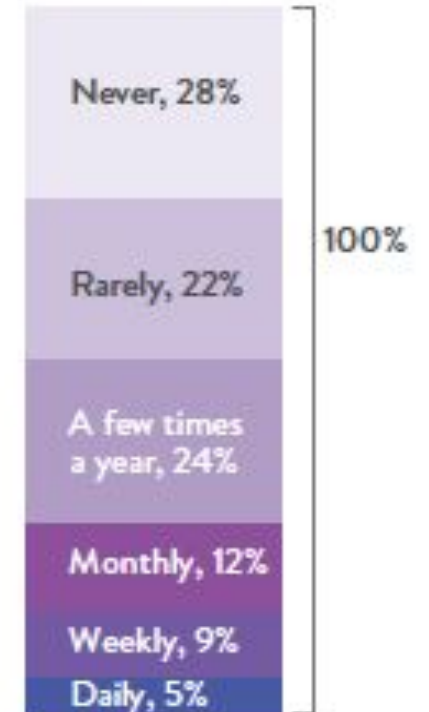
Seizure Clusters and Status Epilepticus

- 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.

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

Our Programs

Management & Systems

Governance

Finances & Development

Communications

Build & Strengthen Organization

OUR CAPACITY

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

Goal 1: Support, Empower, Educate, Raise Awareness, and Build Community (SEE/ACB)

STRATEGIES	MEASURES
<p>SUPPORT: Create an impactful family support force that will allow our families to connect and support one another. Do this by hosting and improving our annual Family Conference (or Meeting of the Minds in alternate years), Walk 'n' Wheel, Patient Navigator/Family Ambassador (PNFA) Program, Online Support Groups, Online Private Caregiver Community, Advocates for LGS, and Patient Family Advisory Council (PFAC).</p> <p>Grow collaborations with other nonprofit organizations internationally, nationally, & locally to ensure access to resources, support services, transition tools, & information.</p> <p>Grow and strengthen impactful family support programs.</p>	<p>Grow peer-to-peer support interactions by 2% annually.</p> <p>Build and maintain annual working partnerships with at least eight (8) national organizations, and regularly share progress in LGS patient-family prioritized (PFP) research and advancing our mission.</p> <p>Add links on the website to at least three (3) international LGS support organizations by the end of 2024.</p> <p>Grow and strengthen family interactions with our support programs by 2% (total for all programs), including EPAP, New Family Onboarding, Family Referral, Kits (New Families, About LGS Treatments, Siblings, Adults), and Bereaved, ensuring program quality via annual program surveys.</p>
<p>EDUCATE: Create high-value educational content for the LGS community through our LGS Community Center (LCC) and LGS Learning and Resource Center (LLRC).</p> <p>Increase high-value scientific knowledge in the LGS community.</p>	<p>Grow the LCC and LLRC by 2% annually, engaging new members with timely, impactful course content that gives families the skills and tools to achieve the best possible care for their loved ones.</p> <p>Increase the number of courses available by five (5) by the end of 2027, adding at least one (1) course per year. Courses should be based on community surveys identifying unmet needs (e.g., Adults with LGS, Behavior, etc.). Establish baseline metrics in 2024 and 2025 and then set goals for growth in 2025 and beyond.</p> <p>Establish scientific and clinical trial educational courses in the LCC and add at least 5 courses (~1 per year) by the end of 2027.</p>
<p>ADVOCACY: Expand the skills of caregivers to advocate for and access appropriate medical care.</p> <p>Advocate for government programs that benefit families living with LGS.</p>	<p>Work with patients and families to advocate annually for solutions that directly benefit or impact LGS families.</p> <p>Advocate annually on Capitol Hill. Gain in-house knowledge of current legislation and survey the LGS Foundation community for PFP by the end of 2025. Using this knowledge, plan our comprehensive advocacy efforts for 2026 and beyond.</p>

Goal 2: Accelerate LGS Research

STRATEGIES	MEASURES
<p>NETWORK: Grow the LGS Collaborative Research Network (LCRN) including our MSAC, Healthcare Providers (HCPs), researchers, advocacy organizations, academic institutes, government experts, and industry partners to advance patient family-prioritized (PFP) LGS research.</p>	<p>Grow relationships with LGS Foundation LCRN members, engaging them in educating the community about LGS at our Family Conference, MoM, and at AES.</p> <p>Engage our MSAC, meeting monthly and growing to 10-15 clinical members and 3-5 basic science members.</p> <p>Double the number of relationships with LCRN members, including academic partners within groups like the Pediatric Epilepsy Research Consortium (PERC) and the Surgery or Medication in LGS (SOM-L) study, by the end of 5 years.</p>
<p>DATABASE: Create and grow the LGS Learn from Every Patient (LEP) database with studies and key learnings addressing PFP outcomes.</p>	<p>Enroll 250 people in Phase 1 of the LEP database by the end of 2024.</p> <p>Enroll 250 people in Phase 2 and 3 of the LEP database by the end of 2027. Design studies to center around PFP research as co-determined by organizational research, MSAC input, and patient family advisors input.</p> <p>Share database progress and learning with the LGS community twice per year.</p>
<p>GRANTS: Invest research grant funding in late-stage predoctoral, postdoctoral, and early career investigators who are conducting impactful PFP research. Release Grant Funding Request for Applications (RFAs) with an emphasis on understanding the evolution of LGS, advancing PFP research, collaboration, and freeing of the data.</p>	<p>Create 1-5 new grant funding mechanisms (e.g. for post-docs, for early career investigators, on a specific topic, etc.) to focus on PFP prioritized research. Release new RFAs in 2024 to reflect these new mechanisms.</p> <p>Maintain a minimum investment annually to fund new LGS research grants.</p>
<p>CONVENE, LEAD, SHARE: Convene targeted meetings on urgent PFP research issues and follow up with grant funding and new funding mechanisms as needed. Serve as a leader in the rare disease community, sharing the scientific and medical link of LGS to other diseases among our many LCRN members and the broader epilepsy and rare disease communities.</p>	<p>Participate, and/or present at at least 10 LGS-relevant meetings annually emphasizing LGS Foundation core messaging and PFP research priorities.</p> <p>Host and grow the Meeting of the Minds on PFP topics every other year and emphasize research at the Family Conference in non-MoM years.</p> <p>Ensure the diverse patient family voice is in all we do by growing our Patient Family Advisory Council (PFAC) to 25 members that meet quarterly.</p>

Goal 3: Build and Strengthen the Organization (Communications)

STRATEGIES	MEASURES
<p>WEBSITE, SOCIAL MEDIA, MESSAGING: Position LGS Foundation online as the leading, trustworthy, professional, data-driven, compassionate and go-to resource for families, researchers, clinicians, advocates in the epilepsy and rare disease communities, and our many partners, with an emphasis on freeing the data.</p> <p>Maximize technology to increase LGS Foundation's online engagement around large initiatives and programs in a way that is impactful to each unique audience and stays true to our core values and goals.</p> <p>Attract and retain online social media followers through meaningful and engaging content.</p>	<p>Increase traffic on LGS Foundation's website by 10% over 5 years, growing site traffic by 2% annually.</p> <p>Grow LGS Foundation's audience on Facebook, Twitter, Instagram, LinkedIn, and YouTube by 10% over five years (total for all channels), growing the number of followers by 2% annually.</p> <p>Drive quality engagements across LGS Foundation's website and social media channels by securing a 2% increase in impressions annually via multiple and varied outlets, emphasizing short video content.</p> <p>Implement at least one awareness campaigns, bolstering branding and educating the public about LGS, achieving at least 2,000 impressions per campaign.</p>
<p>EMAILS: Take a tailored approach to all emails.</p>	<p>By the end of 2024 date we will reach an email open rate of 75% for our targeted emails by improving audience segmentation and personalization efforts.</p> <p>Maintain industry standards for open and click-through rates for each type of email we send (eBlast vs. targeted email).</p>
<p>SEO OPTIMIZATION: Maximize our website Search Engine Optimization (SEO) to increase LGS Foundation accessibility to families and other stakeholders.</p>	<p>By the end of 2024, we will increase our search results page on Google and YouTube.</p>
<p>DIVERSITY, EQUITY, INCLUSION, ACCESSIBILITY: Embrace and encourage differences in age, color, disability, ethnicity, family or marital status, gender identity, physical and mental ability, race, religion, socio-economic status, and other diversity factors.</p>	<p>Implement annual Board of Directors (BOD) and staff training on DEIA, with an emphasis on actionable ways to bring DEIA to our community.</p> <p>Offer a virtual option for in-person meetings so LGS Families can attend.</p> <p>Offer scholarships to more than one caregiver for family conferences so no LGS caregiver is alone and managing their LGS loved one by themselves at the meeting.</p>

Goal 4: Build and Strengthen the Organization (Governance & Executive)

STRATEGIES	MEASURES
<p>TRANSPARENCY: Maintain appropriate infrastructure for organizational growth, maximal transparency, and ongoing credibility.</p>	<p>Maintain an annual 4-star Charity Navigator rating and a Platinum Guidestar rating.</p> <p>Track strategic metrics in dashboards shared at all committee and BOD meetings.</p>
<p>GROW BOARD OF DIRECTORS: Develop a BOD with the skill set needed to realize the strategic plan.</p>	<p>Recruit 1-3 new BOD members annually, reaching up to 15 members by no later than the end of 2027. The BOD should reflect the diversity, equity, inclusion, and accessibility (DEIA) values of our organization and the constituency.</p> <p>Develop the LGS Foundation's BOD skill set with at least one annual training on an area of need as chosen by BOD vote in Q1 of each year.</p>
<p>GROW AND DEVELOP STAFF: Invest in staff expansion and skill development to drive results and develop succession plans.</p>	<p>Grow staff to at least 10-12 employees by the end of 2027, with prioritization of research, administrative support, communications, and fundraising.</p> <p>Train staff in relevant skill areas with each staff member completing 2-6 hours of training each year.</p> <p>Maintain a 70% staff retention rate.</p> <p>Create succession plans for senior staff (Executive Director, Senior Director of Operations, Senior Director of Programs). Begin the plan for ED in 2024, finalizing by the end of 2024, and begin the plan for senior staff in 2024 with finalization by mid-2025 or earlier. The succession plan for the ED should be designed and approved exclusively by the BOD.</p>
<p>Update database(s) of current, reliable, protected information on LGS families and LGS Foundation supporters, complying with all laws and regulations.</p>	<p>Upgrade security to remotely manage and secure employee endpoint devices, as well as LGS Foundation software services.</p> <p>Ensure company-owned hardware security and reliability to ensure integrity and protection of all employee and constituent data, including Personal Identifiable Information (PII).</p> <p>Ensure regular software and security updates for all operating systems and applications.</p> <p>Ensure data protection and file storage through secure cloud-based services are configured with industry best practices in conjunction with regularly scheduled data back-ups or data replication.</p>

Goal 5: Build and Strengthen the Organization (Finance & Development)

STRATEGIES	MEASURES
<p>ENDOWMENT FUND: Develop and maintain an endowment fund and emphasize the role and opportunities associated with Endowment via estate planning, gift annuities, and other planned giving vehicles.</p>	<p>Grow the endowment fund to \$5M, driving an approximately 5% / \$250K annual contribution to LGS Foundation.</p>
<p>INVESTING: Maintain the strategic financial plan in line with the organization's strategic plan.</p>	<p>Update the BOD-approved strategic financial plan by Q4 2024, which outlines a development plan, financial planning, and investing from 2024 to 2027.</p>
<p>GROWTH: Increase capital for growth of programs through partnerships with corporations, foundations, state organizations, and individuals.</p>	<p>Grow total annual revenue to \$1.5M by the end of 2027.</p>
<p>DIVERSIFY: Leverage the unique capacity of each community member to create community-specific connections that can then be stewarded by the LGS Foundation.</p>	<p>Mobilize the LGS Foundation grassroots community through events to raise funds and to make connections with members of their connection circles. Increase the number of people donating online by 50% by the end of 2027.</p>