



2021-2023 Strategic Plan

LGS FOUNDATION
LENNOX GASTAUT SYNDROME



LGS IS TOUGH. SO ARE WE.

TABLE OF CONTENTS

ABOUT US

- MISSION
- VISION
- CORE VALUES & GUIDING PRINCIPLES

OUR ADVANTAGE

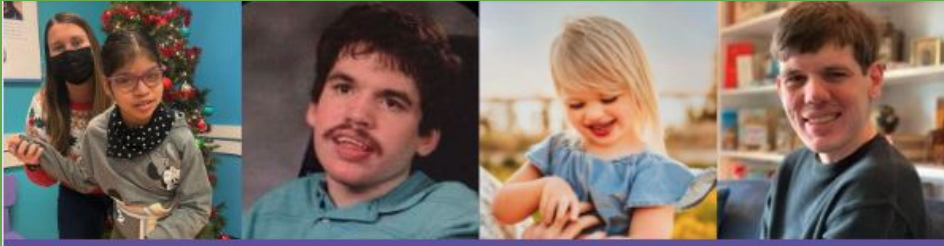
OUR PILLARS/STRATEGIES

OUR PROGRAMS/TACTICS

OUR GOALS 2021-2023





OUR STAFF & COMMITTEES

OUR IMPACT (COMING SOON)




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 US:

MISSION & VISION
CORE VALUES & GUIDING PRINCIPLES

ABOUT US: OUR MISSION AND VISION

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



ABOUT US: OUR GUIDING PRINCIPLES



CORE VALUES & GUIDING PRINCIPLES:

Families First – We work for those living with LGS.

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 alone.

Tirelessness – We will never give up.

ABOUT US:

VALUE PROPOSITION/OUR ADVANTAGE

ABOUT US: OUR ADVANTAGE

Why the LGS Foundation?

Our Purpose



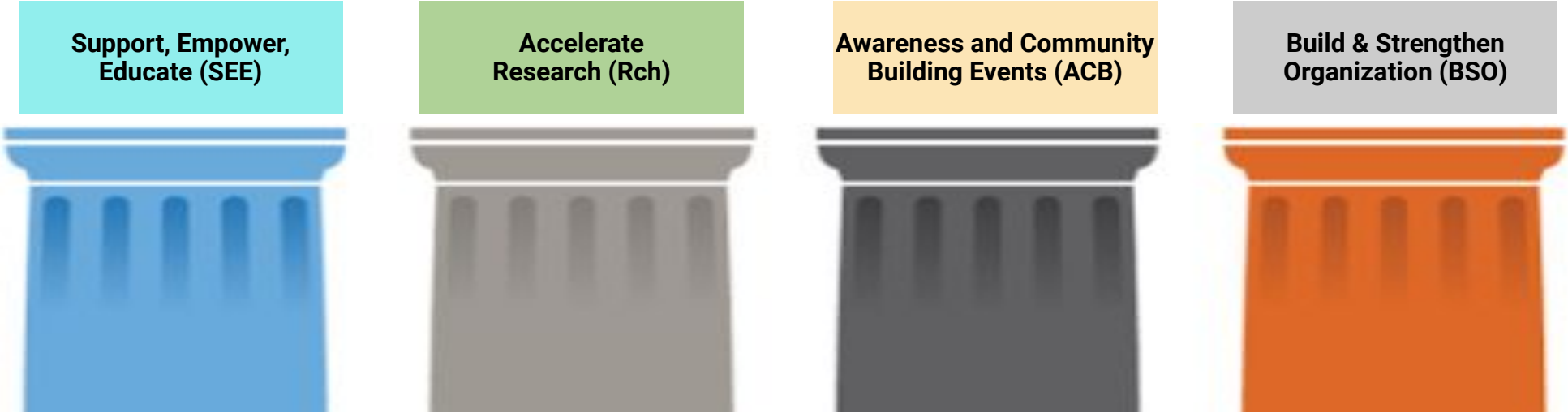
There is a significant disparity between what researchers, healthcare professionals, pharmaceutical companies, and community support services are doing for LGS families, and what families actually want.

At the LGS Foundation, we focus on what has been done in the LGS world, what is working, what isn't, and what patients and families need.

No one else can do what we can, and our work is crucial for saving time, money, and lives while improving quality of life for families.

OUR PILLARS (STRATEGIES) & OUR PROGRAMS (TACTICS)

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



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 leadership, staff 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 & Volunteers
 - Bereavement
 - Community Teams
 - Patient Assistance Program
 - MeetUps
 - Sibs Rock Program
- Resources & Educational Programs:
- New Family Onboarding
 - New Family Materials Program
 - Family Resources & Referral
 - Educational Webinars
 - Newsletter
 - Latest News & Events Column

Accelerate Research

- Cure LGS 365 Research Grants
- Voice of the Community Reports
- Cure LGS 365 Research Grants
- LGS Research Roundtable at AES
- LGS Meeting of the Minds

Awareness and Community Building

- Family Conferences & Scholarships
- Leaders in LGS Award
- LGS Awareness Day
- Illuminate for LGS Awareness
- LGS Walk 'n' Wheel
- Infantile Spasms Action Network
- Seizure Action Plan Coalition

Our Programs

Management & Systems

Governance

Finances & Development

Communications

Build & Strengthen Organization

OUR CAPACITY

LGS FOUNDATION 2021-2023 GOALS

Focus Statement for Our 3-Year Plan

The LGS Foundation will mobilize its resources to:

- **Accelerate Research (Rch)**
 - **Accelerate Patient-Prioritized Scientific Breakthroughs for Better Treatments and Cures:**
 - Accelerate scientific advancements by funding more research to understand the brain regions and cellular and molecular mechanisms that underlie the EEG abnormalities seen in LGS and ensure data is shared freely.
 - Catalyze the growth of tools and consortia that support basic, translational, and clinical research that advance the ‘learn from every patient’ philosophy and lead to patient benefit. Ensure all data is shared freely.
 - Bring the patient and family voice into all aspects of research and establish LGSF as the leading voice of the voices of LGS families.
- **Support, Empower, Educate, Raise Awareness, Build Community (SEE/ACB)**
 - **Build and Engage Robust and Well-Educated Global Communities & Offer Timely, Impactful Support Programs to Families:**
 - Educate, engage, and assist more and diverse individuals impacted by LGS through improved clinical and support services.
 - Empower our diversified grassroots community to broaden and strengthen the base of financial support from private and public sources for LGS research, the LGSF, and an LGSF Endowment Fund.
 - Drive and provide tools to facilitate peer-to-peer support among the national and international LGS community.
- **Build and Strengthen the Organization (BSO):**
 - **Grow and improve upon fundraising, governance, and financial systems and processes.**
 - Ensure strong organizational infrastructure is in place with clear plans for fundraising, governance, and financial management.
 - Increase diversity and inclusion within all aspects of the organization.
 - Enhance staff and volunteer skill sets to ensure execution of the strategic plan with its clear fundraising, management, and programmatic goals.
 - Build recognition of LGS as an evolving, stabilizable disorder that may one day be preventable and reversible.

GOALS: 2021 - 2023

Support & Educate (SEE) Awareness & Community (ACB)

2021	2022	2023
<p>Theme: Research Year</p> <p>Support, Empower, Educate</p> <ul style="list-style-type: none"> • Create high-value educational content for patient families. • Maintain, expand high-value programs for patient families. • Engage patient families in LGSF programs and research/trials (e.g. mountain, evolution, subway). • Expand global reach. <p>Raise Awareness, Build Community</p> <ul style="list-style-type: none"> • Brand creation (FF, Family Voice Matters, Every Family Matters, LGS is tough, so are we). • Build new website, update materials. • Use proven comms strategies to increase reach. • Grow and diversify patient and family community. • Sign-on to group legislative advocacy efforts. 	<p>Theme: LGS Across the Lifespan & LGS is Hard, X (e.g.) Finding Resources Doesn't Need to Be (emphasis on Adults)</p> <p>Support, Empower, Educate</p> <ul style="list-style-type: none"> • Create specific, topical, high-value content for patient families (Adults, Resources, Survey for Needs). • Increase engagement of patient families in LGSF programs and research/trials. • Provide patient navigation help (step-by-step, Adults). • Empower families to seek out the best Care Plan. • Expand US and global reach targeting Ambassadors and MeetUps. <p>Raise Awareness, Build Community</p> <ul style="list-style-type: none"> • Maximize reach with proven comms strategies. • Grow and diversify patient and family community. • Pilot LGSF group legislative advocacy effort based on ongoing partnerships. 	<p>Theme: Support, Empower, Educate</p> <ul style="list-style-type: none"> • Create, refresh, and curate high-value content for patient families. • Streamline engagement of patient families in LGSF programs and research/trials. • Expand patient navigation help (step-by-step). • Empower families to advocate for and seek out the best Care Plan. <p>Raise Awareness</p> <ul style="list-style-type: none"> • Maximize reach through refined comms strategies. • Grow and diversify patient and family community. • Expand LGSF group legislative advocacy effort maximizing partnerships.

GOALS: 2021 - 2023

Accelerate Research

2021	2022	2023
<p>Accelerate Innovative Research</p> <ul style="list-style-type: none">• Fund a goal of up to \$100K in new research grants (30K/50K) focusing on mechanisms of LGS.• Target new and young investigators.• Grow our network of researchers.• Consider 'Learn from Every Patient' Platforms. <p>Catalyze the Conversation</p> <ul style="list-style-type: none">• Host an international research Meeting of the Minds (MoM) on how to cure LGS. Use to guide grant funding strategy.• Reorganize our PAB>MSAB.• Host regular MoM Seminars to keep the scientific conversation going. <p>Free the Data</p> <ul style="list-style-type: none">• Host AES Research Roundtable to share results of LGSF supported work. <p>Thought Leadership</p> <ul style="list-style-type: none">• Publish Voice of the Community Report.• Present at Conferences and Meetings.	<p>Accelerate Patient-Driven Research (Disease-Mod)</p> <ul style="list-style-type: none">• Fund a goal of up to \$125K in new research grants (50K/75K) focusing on mechanisms of LGS.• Target new and young investigators.• Vet, select, and pilot a 'Learn from Every Patient' Platform.• Maximize use of research network and MSAB. <p>Catalyze the Conversation</p> <ul style="list-style-type: none">• Host regular MoM Seminars to keep the scientific conversation going. Include prevention. <p>Free the Data</p> <ul style="list-style-type: none">• Host AES Research Roundtable to share results of LGSF supported work. Grow audience.• Having talks/posters at AES. <p>Thought Leadership</p> <ul style="list-style-type: none">• Publish MoM Results.• Become leading voice on patient unmet needs and value added.	<p>Accelerate Patient-Driven Research (Disease-Mod, Prevent)</p> <ul style="list-style-type: none">• Fund a goal of up to \$150K in new research grants (50K/75K) advancing mechanistic understanding of LGS.• Target new and young investigators.• Fund 'Learn from Every Patient' Platform.• Streamline comms with our research network. <p>Catalyze the Conversation</p> <ul style="list-style-type: none">• Host an international research Meeting of the Minds (MoM) on finding the best treatments in LGS. Use to guide grant funding strategy.• Host regular MoM Seminars to keep the clinical conversation going. <p>Free the Data</p> <ul style="list-style-type: none">• Host AES Research Roundtable to share results of LGSF supported work. Grow audience. Talks/posters. <p>Thought Leadership</p> <ul style="list-style-type: none">• Publish.• Build capacity for LGSF to be champions and lead advocates.

GOALS: 2021 - 2023

Strengthen Org (BSO)

2021	2022	2023
<p>Fundraising and Development</p> <ul style="list-style-type: none"> ● Create formal fundraising plan. ● Establish a fundraising base. ● Implement a formal donor management plan. ● Implement a formal sponsorship program. ● Implement methods to communicate impact to donors. <p>Governance and Executive</p> <ul style="list-style-type: none"> ● Formalize board workings and bring on 1-2 new board members. ● Secure LGSF's internal operating procedures. ● Provide regular updates to committees and board. ● Develop leaders and leadership. ● Establish 3 year plan. <p>Finance</p> <ul style="list-style-type: none"> ● Develop a steady, diversified income stream. ● Determine an investment plan. ● Determine financial efficiency. 	<p>Fundraising and Development</p> <ul style="list-style-type: none"> ● Implement formal fundraising plan. ● Grow fundraising base. ● Enhance and staff a formal donor management plan. ● Enhance formal sponsorship program. ● Maximize methods to communicate impact to donors. <p>Governance and Executive</p> <ul style="list-style-type: none"> ● Enhance board workings and bring on 1-2 new board members. ● Maximize efficiency of LGSF's internal operating procedures. ● Provide regular updates to all stakeholders. ● Develop leaders and leadership circle. Implement 3 year plan. <p>Finance</p> <ul style="list-style-type: none"> ● Maintain, grow a steady, diversified income stream. ● Implement investment plan if possible. ● Maximize financial efficiency. 	<p>Fundraising and Development</p> <ul style="list-style-type: none"> ● Implement formal fundraising plan. ● Grow fundraising base. ● Expand formal donor management plan. ● Expand formal sponsorship program. ● Maximize reach of impact to donors comms. <p>Governance and Executive</p> <ul style="list-style-type: none"> ● Enhance board workings and bring on 1-2 new board members. ● Maintain LGSF's efficient internal operating procedures. ● Provide regular updates to all stakeholders. ● Develop leaders and leadership circle. Implement 3 year plan. <p>Finance</p> <ul style="list-style-type: none"> ● Maintain, grow a steady, diversified income stream. ● Expand investment plan if implemented. ● Maintain efficient financial system.

LGS FOUNDATION

LENNOX GASTAUT SYNDROME



STANDING TOGETHER. STRONGER TOGETHER.