



ONE MONTH, ONE MISSION...
TO RAISE AWARENESS FOR THE
MORE THAN ONE MILLION
CHILDREN AND ADULTS
WORLDWIDE LIVING WITH
LENNOX-GASTAUT SYNDROME!

#LGSawareness #EpilepsyAwarenessMonth

Thank you for being an advocate for Lennox-Gastaut Syndrome (LGS). In this toolkit, we have included information, sample messaging, social media content, and additional ways to get involved that will be helpful when raising LGS Awareness and inspiring others to join in during Epilepsy Awareness Month this November.

Interested in sharing awareness about LGS but not sure where to start?

- Download digital graphics
- Share on your social media - Facebook, Instagram, LinkedIn, TikTok, Twitter, etc.
- Tag the LGS Foundation in your posts!

Here are some hashtags to include with your post:

#LennoxGastautSyndrome

#LGSawareness

#EpilepsyAwarenessMonth

Follow Us on Social Media!



www.LGSFoundation.org

LGS 101: The Facts and Key Points

As an LGS advocate, you're going to interact with a lot of people.

Here is a list of key talking points and statistics to use when spreading awareness.

- Lennox-Gastaut Syndrome (LGS) is a severe epilepsy syndrome that develops in young children and often leads to lifelong disability. **Nobody is born with LGS.** It develops over time.
- In approximately 75-90% of LGS diagnoses, the cause of seizures is known. **We do not know what causes seizures to evolve into LGS though.** Some common causes of seizures include: trauma before or during birth, abnormal brain formation, infections, genetic factors, metabolic issues and autoimmune disorders.
- Approximately 48,000 children and adults in the United States have LGS and approximately **1 million worldwide.**
- In LGS, patients experience **more than one seizure type** (tonic seizures occur in nearly all with LGS). Seizures regularly continue despite treatment.
- Approximately **75% of LGS patients suffer from daily uncontrolled seizures** because no medication or treatment work for them.
- Despite the best treatments, **more than 85% of children with LGS will continue to have seizures into adulthood** and more than 95% will be intellectually disabled. The LGS Foundation is working hard to change this.
- **There is No Cure for LGS, but there is HOPE!** The LGS Foundation is fighting every day to save and improve the lives of those living with LGS.

LGS 101: Flyers & Posters To Share

Flyers and posters are a great way to capture attention and teach people about LGS. Click below to download some of our educational materials to post and share in your community.

[Download Graphic](#)

What is LGS?

Lennox-Gastaut Syndrome (LGS) is a severe epilepsy syndrome that develops in young children and often leads to lifelong disability. Nobody is born with LGS. It develops over time.

LGS affects approximately **48,000** Americans and over **1,000,000** people worldwide

More than one seizure type is always present in LGS.

75% of patients suffer from daily seizures

There is no cure for this devastating disorder

80-90% of children with LGS continue to have seizures into adulthood because no medication or treatment work for them

But there is hope.

The LGS Foundation is here to help. It is our mission to improve the lives of individuals impacted by LGS through advancing research, awareness, education, and family support.

LGS FOUNDATION
LENNOX-GASTAUT SYNDROME

The Lennox-Gastaut Syndrome (LGS) Foundation is A Nonprofit Organization Dedicated To Improving The Lives Of Individuals Impacted By LGS

www.LGSFoundation.org

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LGS FOUNDATION
LENNOX GASTAUT SYNDROME

CELEBRATING 13 YEARS
A decade of service improving the lives of individuals affected by LGS through research, family support programs, and education.
www.LGSFoundation.org

What is LGS?

- Lennox-Gastaut Syndrome (LGS) is a rare epilepsy syndrome. It is one of the Developmental and Epileptic Encephalopathies (DEEs).
- Nobody is born with LGS. It may develop over time from childhood seizures that remain uncontrolled by treatments.
- Children and Adults with LGS share similar features:
 - Seizures that start in childhood
 - More than one seizure type
 - Slow spike-and-wave on EEG
 - Developmental/Intellectual Impairment (75% have this at diagnosis)
- Any seizure type can be seen in LGS. The most common seizure types are:
 - Tonic
 - Atypical Absence
 - Atonic Drop Seizures
 - Generalized Tonic-Clonic
 - Myoclonic
- While developmental/Intellectual Impairment occurs in most with LGS, it is not always present at the start of LGS and is not required for the diagnosis to be made.

What causes seizures in LGS?

Genetic causes account for most unknown cases

30% Cause unknown

70% Cause known

- Trauma before or during birth
- Abnormal brain formation
- Infections
- Genetic factors
- Metabolic disorders
- Seizures as an infant (spasm)
- Head injury
- Autoimmune disorders

Some genes and genomic regions associated with LGS

Gene	Genomic Region
ABT1	15q11-q13
ABT2	15q11-q13
ABT3	15q11-q13
ABT4	15q11-q13
ABT5	15q11-q13
ABT6	15q11-q13
ABT7	15q11-q13
ABT8	15q11-q13
ABT9	15q11-q13
ABT10	15q11-q13
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ABT99	15q11-q13
ABT100	15q11-q13

Who has LGS?

- 1-2% of people with epilepsy
- 3-4% of children with epilepsy
- 48,000 children and adults in the U.S.
- 1,000,000 children and adults have LGS worldwide

How does LGS change over time?

- There is no cure for LGS. Seizures may go into remission, and may also recur.
- 30-50% of children with infantile spasms will develop LGS.
- 80-90% of children with LGS will continue to have seizures into adulthood.
- Up to 75% with LGS will no longer show slow spike-and-wave (SSW) on EEG in adulthood.
- Most with LGS show paroxysmal fast rhythms (PFR) on EEG, mainly during non-REM sleep, at some point in their life.
- 75% with LGS will show cognitive impairment at diagnosis and more than 50% suffer behavioral issues including hyperactivity, sleep disturbances, rage attacks, aggression, and autistic features.
- The mortality rate is 5%. Those with LGS are 24 times more likely to die prematurely.
- Premature death in LGS is often due to SUDEP, seizures, injury, or the underlying brain disorder.

LGS FOUNDATION
LENNOX-GASTAUT SYNDROME

Our mission is to improve the lives of individuals affected by LGS through research, family support programs, and education.

[Download Graphic](#)

LENNOX-GASTAUT SYNDROME (LGS)
KEY LEARNINGS FROM CAREGIVERS
November 2021

MY LGS KID

- Is silly
- Loves music
- Is cuddly
- Loves snuggling
- Is affectionate
- Has a great sense of humor

THE LGS COMMUNITY IS

- Resilient
- Caring & compassionate
- Fiercely independent
- Self-advocating
- Innovative

THE LGS FAMILY EXPERIENCE

- has many components such as trauma, chaos, isolation, denial, heartbreak, and exhaustion. But it also includes teamwork, compassion, and self-growth.

KEY CHALLENGES

- No respite care
- Care coordination, logistics
- Emotional burden, isolation (difficulty traveling, missed social opportunities)
- Equipment (bed, lift, chair, brace)
- Family dynamics
- Fear (a bad seizure, SUDEP, guardianship)
- Finding the right pediatric & adult VHCs
- Financial stress (high costs, coverage gaps, inability to work)
- Peer & family judgement
- Lack of understanding of LGS
- Safety (sleep, bathrooming)
- Transition to adult care

MY KID'S CHALLENGING BEHAVIORS

- Expressing anger physically, throwing things
- Staring
- Banging head
- Repetitive constant movement/rotation
- Groaning, stiffening by the hair
- Staring, holding, throwing things

MY KID'S UNSAFE BEHAVIORS

- Putting things in his mouth
- Running without sense of environment
- Grabbing & pulling things down on himself
- Disorienting, missing tabs
- Unsubordinated

WEIGHING TREATMENTS VS. BEHAVIORS

- Sometimes reducing seizure activity is not worth the behaviors that come along with the treatments

BAD SEIZURE

- Drop and tonic-clonic seizures are the scariest
- For us it's the length. More than a couple of minutes and you're going to see regression in abilities
- The worst is when she has a seizure cluster and we can't sleep with her in the night

SAFETY MODIFICATIONS

- Monitoring units
- Pursuing food
- Thickening liquids
- Using a harness in the car
- Bringing a bedside cot for adult diaper changes
- Using backseat & in-home cameras
- Safety bed, lift, padded walls & bars
- Blow-up mattress
- Alarms on all doors & windows
- From furniture guards

A GOOD DAY IS WHEN...

- The kids have seizures
- We are able to participate in our therapies
- There's a moment of happiness
- There's a good mood with good energy
- It's a normal day, one that's earned
- It's a day that follows the routine

"You're ignoring those with special needs because you're not sure how to communicate with them. Be patient and put effort into communicating so they feel seen and included."

ZOGENIX

Share Your Story Online and/or via the LGS Foundation

Make it personal! If you have a personal story and connection to LGS that you feel comfortable sharing with your community, we strongly encourage you to do so! Not only will you be spreading awareness, you will also be helping your network understand LGS and increase the chances of receiving their support.

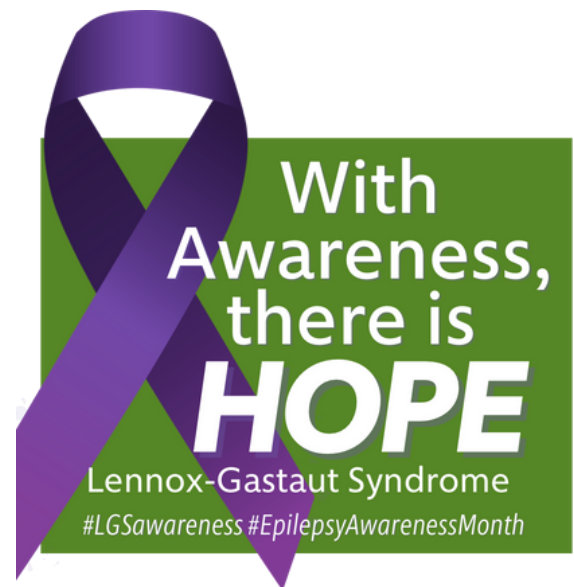
[CLICK HERE](#) to share your story with the LGS Foundation.

Social Media

We are turning social media PURPLE & GREEN for LGS Awareness during Epilepsy Awareness Month! Help us create an active dialogue and online community while reaching new audiences by:

- Sharing
- Liking
- Commenting

Through your efforts on social media others will learn more about LGS and the LGS Foundation's community events, programs & resources.



Be creative and craft your own message about why November & LGS Awareness are important to you. Here are some quick tips:

1. **Keep it short and punchy.** The most effective posts are factual and to the point.
2. **Tying facts and statistics to your posts can be a powerful tool.** Use the examples below on social media (Facebook is still our favorite, but Instagram, LinkedIn, and Twitter are great, too), via email, in person or on the phone!
3. **Strengthen your posts with visual aids.** Check out our social-media-ready graphics below to help catch your network's eye

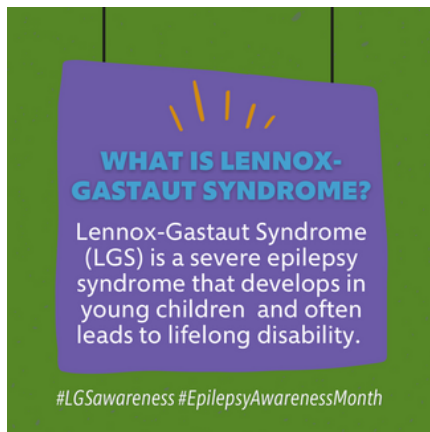
Social Media

Did you Know?

Did you know that Lennox-Gastaut Syndrome (LGS) affects approximately 48,000 children and adults in the United States and roughly 1 million individuals worldwide?

[#LennoxGastautSyndrome](#) [#LGSawareness](#) [#EpilepsyAwarenessMonth](#)

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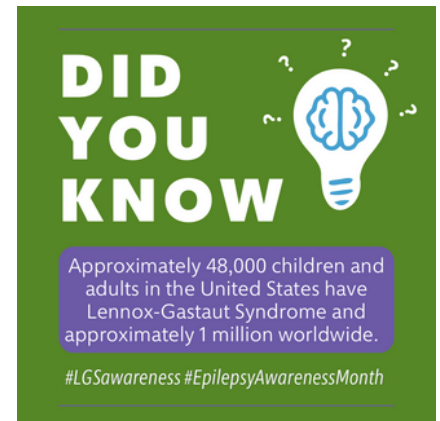


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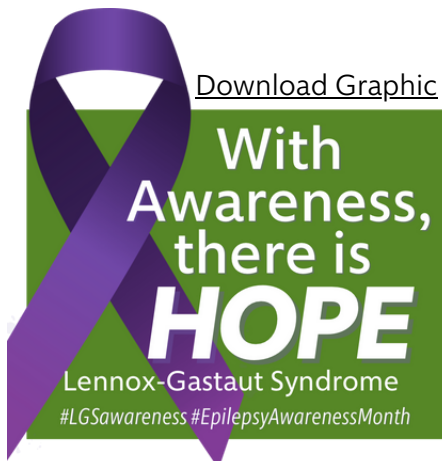
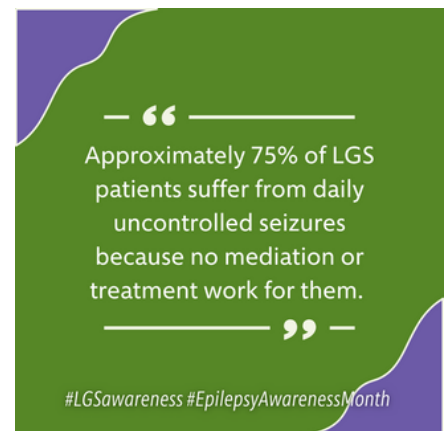


LGS is a drug resistant or refractory epilepsy

Approximately 75% of LGS patients suffer from daily uncontrolled seizures because no medication or treatment work for them.

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There is No Cure for LGS, but there is HOPE!

The LGS Foundation is harnessing the power of the patient family community to advance research, care, support, education, and awareness of LGS. Join us! Together we can change the future for those with LGS.

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Social Media

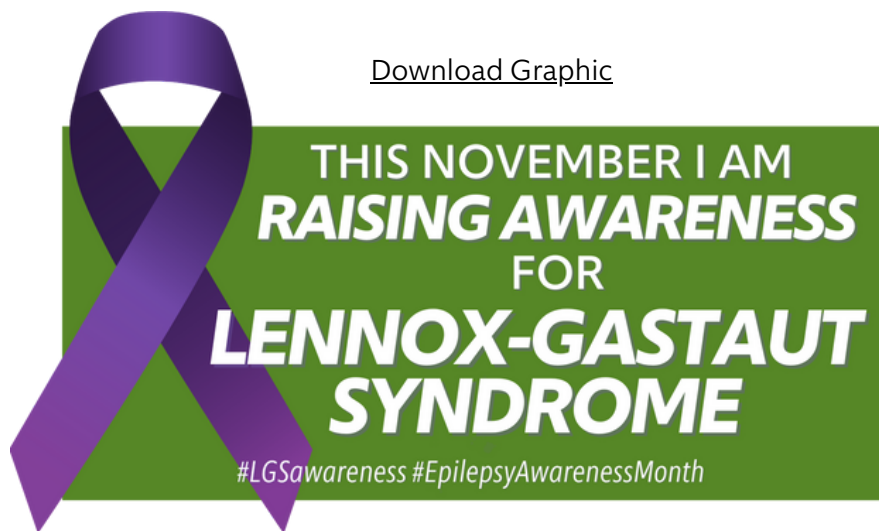
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