

LGS FOUNDATION[®]

LENNOX-GASTAUT SYNDROME

www.lgsfoundation.org 

LGS FOUNDATION

2023 ANNUAL REPORT

STRONGER TOGETHER
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MESSAGE FROM THE BOARD PRESIDENT

Together, We Are Changing the Future For Those Impacted By Lennox-Gastaut Syndrome



Karen, Jeff, and Danny

Our son, 38-year-old Danny, was 22 when the Lennox-Gastaut Syndrome (LGS) Foundation was founded. Prior to that time, there was little information, and even less hope. We were totally isolated. While there is still no cure for LGS, through the LGS Foundation, there is a community of families, advocates, and medical professionals united to provide family support and create possibilities for those impacted by this devastating and debilitating disease.

At the LGS Foundation, patient-family needs drive all that we do. Educating, supporting, and empowering families are our priorities, and includes support programs in various formats, like our [About LGS Treatments Kits](#) which were sent to over 600 LGS families last year. Also included are our [Patient Assistance Grants](#) for durable medical equipment. We've funded nearly \$70,000 to provide families with equipment not covered by insurance. Establishing a strong support community means no one needs to be on this journey alone.

The LGS Foundation also funds cutting-edge LGS research through our ["Finding the Cures, Together" Program](#), partnerships within the medical community, and our biennial [LGS Research Meeting of the Minds Conference](#), which ensure that we drive scientific research on projects that will actually improve the lives of those impacted by LGS. Together, we are creating a hopeful path forward.

My husband Jeff and I, in partnership with the LGS Foundation Board of Directors and Staff, are committed to providing leadership and funding with the hope that one day no other family has to endure daily seizures, procedures, tests, hospitalizations, or experience the heartbreaking devastation caused by LGS. Thank you for supporting us on this journey!



Standing Together. Stronger Together.

While there is still no cure for LGS, through the LGS Foundation there is a community of families, advocates, and medical professionals united to provide family support and create possibilities for those impacted by this devastating and debilitating disease.

Karen Groff

Board President
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 48,000 children and adults in the United States and over

1 Million worldwide have LGS.

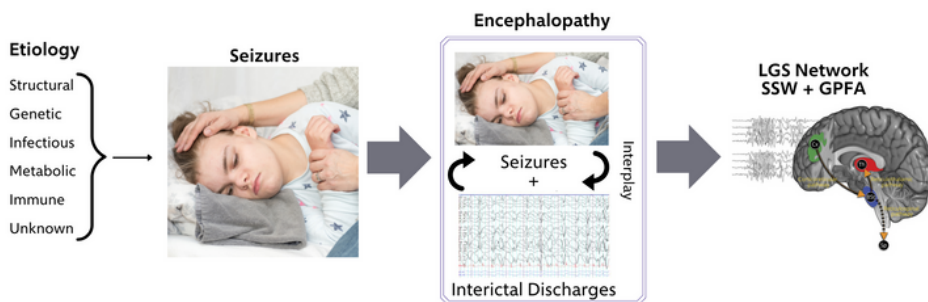


75% of those with LGS suffer from daily seizures



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. J, Neurology 2019.

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



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

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

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 11,000 members. 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 have granted scholarships to over 200 LGS families to attend our biennial International Family and Professional Conference so they can meet other families and learn more about LGS treatments and research. And we have funded more than \$1.5 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! The LGS Foundation continues to pioneer the development of disease-modifying therapies in LGS.

Excitingly, in 2023, we began building 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.

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
- Swing FORE the Cures Golf Outing
- 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

LGS IS TOUGH. SO ARE WE.

2023 HIGHLIGHTS

Educating,
Empowering,
& Supporting
LGS Families

7,000+ In Our Online
Private Support
Community
Caregivers

90,000+ Across All
Social Media
Channels
Followers

600+
New Family
Welcome Kits
Sent

"There is something devastating about raising a child and never knowing where they fit. The LGS Foundation has given us a place and people to love and call home. The people I've met along this journey are family to us."

- ANDEE, MOM TO KANNON

600+
About LGS
Treatments
Kits Sent

ACCELERATING LGS RESEARCH WITH LGS FAMILIES AS PARTNERS

\$1.5
Million

Invested in
LGS Research
since 2008

500

Have joined the
LGS Collaborative
Research Network

100

Enrolled in the LGS
Learn From Every
Patient Database

19

International
Conferences
since 2008

400+
Sibling &
Caregiver Kits
Sent

25 **ADVOCATES
FOR LGS**

"Being an advocate to me means to bring recognition, change, awareness, light and hope to a community that so desperately needs it."
-Rachel, Advocate for LGS



280 **FAMILIES SUPPORTED** in 2023

"Being able to use what my family has experienced because of our son's diagnosis, to support others along their LGS journey is a profound gift to me."
-Tricia, Family Ambassador

103 **FAMILY MEMBERS
ATTENDED THE LAST
CONFERENCE ON
SCHOLARSHIP**

"Attending the LGS Conference is good for the mind, body, spirit and soul." - LGS Caregiver

OUR IMPACT



Because of your support...
The LGS Foundation is dedicated to funding cutting-edge patient-led LGS RESEARCH that is making tremendous strides toward ending the suffering and devastation of children like our six-year-old son, Cash.



Because of your support...
The LGS Foundation is able to give special attention and SUPPORT for Jackson's brother and sister. Jackson's needs are always first, even when at times the focus should be on our other two children.

“Before I joined the group, I felt so lost. Here I find support and comfort. It's really a great feeling having other people to turn to who truly understand what we are going through.”

-Alexis, LGS Mom



Because of your support...
The LGS Foundation provided us a SCHOLARSHIP to attend the LGS Family and Professional Conference and to receive invaluable assistance, just when we were so desperate for help.



Because of your support...
The LGS Foundation provided an iPad for our 10-year-old son, Micah. Though a simple gift to some, we are so grateful because our non-verbal child is now learning how to communicate in his own special way!

“The LGS Foundation is amazing. You become family instantly. Any questions or concerns you have, you can ask and will get responses.”

-LGS Caregiver

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.



*Karen Groff, M.Ed.
President
Ohio*



*Natalie Gilmore
Past President
Pennsylvania*



*Fred Roedl, MBA
Vice President
Florida*



*Kevin Merritt, CFA, MBA
Treasurer
Connecticut*



*Christopher Mitchell, JD
Secretary
Washington DC*



*Tiffany Johnson, MBA
Board Member
Texas*



*Dale Todd
Board Member
Iowa*

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*



*Ashley Burns
Director Of Finance
And Administration*



*Jennifer Griffin
Director Of Family Support*



*Eric McVicker
Director Of Development*



*Kayleigh Keen
Communications & Community
Engagement Manager*



*Hanna Jorgenson
Communications
Coordinator*

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*



*Renee Shellhaas, MD, MS
Washington University*



*Jim Wheeless, MD
Le Bonheur Children's
Hospital*

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.



FINANCIAL STATEMENT

REVENUE	Operating Revenue	Restricted Revenue	Total
Contributions	\$309,511	\$5,075	\$314,586
Special Events	\$776,319	\$(67,631)	\$708,688
Contracts	\$1,840	-	\$1,840
Registration	\$31,006	-	\$31,006
Other Income (Loss)	-	-	-
Net Assets Released from Restrictions	-	-	-
Investment Income (Interest)	\$14,542	-	\$14,542
TOTAL REVENUE			\$1,070,662

EXPENSES

Program Services	\$1,065,830		\$1,065,830
General & Administration	\$114,056		\$114,056
Fundraising	\$55,680		\$55,680
TOTAL EXPENSES			\$1,235,566

The LGS Foundation is proud to be a top-rated charity, regularly reviewed and held accountable by independent third-party organizations, including:



FINANCIAL STATEMENT

ASSETS

Total

Cash & Cash Equivalents	\$681,916
Pledges Receivable, net	\$57,180
Prepaid Expenses	\$13,344
Property and Equipment, net	\$9,540
Investments, Long-term	\$524,425
TOTAL ASSETS	\$1,286,405

LIABILITIES

Accounts Payable and Accrued Liabilities	\$21,168
Grants Payable, net	\$67,490
Lease Liability	-
Deferred Revenue	\$155,000
Note Payable	-
TOTAL LIABILITIES	\$243,658

EQUITY

Designated Net Assets for Research	-
Designated Net Assets for Research Grant Obligations	-
Retained Earnings	\$1,216,006
Net Revenue	\$(173,300)
TOTAL EQUITY	\$1,042,706
TOTAL LIABILITIES & EQUITY	\$1,286,364



Thank you for being part of our 2023!

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.



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Let's Connect on Social Media!

