LGS FOUNDATION®
LENNOX-GASTAUT SYNDROME
www.lgsfoundation.org

LGS FOUNDATION

2024 ANNUAL REPORT

STRONGER TOGETHER
STRONGER TOGETHER
STRONGER TOGETHER
STRONGER TOGETHER
STRONGER TOGETHER

IN THIS REPORT

TABLE OF CONTENTS

MESSAGE FROM THE BOARD CHAIR

Strength in Community, Hope in Action

Fred and his family

As Chair of the Board of Directors for the Lennox-Gastaut Syndrome (LGS) Foundation, I am honored to serve and proud to share our annual report for 2024. I continue to be inspired by the resilience of those affected by LGS and their families. My family knows first-hand the devastation caused by LGS, as my oldest son, Brian, lived with this debilitating condition for forty-three years until his passing in 2016. To those currently living with LGS, you know it can be an isolating and frightening experience. Please be assured the LGS Foundation is walking this journey with you.

In 2024, the Foundation has taken significant steps forward in building an enduring organizational infrastructure that will position us to deliver on our commitment to improve the lives of those living with LGS. Through collaborative partnerships, funding groundbreaking research, and unwavering advocacy and support programs, we continue working toward a future with better treatments and, ultimately, cures for LGS.

This report contains detailed information on the many exciting accomplishments the Foundation has achieved this past year. Each one is significant in fulfilling our mission. In addition, I would like to highlight another exciting event in 2024: the creation of the LGS Foundation Endowment Fund. Establishing an Endowment represents a landmark moment for the Foundation, reflecting our commitment to a future where LGS is no longer a barrier to living full and meaningful lives. It also represents a critical step for the Foundation in ensuring a sustainable source of funding to support vital programming.

I invite you to join us in making this endowment a lasting legacy for those affected by LGS. Your gift, whether large or small, will help us build a financial future that will allow us to continue our mission without interruption, even in times of financial uncertainty. For more information about how you can contribute to the LGS Foundation Endowment Fund, please visit our website or contact Tiffany Johnson, Director of Development (tiffany@lgsfoundation.org).

This year has been one of both progress and reflection. While we celebrate our achievements, we know there is much more work to do. Rest assured, the LGS Foundation board and staff will continue to work tirelessly for our LGS children and families. Thank you for your ongoing dedication, support, and belief in our mission. Together, we are making a difference!

> *New drug therapies, effective surgical options, refined genetic testing and ground-breaking caregiving technologies are now available. This progress did not just happen. It is the result of tireless advocacy by LGS families and the research funding efforts of the LGS Foundation. This momentum toward quality-of-life improvements and LGS cures must continue!*

Fred Roedl
Board Chair
LGS Foundation

ABOUT LGS

LENNOX-GASTAUT SYNDROME

Lennox-Gastaut Syndrome (LGS) is a severe epilepsy syndrome that develops in young children and regularly leads to lifelong disability.

Over 50,000 children and adults in the United States and over

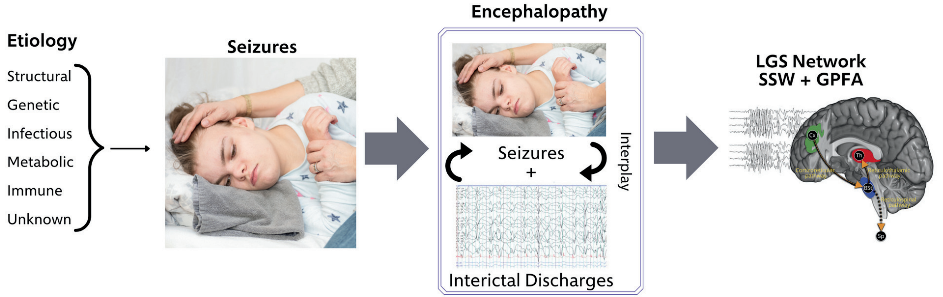
1 Million

worldwide have LGS.

75% of those with LGS suffer from daily seizures

82% of those with LGS suffer from prolonged seizures

Regardless of etiology, all with LGS converge onto the same underlying brain network disorder.

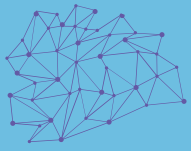


Warren AEL, Harvey AS et al. l, Neurology 2019.

There are many causes of seizures that can evolve into LGS. These include:

Trauma at Birth	Genetic Factors
Abnormal Brain Formation	Chromosomal Abnormalities
Infections	Head Injury
Metabolic Disorders	Autoimmune Disorders

In 70-90% of cases, the cause (etiology) of seizures that evolved into LGS is known



98% of those with LGS want a treatment that targets the underlying biology of LGS, and not just seizures.

OUR STORY

How It Started

It all started with a sister who saw the suffering her family went through taking care of her younger brother who had LGS. Her parents were isolated, alone, and cut off from the world. So she started the LGS Foundation in 2008, and within a year, dozens of families from across the globe had come together to build the LGS Foundation community of support.

Our Impact

Today, that community has grown to more than 12,000 members in 23 countries. We have a thriving online community of families, offer monthly support groups, and have nearly 50 Patient Navigators and Family Ambassadors who help families navigate the LGS diagnosis and treatment odysseys.

Our LGS Collaborative Research Network has grown to 500 members who are committed to advancing patient-driven LGS research. We granted scholarships to over 100 LGS families to attend our 9th biennial International Family and Professional Conference so they could meet other families and learn more about LGS treatments and research. We granted over $150,000 for medical equipment. And we have funded more than $1.8 Million to accelerate research and bring the patient-family's voice into everything we do. Our community is committed to writing a new future for those with LGS!

Looking Ahead

The future is brighter than it has ever been for those living with LGS. New treatments that target totally novel seizure mechanisms are in the pipeline for LGS. Further, patient families told us they wanted research to target the underlying biology of LGS, not just the seizures, and we are now funding the brightest minds in the world to work on this! Other hot topics that we'll be sharing resources on are SUDEP, behaviors, and genetics. The LGS Foundation continues to pioneer the development of disease-modifying therapies in LGS.

In 2025, we'll be launching into Phase 2 of our Learn From Every Patient Database, which will help us learn what works and what doesn't in LGS treatment and apply our learnings to future patients. The future is bright because those with LGS are all coming together to fund better treatments and cures for LGS.

ABOUT THE LGS FOUNDATION

OUR WORK

Our Vision

To end the devastation and suffering caused by Lennox-Gastaut Syndrome (LGS).

Our Mission

To improve the lives of those impacted by LGS through advancing Research, Awareness, Education, and Family Support.

Research Programs

- Learn from Every Patient Database & Natural History Study
- Cure LGS 365 Research Grants
- LGS Meeting of the Minds
- LGS Foundation Seminar Series
- Research Advisory Councils and Focus Groups
- Patient Family Grant Reviewers

Education & Awareness

- LGS Learning & Resource Center
- Navigating LGS Video Series
- International Family & Professional Conference
- Walk ‘n’ Wheel for LGS
- International LGS Awareness Day
- LGS Community Center
- Advocates for LGS

Family Support Programs

- Online Private Support Community
- Monthly Online Support Groups
- New Family Welcome Program
- LGS Online Community Center
- In-Person Meet Ups
- Elevate Patient Assistance Program
- Patient Navigators & Ambassadors
- New Family Welcome Kits
- About LGS Treatments Kits
- VIP Sibling & Caregiver Kits
- Adult C.A.R.E. Binders

LGS IS TOUGH. SO ARE WE.

2024 HIGHLIGHTS

Support for LGS Families

3,000+ LGS Educational Kits Mailed to Families

"As a parent dealing with this new diagnosis, the welcome kit helped me better understand and explain to family and teachers more about my child's condition."

-LGS Caregiver

$15K+	Awarded to patient-families to assist with essential durable medical equipment
800+	LGS Caregivers received individualized one-on-one support from our team
4 Monthly Support Groups	Newly Launched this year for Spanish speaking families: LGS Grupo de Esperanza
7.5K+	Members in our private Global Online Caregiver Support Community

9th International Family & Professional Conference

Accelerating LGS Research

180+ Families enrolled in Phase 1 of the LGS Learn from Every Patient Database

$125K In Research Grants Awarded to New Cure LGS 365 Grant Recipients

"I am excited by the prospect of contributing to LGS research in a manner that can ultimately lead to improved treatments for patients."

- Colleen Carpenter, PhD
Cure LGS 365 Grant Recipient

Increasing Awareness & Education

400+ Global leaders, healthcare professionals, and families united in Phoenix, AZ for 3 days of educational sessions, treatment updates, and workshops at the 9th International Family & Professional Conference.

133 Financial scholarships provided to patient-families who would otherwise be unable to attend.

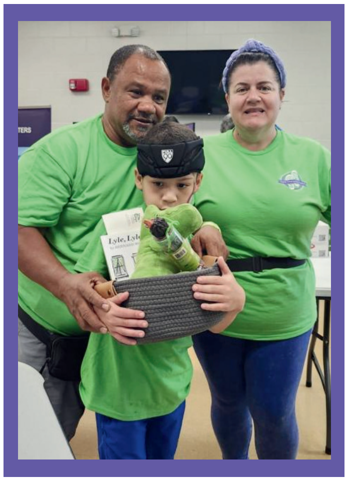
"Leaving the conference, I felt a mix of emotions, but most prominently, I felt hopeful and empowered. The wealth of information and support available provided a renewed sense of optimism."

-LGS Caregiver

120+	locations across 6 countries Illuminated for LGS during Epilepsy Awareness Month
43 Advocates for LGS	Advocates attended Rare Disease Day on Capitol Hill and Rare Across America

HEARING FROM OUR FAMILIES

OUR IMPACT



"My son, was diagnosed at the age of 3. Since I found the Foundation, they have been very kind, attentive and helpful. They have also helped us with equipment for our son. In their activities we have met other families with whom we can exchange knowledge and doubts. Thank you."

-Meitxy, Mom to José

"Since my brother was diagnosed with LGS, the LGS Foundation had been an extraordinary resource to me as I am an LGS sibling. This picture was taken at the very first LGS Conference we attended, and we have attended every other event we can since then!"

-Shaye, Sister to Deven

"My son is 38 and an LGS warrior! Our family has been blessed to be involved with the Foundation for several years. We have found a new "family" - people who understand our life and what we go through on a daily basis. We were honored to be able to attend the conference this year and to learn so much that has helped our son live a better life and helped our family learn new ideas and concepts that have assisted us on this difficult journey."

-Diana, Mom to Billy

"I want you to know how thankful and appreciative I am for providing this supportive chair to my son. Insurance denied him for many important pieces of equipment despite trying to appeal them and it's been very discouraging. This chair has made a huge difference in his daily life."

-Lauren, Mom to Paxton

"My daughter was diagnosed with LGS at 3 years old. The Foundation has helped us with the struggles we have faced. They offer many was to support families, the best, in my opinion, is the Facebook group where families can communicate and support each other."

-LGS Caregiver

LGS FOUNDATION: THE PEOPLE

BOARD OF DIRECTORS

Our Board of Directors comprises community and national leaders with expertise in various areas, including training, advocacy, education, finance, law, fund development, and business management. Those who serve on our Board of Directors do so voluntarily, without compensation. It is their willingness to share their gifts and talents that drive our organization forward.

Fred Roedl, MBA
Board Chair
Florida

Kat Belendiuk, PhD
Vice Chair
Montana

Kevin Merritt, CFA, MBA
Treasurer
Connecticut

Dale Todd
Secretary
Iowa

Jacqueline Villatoro
Board Member
New York

Deena Andreola
Board Member
New Jersey

STAFF

Our Staff brings a wealth of experience and expertise to the LGS Foundation, united by their passion for our mission to end the devastation and suffering caused by LGS.

Tracy Dixon-Salazar, PhD
Executive Director

Kathy Leavens
Senior Director Of Programs

Amber Mathas
Senior Director Of Operations

Tiffany Johnson
Director Of Development

Jennifer Griffin
Director Of Family Support

Kayleigh Keen
Communications & Community Engagement Manager

Hanna Jorgenson
Communications Coordinator

Quinn Edwards
Executive Assistant

Sami Cox
Administrative Assistant

LGS FOUNDATION: THE PEOPLE

MEDICAL SCIENCE ADVISORY COUNCIL

The LGS Foundation's Medical Science Advisory Council (MSAC) is established by the Board of Directors at its discretion and consists of medical practitioners, scientists, and others with expertise in the diagnosis, treatment, management, and investigation of LGS and its effects. The MSAC helps guide program opportunities and advises on educational needs, policy development, and strategic planning.

Elaine Wirrell, MD
MSAC Chair
Mayo Clinic Rochester

Peter Crino MD, PhD
University of Maryland,
School of Medicine

Scott Perry, MD
Cook Children's
Hospital

Juliet Knowles, MD, PhD
Stanford University

Renee Shellhaas, MD, MS
Washington University

Jim Wheeless, MD
Le Bonheur Children's
Hospital

Fabio Nascimento, MD
Washington University,
St. Louis

Jennifer Gelinas, MD, PhD
University of California
Irvine

LGS FOUNDATION: THE PEOPLE

CORPORATE ADVISORY COUNCIL

The Corporate Advisory Council, composed of dedicated individuals from a variety of industries, receives regular progress updates from the LGS Foundation on its mission of improving the lives of those impacted by LGS. The Council guides the LGS Foundation as it seeks to end the devastation and suffering caused by LGS. Council members have no fiduciary responsibility, and any advice given is non-binding, guided by our Corporate Relations Policy. By partnering with those working to help LGS families, we are building better futures for our loved ones with LGS.

Jazz Pharmaceuticals

ucb
Inspired by **patients.**
Driven by **science.**

LONGBOARD
PHARMACEUTICALS

Takeda

NEURELIS™

ASSERTIO

NEUROPACE

SK life science
a subsidiary of SK biopharmaceuticals

epygenix
THERAPEUTICS

MARINUS

azurity®
pharmaceuticals

LivaNova
Health innovation that matters

INVITAE

Eisai

BEACON
BIOSIGNALS

BANKING REPORT

FINANCIAL STATEMENT

ASSETS	Total
Cash & Cash Equivalents	$182,852
Pledges Receivable, net	$81,222
Prepaid Expenses	$60,652
Investments, Long-term	$658,201
TOTAL ASSETS	**$982,927**

LIABILITIES	
Accounts Payable and Accrued Liabilities	$4,954
Grants Payable, net	$139,990
Lease Liability	-
Deferred Revenue	$115,500
Note Payable	-
TOTAL LIABILITIES	**$260,444**

EQUITY	
Designated Net Assets for Research	-
Designated Net Assets for Research Grant Obligations	-
Retained Earnings	$1,037,746
Net Revenue	$(319,263)
TOTAL EQUITY	**$718,438**
TOTAL LIABILITIES & EQUITY	**$982,927**

BANKING REPORT

FINANCIAL STATEMENT

REVENUE	Operating Revenue	Restricted Revenue	Total
Contributions	$372,927	-	$372,927
Special Events	$740,510	-	$740,510
Contracts	$28,572	-	$28,572
Registration	$9,495	-	$9,495
Grant Revenue	$56,000	-	$56,000
Other Income	$3,503	-	$3,503
Investment Income (Interest)	$18,447	-	$18,447
TOTAL REVENUE			**$1,229,455**

EXPENSES			
Program Services	$1,366,675		$1,366,675
General & Administration	$130,467		$130,467
Fundraising	$52,790		$52,790
TOTAL EXPENSES			**$1,549,932**

The LGS Foundation is proud to be a top-rated charity, regularly reviewed and held accountable by independent third-party organizations. At the LGS Foundation, 97% of funds raised go directly to the mission.

Platinum Transparency 2023
Candid.

GREATNONPROFITS 2023 TOP-RATED NONPROFIT

Charity Navigator
FOUR-STAR

LGS FOUNDATION

STRATEGIC PRIORITIES FOR 2025 AND BEYOND

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.*

SUPPORT AND EDUCATE FAMILIES

Strengthen family connection initiatives, including:

- **LGS Research Meeting of the Minds: Advancing Evidence-Based Care Across the Lifespan**
  - This is important because bringing together healthcare professionals (HCPs) fosters collaboration, accelerates the sharing of best practices, and ensures that individuals with LGS receive the most up-to-date, evidence-based care throughout their lives. It also helps identify gaps in treatment, explore new research directions, and build a stronger network of experts dedicated to improving outcomes for LGS patients.
- **Walk ‘n’ Wheel**
  - This is important because it unites the LGS community in a visible and empowering way, raising critical funds and awareness for research. The event also helps families feel connected, reducing isolation and reinforcing the message that they are not alone in their journey with LGS.
- **International Awareness Day Activities**
  - This is important because raising our voices together on a global scale helps increase understanding of LGS, drive research funding, and advocate for better care and treatments. Awareness is a key step toward finding cures and ensuring that those affected by LGS receive the support they need.
- **LGS Community Center**
  - This is important because it fosters connection, support, and empowerment for families affected by LGS. Through support groups, a collaborative research network, volunteer opportunities, and patient navigators, it ensures no one faces LGS alone while advancing care, advocacy, and research.

EMPOWER LGS FAMILIES TO FIND THE BEST CARE

Launch LGS Community Center Educational Courses

This is important because expert-led courses on sleep, behavior, and mortality provide families with critical knowledge and practical strategies to improve care, advocate effectively, and navigate the challenges of LGS with confidence.

Provide tools and training to help families:

- Navigate the healthcare system
- Advocate for appropriate medical care

Educate families on:

- The latest LGS research
- Treatment advancements to support informed decision-making

LGS FOUNDATION

STRATEGIC PRIORITIES FOR 2025 AND BEYOND

RAISE AWARENESS AND BUILD COMMUNITY

Fundraising and Partnerships:

- **Raise $100,000 for our Endowment**
  - This is important because it ensures the long-term sustainability of the LGS Foundation, providing stable funding for critical programs, research, and support services.

- **Raise $1M for Learn From Every Patient Database Phase 2 (LEP2)**
  - This is important because expanding LEP2 will improve research, optimize treatments, and personalize care, using collective patient data to drive better outcomes for everyone with LGS.

Click Here to Learn More about the LGS Learn from Every Patient Database

RESEARCH

Learn From Every Patient Database Phase 2 Milestones:

- Create and test builds 2 and 3 in survey portal
- IRB approval
- Launch Caregiver Survey 1
- Strengthen partnerships with researchers, clinicians, and organizations to drive progress in LGS treatment and care, funding key initiatives in patient-driven priorities.
- Launch 3 additional surveys in 2025

Consensus Opinion Milestones:

Develop expert consensus recommendations through three rounds of surveys/questionnaires by engaging international adult and pediatric epileptologists and LGS caregivers.

- Publish formal recommendations to establish a standard of care.
- Ensure optimal treatment for LGS patients worldwide.
- Provide a roadmap for managing comorbidities and expected outcomes.

2024

CURE LGS 365 RESEARCH GRANT RECIPIENTS

International Consensus for the Diagnosis and Management of Lennox-Gastaut Syndrome

Anthony Fine, MD - Mayo Clinic
Juliet Knowles, MD, PhD - Stanford University School of Medicine

Highlights:

- The care of people with Lennox-Gastaut syndrome (LGS) can be significantly variable in terms of diagnosis and management.
- There is limited consensus for first, second-, or third-line treatments in LGS.
- Initial literature review will focus on the following topics: (1) Recommended diagnostic investigations for newly diagnosed, suspected, and/or presumed LGS, (2) Prophylactic antiseizure medication management and management of status epilepticus, including nonconvulsive status epilepticus, (3) Nonpharmacologic therapies, including dietary therapy, surgical treatments, and neuromodulation, (4) Management of comorbidities including SUDEP, and (5) Evolution of clinical and electroencephalographic findings from early LGS to adulthood and transition of care.
- Expert consensus recommendations will be developed through 3 rounds of surveys/questionnaires to a group of international and geographically diverse adult and pediatric epileptologists and caregivers using the Delphi process.

Identifying Risk Factors for the Progression of Infantile Epileptic Spasm Syndrome (IESS) to LGS

Juliet Knowles, MD, PhD - Stanford University School of Medicine
Zach Grinspan, MD, MS - Weill Cornell School of Medicine

Highlights:

- Up to 50% children with Infantile Epileptic Spasm Syndrome (IESS) will develop LGS in 1-2 years.
- Identification of children with higher risk who develop LGS after IESS will help to develop therapies to prevent LGS onset.
- The Pediatric Epilepsy Learning Health System (PELHS) has harmonized medical records for 487,000 children with history of seizures or epilepsy from 20 academic medical centers.
- The purpose of this study is use PELHS to identify risk factors and predict progression to LGS in a cohort of children with history of IESS.

Results will be shared when the grants are completed.

Thank you for driving progress and hope with us in 2024!

The LGS Foundation is the only global nonprofit organization dedicated to improving the lives of individuals impacted by LGS through advancing research, awareness, education, and family support.

☎ Phone

(718) 374-3800

@ Email

giving@lgsfoundation.org

Website

www.lgsfoundation.org

Address

6030 Santo Road
Suite 1, Unit 420878
San Diego, CA 92142

Let's Connect on Social Media!