Includes Input From More Than 1,300 LGS Caregivers

The LGS Patient Experience

A study of the real-world experience of patients and caregivers living with Lennox-Gastaut syndrome.

Patient Journeys.

www.PatientJourneys.org

Introduction

Thanks to the participation of more than 1,300 individuals affected by Lennox-Gastaut syndrome (LGS), we have compiled this overview of commonly reported experiences of those living with the disease. We hope that the knowledge of your peers' experiences with LGS aids in your own understanding of the disease and how it may be managed. Armed with this broad understanding of the possible realities of living with LGS, we hope that you will feel better able to make informed decisions about yourself or the person you care for regarding medical care.

It's important to remember that the content in this report is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.

We sincerely thank you for taking the time to share your experience with many other individuals affected by LGS, and hope you take comfort in knowing that there is a community of people working alongside you to learn more about this disease.

Study Highlights

- Most of the survey respondents for this study reported symptoms beginning within the first 3 years of the patient's life
- 40% reported not receiving a confirmed diagnosis until the ages of 4 through 12
- 62% of patients were diagnosed with a different or general seizure disorder prior to receiving a confirmed LGS diagnosis
- The majority of survey respondents characterized the level of impairment from LGS as "severe"
- Seizures were considered to be the most impactful health issue faced, with approximately half of the survey respondents reporting more than 20 seizures per month
- More than 70% reported considering or actively pursuing new treatment options for seizure control

ABOUT THE STUDY

Overview and Methodology

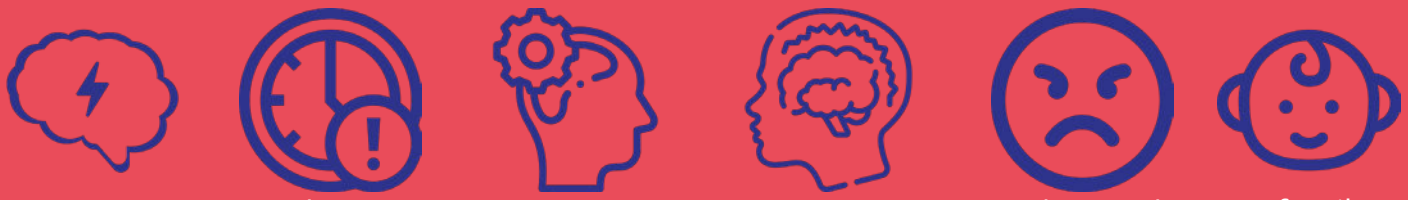
The data for this analysis was collected using an online survey of 1,391 patients and caregivers living in the United States with a reported diagnosis of Lennox-Gastaut syndrome (LGS).

Key Areas of Research

- Symptom history
- Impact of the disease on daily life
- Experiences obtaining a confirmed diagnosis
- Familial history of seizures
- Challenges, frustrations, and support needs
- Valued sources of information
- Experience with various treatments
- Seizures and how well they are controlled

Common LGS Symptoms

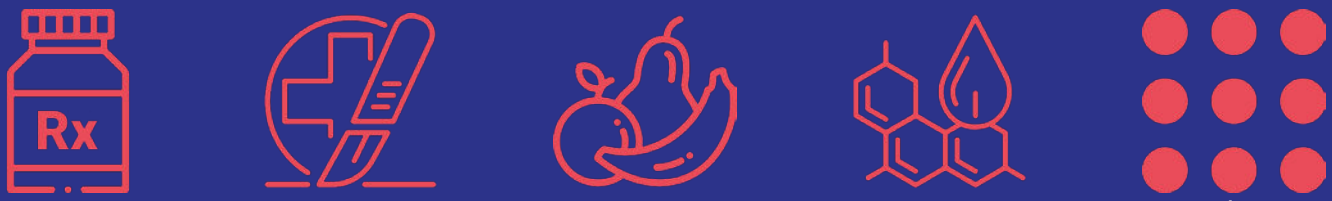
Most survey respondents experienced the following initial symptoms. More information about experiences with the diagnosis of LGS can be found on page 7 of this report.



Seizures | Development Delays | Cognitive Issues | Epileptic Spasms | Behavioral Issues | Infantile Spasms

Treatments Used to Manage Seizures

Survey respondents reported having experience with a broad range of treatment options. More information about treatments, can be found on page 11 of this report.



Prescription Anti-Seizure Medications | Surgery (Including VNS or Implants) | Diet | Non-FDA-Approved CBD Available Online, in Stores, or in Dispensaries | Other

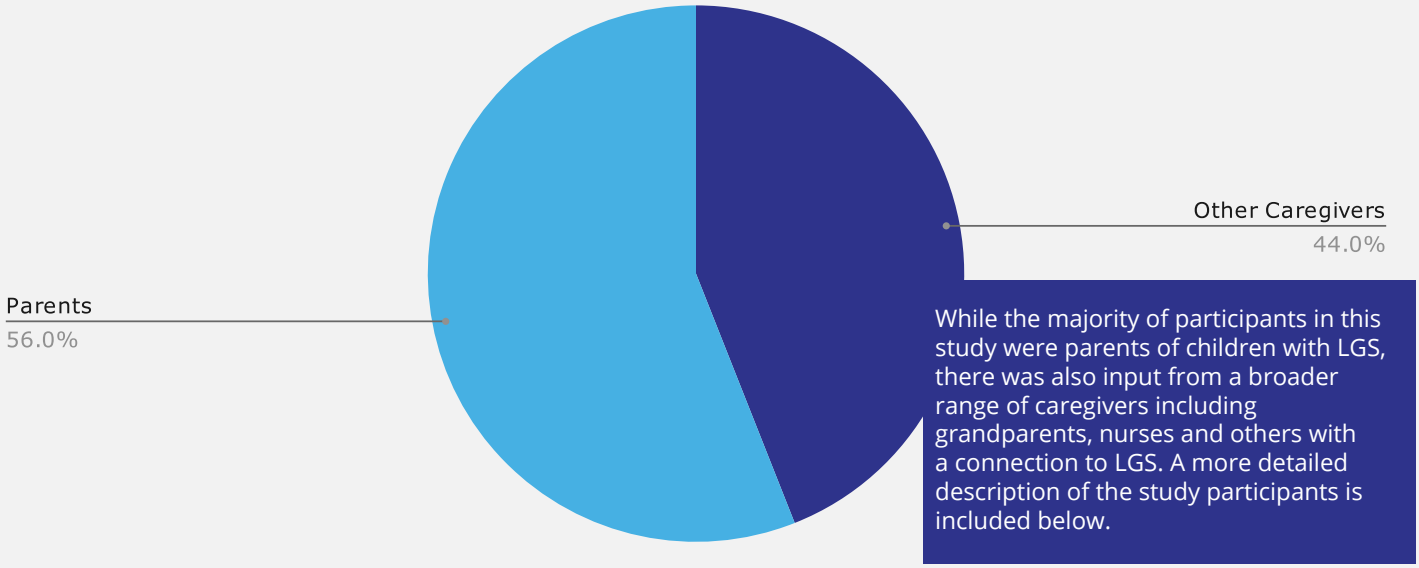
Top Social Media Platforms

Survey respondents reported using the following social media platforms to get and share information about LGS. More information can be found on page 12.

Facebook | YouTube | Pinterest | TikTok

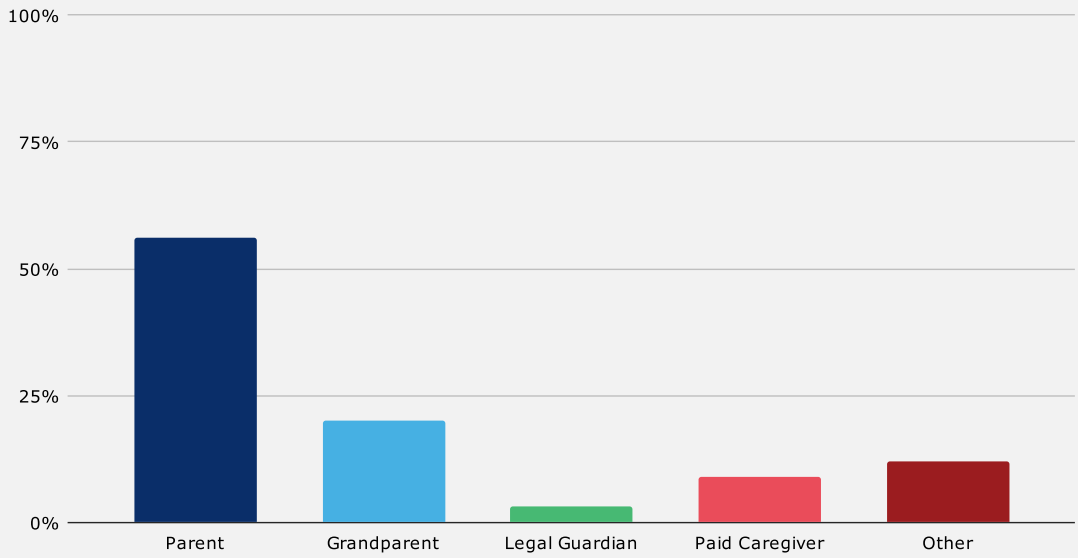
A Closer Look at Who Participated in This Study

The majority of survey respondents in this study were parents of children living with LGS.



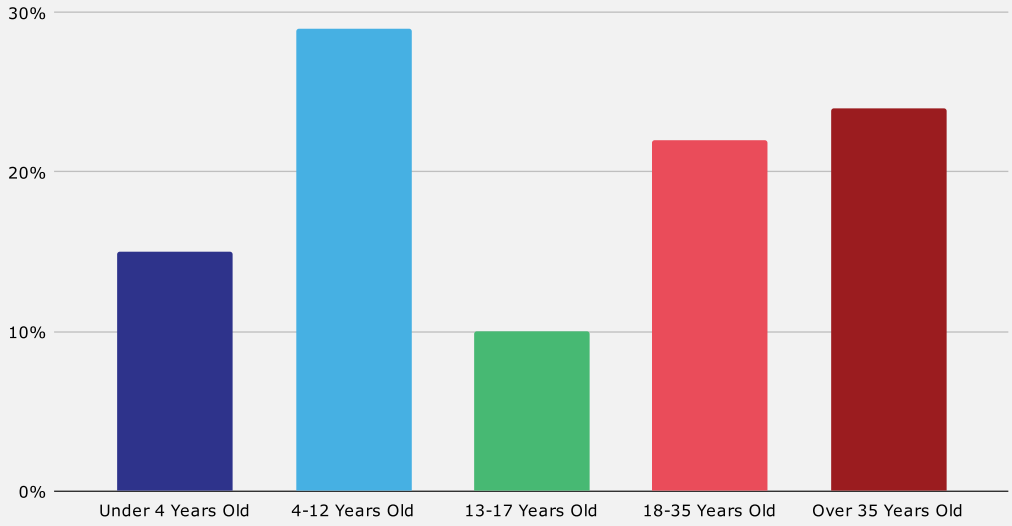
Input From a Broad Range of Caregivers

The majority of survey respondents in this study were parents of children living with LGS.



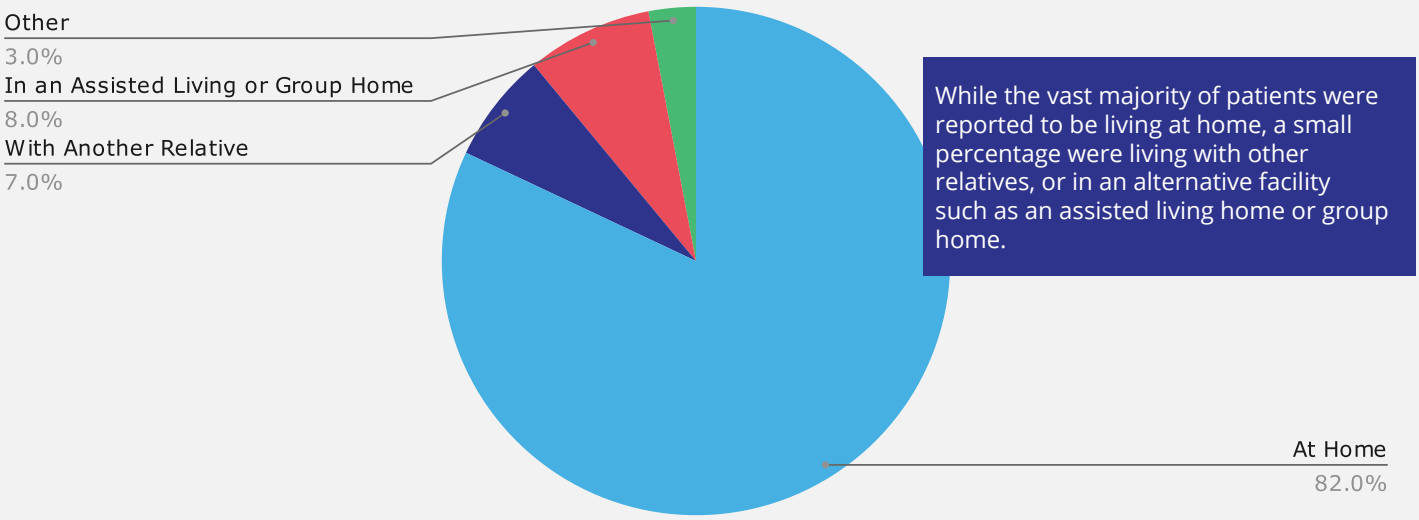
Patient Age at the Time of This Study

The patients represented in this study are relatively evenly distributed across age groups from under 4 to over 35 years old.



Living Situation

Most LGS patients referred to in this study were living at home with their parents at the time the survey was taken.



While the vast majority of patients were reported to be living at home, a small percentage were living with other relatives, or in an alternative facility such as an assisted living home or group home.

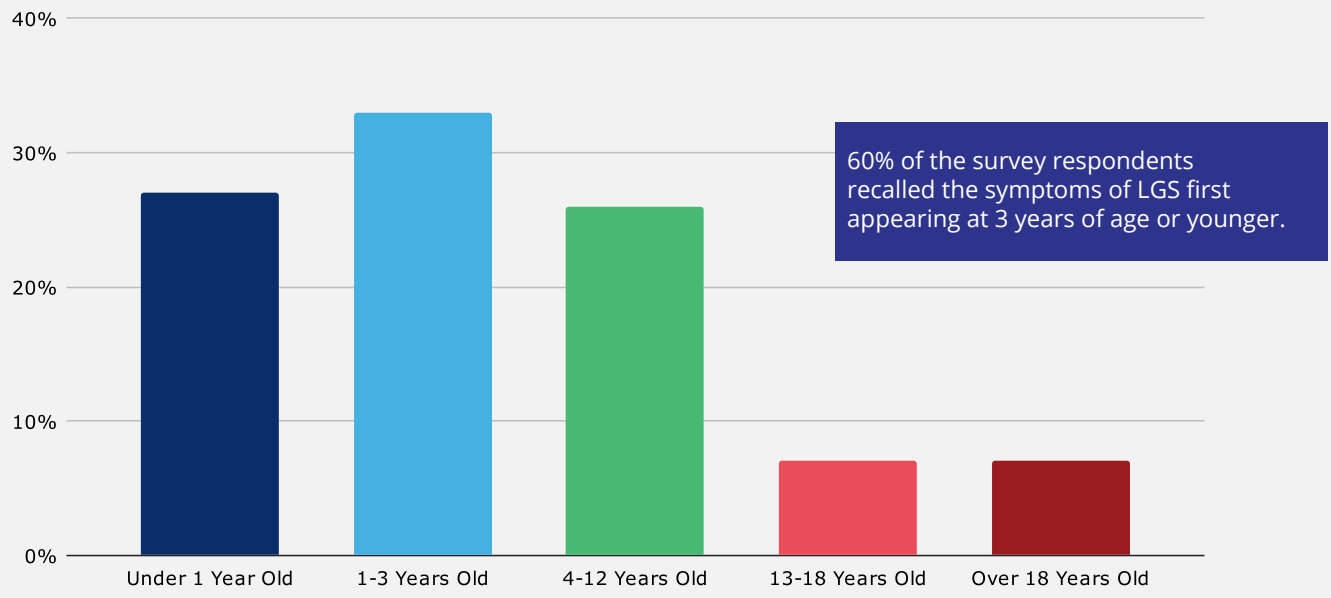
Early Symptoms That Led to Seeking Medical Care

Seizures and development delays were reported to be the most common early symptoms contributing to seeking medical care and obtaining a confirmed diagnosis.

Seizures	Development Delays	Cognitive Issues	Epileptic Spasms	Behavioral Issues	Infantile Spasms
72%	57%	47%	29%	34%	31%

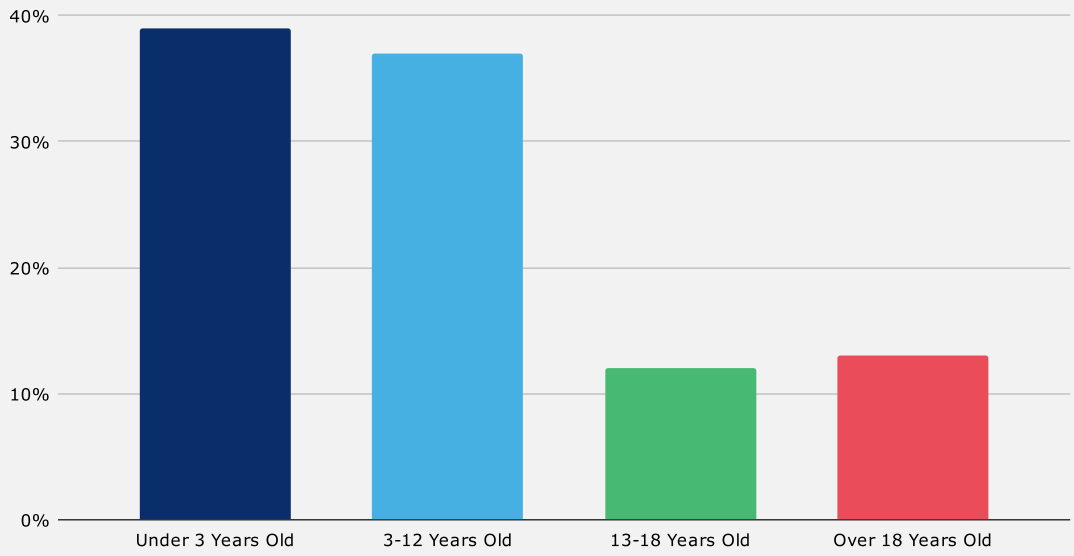
Percentage of survey respondents who recalled these symptoms occurring.

Patient Age When the Symptoms of LGS First Began



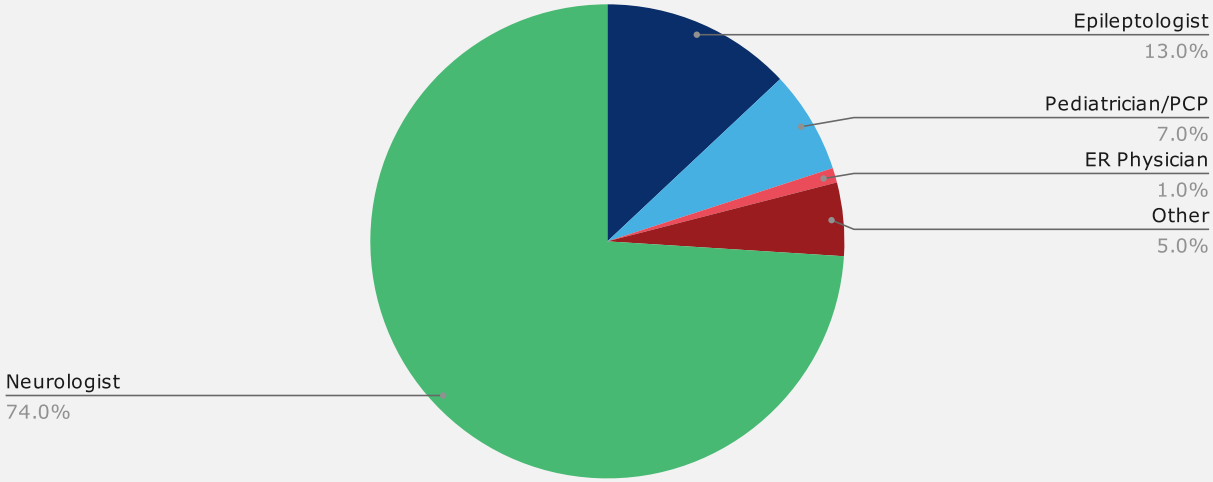
Patient Age at Diagnosis

The vast majority of LGS patients referred to in this study were diagnosed early in life. Over 35% received a confirmed diagnosis before they reached 3 years of age. Only a small percentage (approximately 13%) were diagnosed as adults.



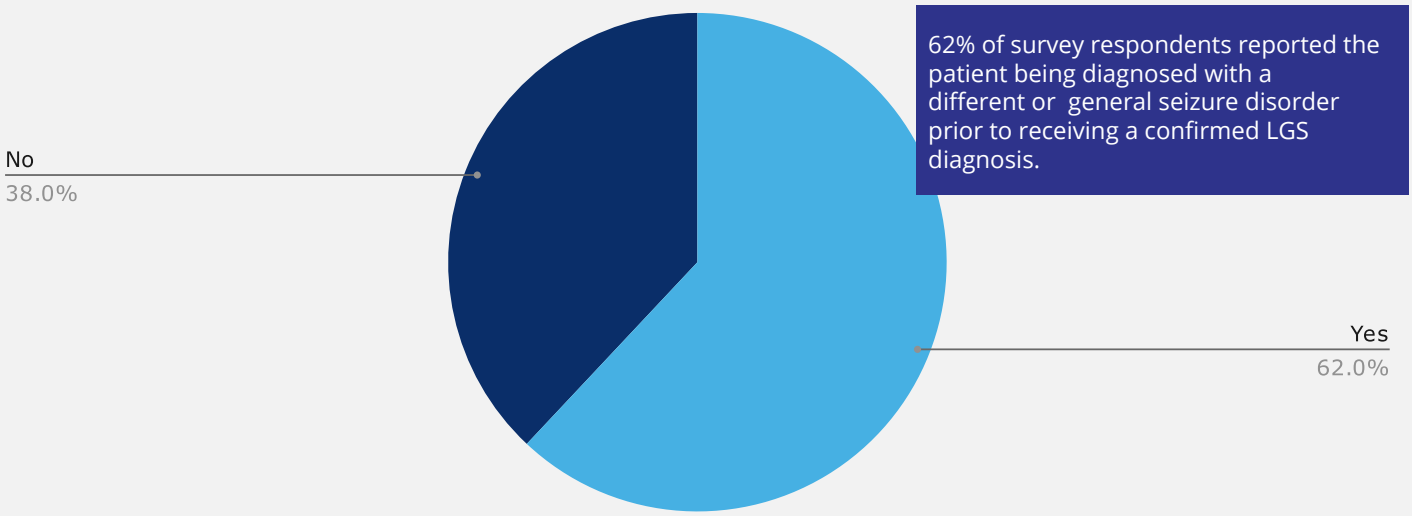
Diagnosing Physician

74% of patients were diagnosed by a neurologist, while another 13% were diagnosed by an epileptologist. An epileptologist is a neurologist who specializes in caring for people with epilepsy.



Other Diagnoses

More than half of the patients referred to in this study were diagnosed with a different seizure disorder prior to being diagnosed with LGS.

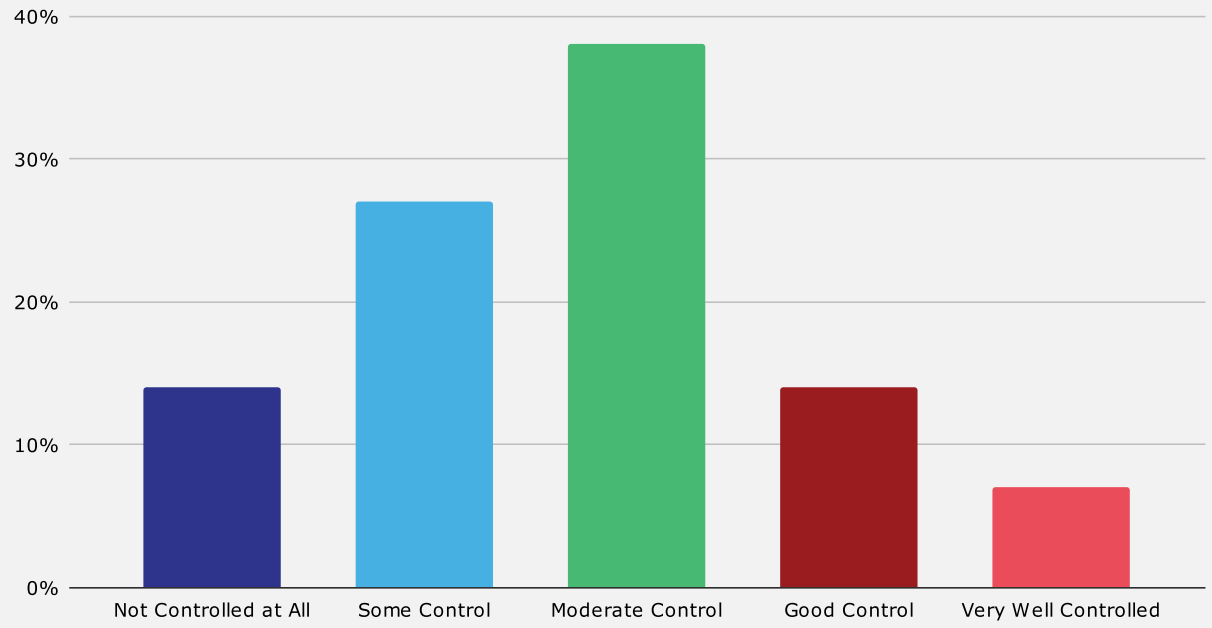


Prior Diagnoses Mentioned in This Study

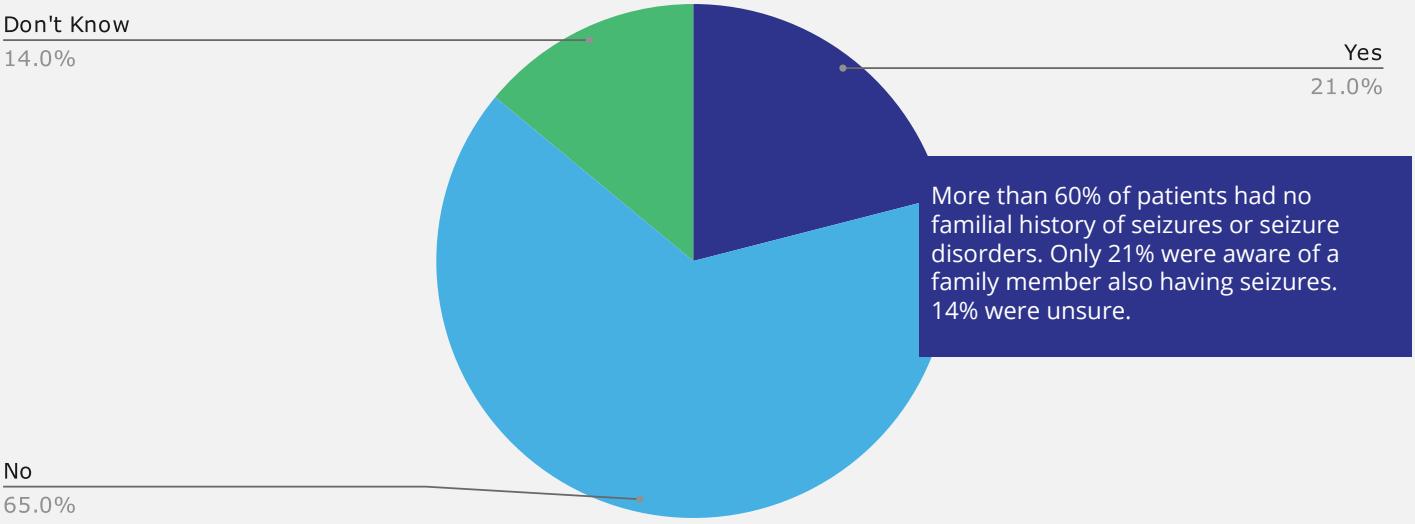
- Cerebral Palsy
- Subdural Hematoma
- Symptomatic Epilepsy Syndrome
- Fragile X Syndrome
- Idiopathic Seizure Disorder/ Infantile Spasms
- Doose Syndrome
- Nevus Sebaceus Syndrome
- Pachygyria
- Autism

Current Level of Seizure Control

Most survey respondents reported low to moderate degrees of seizure control, with 14% saying the seizures were “not controlled at all”. Conversely, only 6% felt the seizures were “very well controlled”.

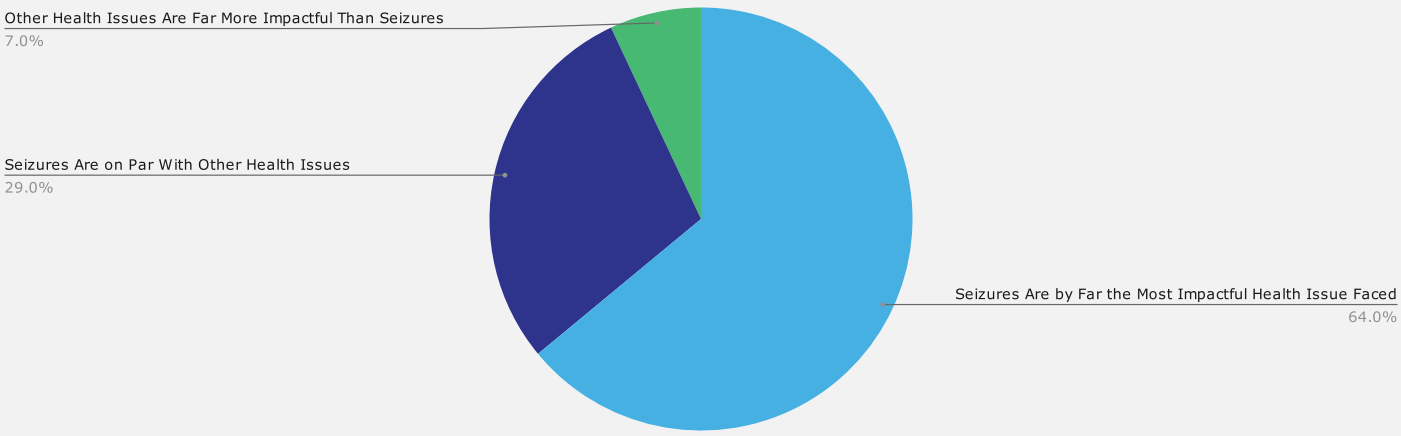


Family History of Seizures or Seizure Disorders



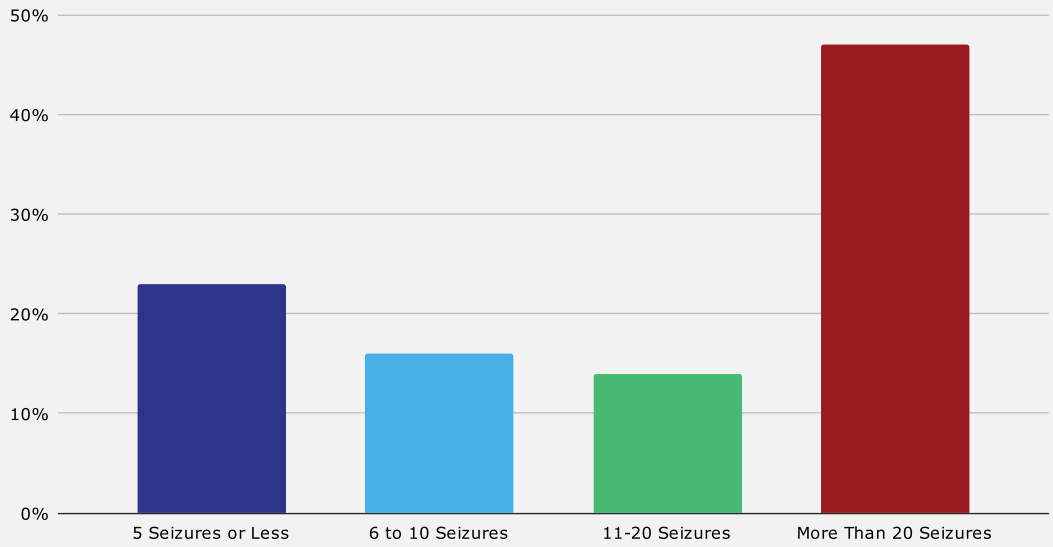
How Seizures Relate to Other Health Concerns

Seizures are considered to be one of the most significant health issues for patients. 64% of survey respondents feel that seizures are by far the most impactful health issue faced.



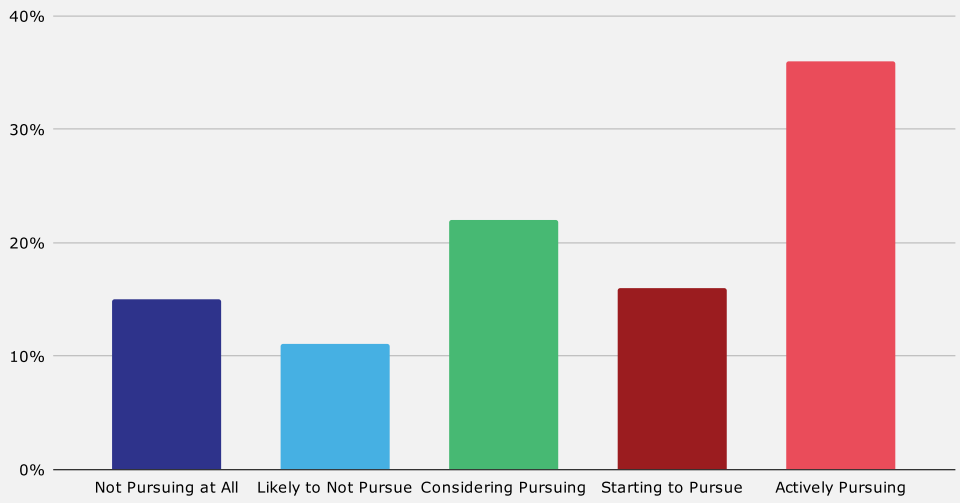
Number of Seizures Experienced in an Average Month

Almost half of the patients in this survey experience more than 20 seizures per month.



Looking for New/Different Seizure Treatments at This Time

Many of the survey respondents indicated they are evaluating new or different treatment options to manage their seizures. More than one-third said they were “actively pursuing” treatment alternatives.



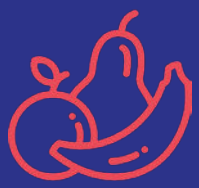
Treatments Used to Manage Seizures

Prescription Anti-Seizure Medications

93%

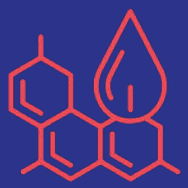
Surgery (Including VNS or Implants)

39%



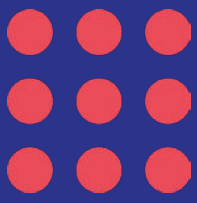
Diet

38%



Non-FDA-Approved CBD Available Online, in Stores, or in Dispensaries

25%

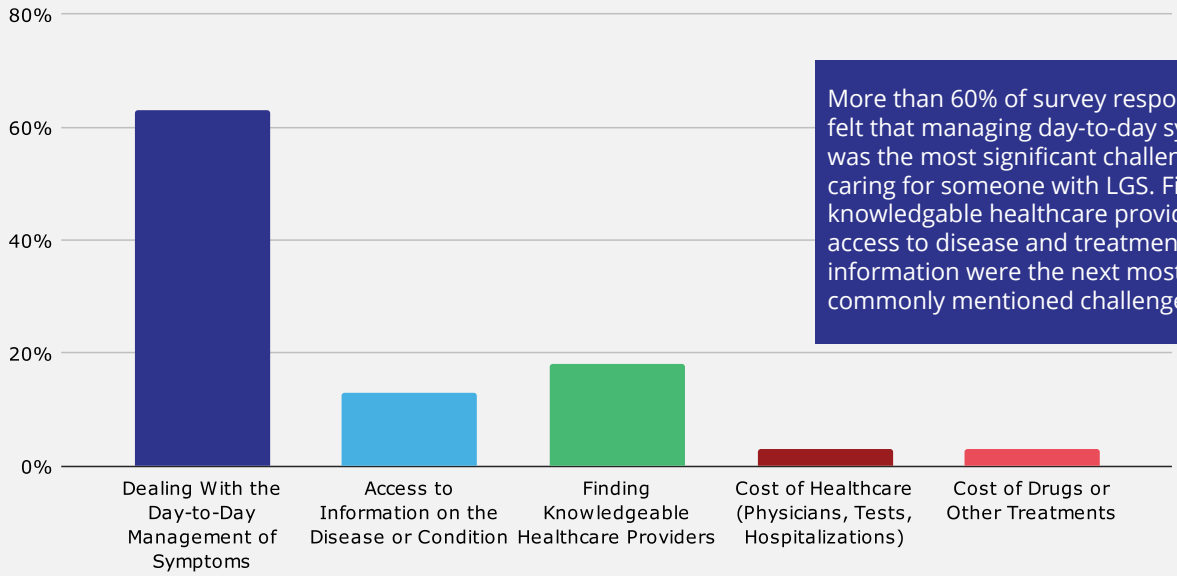


Other

10%

Percentage of survey respondents who mentioned these treatments.

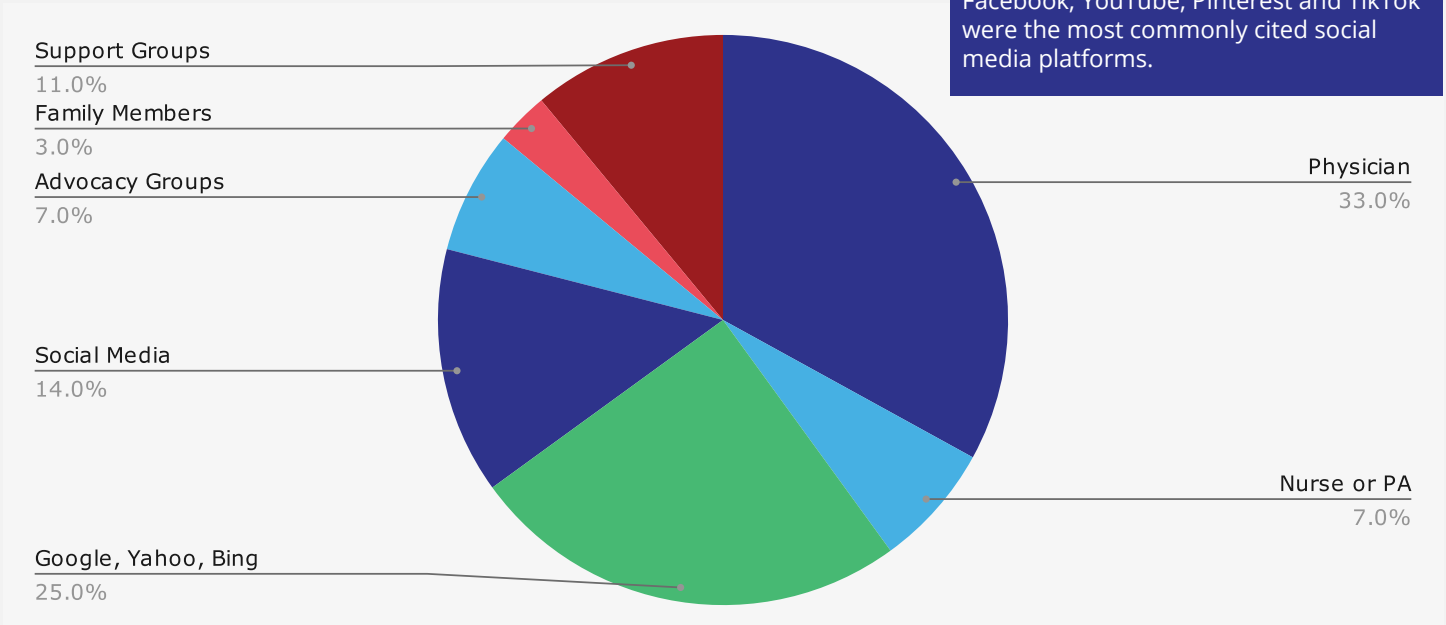
Challenges Caring for Someone With LGS



More than 60% of survey respondants felt that managing day-to-day symptoms was the most significant challenge in caring for someone with LGS. Finding knowledgable healthcare providers and access to disease and treatment information were the next most commonly mentioned challenges.

Valued Sources of Information

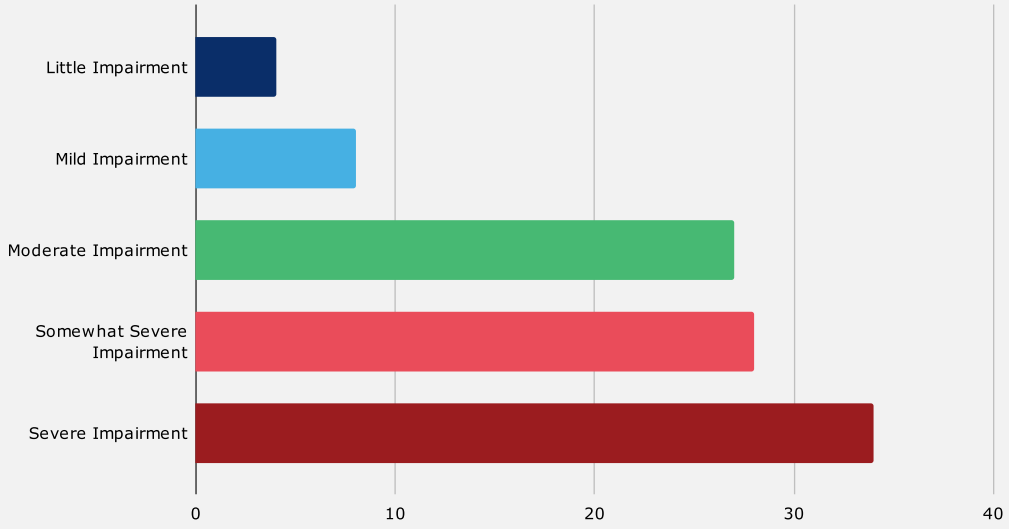
Not surprisingly, physicians were mentioned most frequently as a valued source of information. Online search engines and social media were mentioned next most frequently.



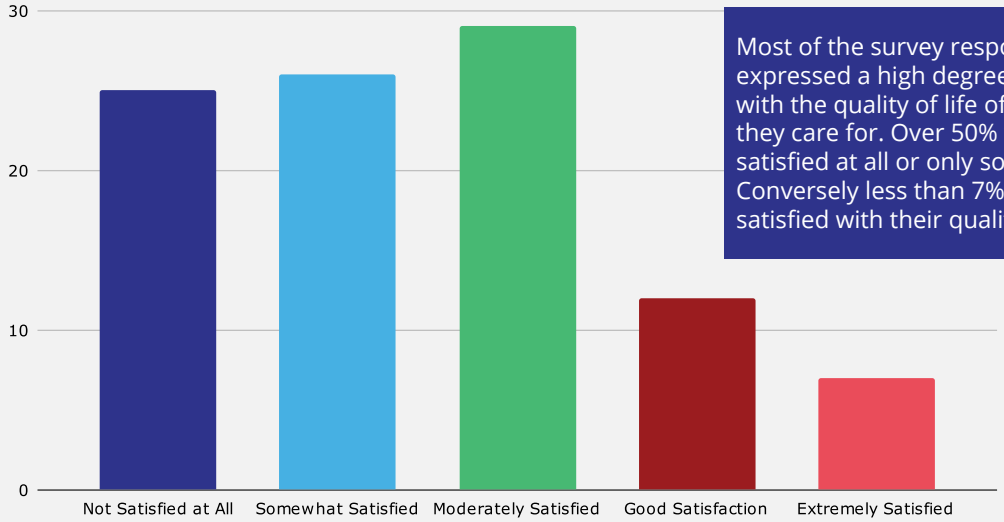
Facebook, YouTube, Pinterest and TikTok were the most commonly cited social media platforms.

Impairment of the LGS Patient

Survey respondents provided their view of how LGS impacted the patient they care for. Approximately 4% characterized the impairment as little, while 28% felt the impairment is somewhat severe, and 34% felt the impairment is severe.



Quality of Life for the LGS Patient



Most of the survey respondents expressed a high degree of dissatisfaction with the quality of life of the LGS patient they care for. Over 50% were not satisfied at all or only somewhat satisfied. Conversely less than 7% were extremely satisfied with their quality of life.

QUOTES

We'd like to thank many of our survey respondents for sharing their feelings and emotions with us. It is our hope that through these quotes, others will find comfort in knowing they are not alone.

"We're **not satisfied** with her current quality of life."

"I'm tired of seizures."

"We are **always looking** for anything we can to help our son."

"**She is wiped out from meds** and still having drop seizures. Some behavioral issues as well, granted exacerbated by Covid lockdown/ isolation."

"Refractory condition makes us always **on the lookout for new treatments.**"

"School started. **It's not easy.**"

"The neurologist is doing her best and I have faith **she will do her best** by him."

"My son deserves a life."

"We've tried many medications and the ketogenic diet. She's had significant decreases, but she **still has seizures most days.** She's nonverbal, almost 5, and has the cognitive abilities of a 20-month-old. "

"I feel like I've **exhausted all possible interventions.**"

"Stable. Not perfect."

"Many hospital stays and **surgeries.**"

QUOTES

"**Always trying different meds** to better manage seizures"

"My daughter has **between 50 to 100 drop seizures a day** nothing has worked and I am willing to try anything."

"Still exploring because **not sure enough of what others have tried** with their little ones."

"We have a **plan for if/when the medications stop working,** but I'm hopeful they will continue to work.**"**

"**First day** finding out diagnosis."

"**Moved to try and get better care** but doctors seem to be running out of options and are frustrated."

"We are constantly monitoring her seizure activity because **as she grows the seizures evolve.** We currently are in a pretty good place with her meds."

"**Trial and error.**"

"**Not much support or help from doctors** just increase meds and see what happens. Very difficult."

"I am searching for answers but always come up short. It always says the same thing everyone is different and there is not a clear answer on how to fix it so **I just cry and try again**."

"Can't go out in public often, **limits activities that we can do as a family**, has to be constantly monitored, wears a helmet."

"**Will never give up.**"

SUMMARY

Lennox-Gastaut Syndrome (LGS), like many rare diseases, is clearly a challenging and difficult disorder to live with. Although each individual's experience is different, life after diagnosis has many challenges for the patients and their family and friends. This study, which includes experiences from over 1,300 caregivers, captures the group's experiences across the diagnostic and disease management process.

Many of the patients in this study were diagnosed relatively early in life. Several experienced seizures and development delays, which led to seeking medical care, and ultimately a confirmed LGS diagnosis.

Clearly, one of the most significant challenges faced by the survey respondents of this study is managing the seizures associated with LGS. Almost 50% of the survey respondents in this study reported patients experiencing more than 20 seizures per month. Not surprisingly, the group reported high levels of dissatisfaction with their ability to control seizures and the impact this lack of control is having on the patient's life. Many reported actively looking for new and different treatments. Commonly used treatments used to manage seizures included prescription anti-seizure medications, surgery, and diet modification.

Finally, survey respondents voiced a high-degree of dissatisfaction with the quality of life of the LGS patient they care for, indicating a need for new and different approaches to managing this disease.

ABOUT PATIENT JOURNEYS

At Patient Journeys, our mission is to support rare disease patients and their caregivers by helping them access the best care possible. We believe, that by sharing information and experiences with each other, we can accelerate the diagnostic process and help patients receive the right treatment sooner.

Patient Journeys was started by the parents of children living with rare disorders who have experienced first-hand the challenges that exist with getting accurate and relevant information, and the critical role patients and caregivers can play to help support others in need.

If you have any questions or comments, please email us at info@patientjourneys.org.