

# ABOUT LGS TREATMENTS KIT

## Introduction & How to Use This Kit

**"This About LGS Treatments Kit is the first of its kind and is designed to share information about available treatments for seizures in LGS."**

Dear Friends,

In 1995, our daughter, Savannah, had her first seizure. She was 2. As with all who have LGS, it wasn't present when her seizures started. It evolved over time as her uncontrolled seizures interfered with the finely orchestrated process of early life brain development. By age 5, the hallmark EEG features of LGS were present, and Savannah was officially diagnosed with LGS.

Back then, there was no LGS Foundation. We had to check out internet time at the library and tried to learn all we could from a hodgepodge of information and old books. We didn't meet another family living with LGS until years into our diagnosis. And finding information to guide our journey was nearly impossible.

Fortunately, today there is a thriving LGS Foundation. LGS is tough. We live it. But finding information doesn't need to be tough, so the LGS Foundation does everything it can to bring information about LGS to families living with the condition.

This About LGS Treatments Kit is the first of its kind and is designed to share information about available treatments for seizures in LGS. There is a lot of info in this kit! As you navigate it, remember to take your time and pace yourself. You don't have to read it all in one day. And remember that you are not alone. The LGS Foundation and our community of support are here to help you. While there is no one precise treatment that works for most with LGS, there are many options available to try. We hope you find this guide useful as you seek treatments for seizures for your loved one with LGS.

Most with LGS try treatment after treatment, always searching for anything to relieve seizures. Our journey was the same. By the time Savannah was 18, she had tried and failed 26 treatments for LGS, including medications, diets, epilepsy surgery, and alternative therapies. Despite aggressive treatment, she continued to seize every day and would go into status epilepticus weekly. If you had told us that treatment #27 would help our daughter, I would not have believed you. And yet, giving up was not an option. Incredibly, it was treatment #27 that changed our lives. Savannah's seizures dropped by 95%, and I feel like I met Savannah for the first time when the seizure haze lifted.

We sincerely hope you will find your optimal treatment for LGS quickly and not suffer a neverending cycle of treatments. We hope this kit will help.



Never lose hope,

Tracy Dixon-Salazar, PhD  
Executive Director, LGS Foundation  
Savannah's Mom

**"If you had told us that treatment #27 would help our daughter, I would not have believed you."**

**LGS is tough.**  
**Finding information doesn't need to be.**

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# ACKNOWLEDGEMENTS

***This Comprehensive Kit was Made Possible thanks to:***



DOWNLOAD AN  
ELECTRONIC VERSION  
OF THIS KIT



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**Sign Up to Receive Our  
Monthly E-Newsletter**



*Use your cell  
phone camera  
to scan me!*

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Thank you to Assertio for partnering with us to make these About LGS  
Treatments Kits a reality!

To create this comprehensive kit, we created content for LGS and also shared  
what others have done. Thank you to the people and organizations whose  
information is linked and cited in this kit. A special thank you to our LGS  
Families whose wisdom is shared throughout these pages.

None of the information in the About LGS Treatments Kit constitutes medical  
advice, diagnosis, treatment, or recommendation. Always seek the advice of  
your doctor, or other qualified health professional, with any questions about or  
related to a medical condition.

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# CONTACT US

***LGS is Tough. So are We!  
You are Not Alone!***

## **LGS FOUNDATION<sup>®</sup>** LENNOX-GASTAUT SYNDROME



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[Info@LGSFoundation.org](mailto:Info@LGSFoundation.org)



Phone:

(718) 374-3800

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### ***Follow the LGS Foundation on Social Media***



Facebook: [@lgsfoundation1](#)

Twitter: [@lgs\\_foundation](#)

Instagram: [@lgsfoundation](#)

YouTube: [@lgsfoundation](#)

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*“Make the most of every moment, and hang on to the good ones to help get you through the hard times. Never lose hope.”*

- Savannah, Mother of Son with LGS

Kit Date: March 2023

# INTRODUCTION TO TREATMENTS

## Types of Treatments for Seizures in LGS

There are no cures for LGS, but numerous treatments for seizures are available.

Seizures are the main symptom in LGS, and all with LGS have epilepsy (recurrent seizures). The goal of seizure treatment is no seizures with no side effects. This is often not possible in LGS. The goal for many families often becomes to minimize seizures, minimize treatment side effects, reduce the total number of medications a person takes, and attain the best quality of life for the individual with LGS and their loved ones.

The LGS Foundation is dedicated to finding better treatments and cures for LGS.

There are 5 main types of therapies that families might use to treat seizures in LGS.



### Anti-Seizure Medications

There are 8 FDA-approved medications that treat seizures associated with LGS. There are also over 20 FDA-approved medications that treat specific seizure types found in epilepsy. Individuals with LGS are often on a cocktail of multiple medications to treat their seizures.



### Diets

Several diets are frequently used to treat seizures in LGS. The Ketogenic Diet is a high-fat, restricted carbohydrate diet used to treat epilepsy since the 1920s. Modified variants of the Ketogenic Diet include the Modified Atkins diet and MCT Oil diet. The Low-Glycemic Index Diet is also often used in LGS.



### Neuromodulation

Neuromodulation is the use of technology to alter how nerves function. It is another option in addition to anti-seizure medications and diets. The main neuromodulation treatments that are used in LGS are Vagus Nerve Stimulation (VNS), Deep Brain Stimulation (DBS), and Responsive Neurostimulation (RNS).



### Epilepsy Surgery

Epilepsy Surgery is any type of brain or nerve surgery where parts of the brain or nerves are removed, disconnected, destroyed, or stimulated to stop seizures. Numerous types of surgery exist. The most common brain surgeries used in LGS are (1) Corpus Callosotomy and (2) surgery to implant Neuromodulation devices.



### Complementary and Alternative Therapy

Complementary and alternative therapies are products or practices used together with standard medical care. These include practices such as massage, acupuncture, chiropractic, homeopathy, naturopathy, and others.

**This Kit contains info on all these types of treatments. Pace yourself. You don't have to read it all in a day. You can always come back to it as you need to.**



#### What is LGS?

Scan this QR code to learn more



#### What causes LGS?

Scan this QR code to learn more



#### How is LGS Diagnosed?

Scan this QR code to learn more

#### Want to Learn More?

SCAN QR CODES  
WITH PHONE  
CAMERA TO  
LEARN MORE  
ABOUT LGS

None of the information herein constitutes medical advice, diagnosis, treatment, or recommendation. Always seek the advice of your doctor, or other qualified health professional, with any questions about or related to a medical condition.

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# ANTI-SEIZURE MEDICATIONS



## List of Anti-Seizure Medications

### Medications for Seizures in LGS (FDA-Approved)

Second Generation (introduced 1960-1975):

- Clobazam / Onfi (pill), Sympazan (dissolvable strip)

Third Generation (introduced 1980 or later):

- Lamotrigine / Lamictal
- Felbamate / Felbatol
- Topiramate / Topamax (pill), Eprontia (liquid)
- Rufinamide / Banzel
- Cannabidiol / Epidiolex
- Fenfluramine / Fintepla

### Medications for Seizures in Epilepsy (FDA-Approved)

First Generation (introduced before 1960):

- Phenobarbital / Phenobarbital
- Phenytoin / Dilantin
- Ethosuximide / Zarontin

Second Generation:

- Valproic Acid / Depakene
- Divalproex Sodium / Depacon and Depakote
- Clonazepam / Klonopin

Third Generation:

- Vigabatrin / Sabril
- Zonisamide / Zonegran
- Oxcarbazepine / Oxtellar XR, Trileptal (contraindicated in LGS)

Third Generation (continued):

- Gabapentin / Neurontin
- Tiagabine / Gabitril
- Levetiracetam / Keppra
- Pregabalin / Lyrica
- Stiripentol / Diacomit
- Lacosamide / Vimpat
- Eslicarbazepine Acetate / Aptiom
- Retigabine / Ezogabine
- Perampanel / Fycompa
- Brivaracetam / Briviact
- Everolimus / Afinitor
- Cenobamate / Xcopri



SCAN QR CODE  
TO LEARN MORE  
ABOUT EACH  
MEDICATION

Loscher & Klein, 2021

### Medications for Seizure Clusters (aka: Rescue/Emergency Medications, FDA-Approved)

- Diazepam Rectal Gel / Diastat
- Diazepam Nasal Spray / Valtoco
- Midazolam Nasal Spray / Nayzilam

### Clinical Trials for Seizures in LGS (Medications & Rescue Therapies)

- The SKYWAY Study for Soticlestat (a medicine to treat seizures in LGS)
- The PACIFIC Study for LP365 (a medicine to treat seizures in LGS)
- The STARS Study for Staccato Alprazolam (a medicine in an inhaler device for prolonged seizures)
- The STELLINA Study for Valtoco (a nasal spray for seizure clusters being studied in children 2-5 years old)
- The CARISBAMATE Study (a medicine to treat seizures in LGS)



**Summary of Antiepileptic  
Drugs in the United States**

*Great In-Depth  
Resource!*



*Scan for more info  
on clinical trials*

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# TRACKING ANTI-SEIZURE MEDICATIONS



## It is Important to Track Your Loved One's Treatments

**Included in this Kit:**

[illegible]

## Current Treatments & Supplements Tracker

Use this handy tracker to track current treatments or use your own.

**Daily Medication Administration Tracker**

Daily medications can be hard to keep track of in LGS. This tracker might help.

**Daily Medication Tracker**

Did they get their medication each day this week?

For the Week of \_\_\_\_\_

Time	Medication	M	T	W	T	F	S	S	Dose
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**Know Allergies to Medications (list here):**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Medication Administration Tracker

Use this handy tracker to track if medications are given each day.

**List of Past Medications & Other Treatments**  
 Past treatments and their effects can be hard to keep track of at LGS. This tracker might help.

**What prescription and non-prescription medications have they been on?**

Date: \_\_\_\_\_

DATE	MEDICATION	DOSE	TIMES GIVEN	DID IT HELP?	SIDE EFFECTS & OTHER NOTES

DEVICE, DIET OR SURGERY	DATE OF PROCEDURE	DID IT HELP?	NOTES ABOUT THE DEVICE, DIET OR SURGERY

## Past Treatments & Supplements Tracker

Use this handy tracker to track treatments no longer used.



**Pro Tip**

USE A CLIPBOARD OR FOLDER TO KEEP THESE HANDY

None of the information herein constitutes medical advice, diagnosis, treatment, or recommendation. Always seek the advice of your doctor, or other qualified health professional, with any questions about or related to a medical condition.

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Current treatments and their effects can be hard to keep track of in LGS. This tracker might help.

### ***What prescription and non-prescription medications are they on now?***

[illegible]



Surgeries, diets, devices, therapies and their effects can be hard to keep track of in LGS. This tracker might help.

***What surgeries has your loved one had? What diets, etc. are they on now?***

[illegible]

# Daily Medication Administration Tracker

Giving daily medications can be hard to keep track of in LGS. This tracker might help.

Daily Medication Tracker

Did they get their medication each day this week? Check the box if yes.

For the Week of: \_\_\_\_\_

Time	Medication	M	T	W	T	F	S	S	Dose
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Past treatments and their effects can be hard to keep track of in LGS. This tracker might help.

### What prescription and non-prescription medications have they tried?

## MEDICATION

## START/STOP DATES

## SIDE EFFECTS & OTHER NOTES

[illegible]

Past diets, devices, therapies, and their effects can be hard to keep track of in LGS. This tracker might help.

Today's Date: \_\_\_\_\_

[illegible]

# ABOUT SEIZURE EMERGENCIES

**Seizure clusters and status epilepticus are common in LGS and are seizure emergencies.**



## What is a Seizure Cluster?

The definition of a seizure cluster varies from one individual to another, but in general, the term refers to a group of seizures occurring over a number of hours in a way that differs from an individual's usual seizure pattern. For one patient, having three seizures over the course of two hours may represent a seizure cluster, while for another, a seizure cluster may be dozens of seizures over a few minutes. Adverse effects of seizure clusters include risk of injury from the seizures themselves, prolonged recovery time after seizures, and missed work, school, or social activities. Seizure clusters may progress into status epilepticus.

## What is a Status Epilepticus?

The official definition of status epilepticus has evolved over time, but the term generally refers to a prolonged seizure that may not stop on its own without intervention. The most recent definition presented by the International League Against Epilepsy identifies generalized convulsive (tonic-clonic) status epilepticus as a seizure lasting longer than five minutes, with an increased risk of brain injury if the seizure continues for too long. For other seizure types, such as focal or absence seizures, these time points may be more prolonged.

**The majority of seizures in individuals with LGS are short and terminate on their own in less than two to three minutes. However, if status epilepticus occurs, it is a medical emergency that may result in severe consequences if not treated rapidly.**



## What is a Non-Convulsive Status Epilepticus?

Non-convulsive status epilepticus (NCSE) is a prolonged seizure that looks like an altered mental state as opposed to the dramatic convulsions seen in generalized tonic-clonic status epilepticus. There are 2 main types of NCSE.

- In the first type of NCSE, patients are confused or behaving abnormally and appear to be having a non-stop absence (petit mal) seizure or a non-stop focal impaired awareness (complex partial) seizure.
- The second type of NCSE is subtle and occurs after a long generalized tonic-clonic seizure. The person will have continuous subtle motor jerks, especially of the face or hands, and this persists over time. Brain damage can occur if not treated in a timely manner.

## What Causes Seizure Clusters and Status Epilepticus?

People with intractable epilepsy (seizures that are not controlled by medication) are at higher risk for having seizure clusters or status epilepticus, but these episodes may also occur in people whose seizures are usually well controlled. Some common triggers for seizure clusters or status epilepticus include:

- Illness
- Missed antiseizure medication doses
- Sleep deprivation
- Stress
- Having a Developmental and Epileptic Encephalopathy (DEE), such as LGS
- Menstrual cycle

Seizure clusters or status epilepticus may also occur without an apparent trigger. Keeping a seizure diary may be helpful in identifying seizure patterns triggers.



**Request a New Family Welcome Kit**

Scan this QR code to learn more

**NEW TO LGS?  
YOU ARE NOT ALONE!**



None of the information herein constitutes medical advice, diagnosis, treatment, or recommendation. Always seek the advice of your doctor, or other qualified health professional, with any questions about or related to a medical condition.

**LGS FOUNDATION**  
LENNOX-GASTAUT SYNDROME

# TREATING SEIZURE EMERGENCIES

## How Can Seizure Clusters and Status Epilepticus Be Treated?

**Prompt treatment of seizure clusters and status epilepticus is important in limiting the duration of seizures and may prevent the need for more intensive treatment.**

Medications to treat seizure clusters or status epilepticus are often called emergency or rescue medications. Several rescue medications are now available for out-of-hospital treatment. All of these medications are part of the benzodiazepine group of drugs, which are regularly used to treat prolonged seizures in the hospital. While benzodiazepines used in the hospital are usually given intravenously (IV), they are available for out-of-hospital treatment and may be given orally, rectally, or nasally. All benzodiazepines have the same potential side effects, which include drowsiness, dizziness, and impaired coordination. At high doses, they may cause respiratory depression. People who are given these medications should be monitored closely.



### Oral Medications

Oral Medications used for seizure clusters include clonazepam, lorazepam, and diazepam. These medications may be swallowed or given by a gastrostomy tube, and some come in forms that can dissolve on the tongue. Absorption of medications given by mouth is slower than the other treatment options. It is important that a person be alert and responsive before administering oral medication to reduce the risk of aspiration. A person experiencing a seizure may also inadvertently bite down and injure someone trying to put something in his or her mouth, so do so with caution.



### Rectal Medications

Rectal Medication used for seizure clusters or status epilepticus is diazepam gel. Diazepam gel is provided as a needleless syringe and is administered into the rectum, where it is quickly absorbed into the bloodstream. It is often preferred for use in young children, as the method of administration is undesirable for many adolescents and adults.

CHECK OUT THIS  
VIDEO FROM  
ABOUT SEIZURE  
RESCUE  
MEDICATIONS



### Nasal Medications

Nasal Medications may be used to treat seizure clusters, but are not FDA-approved for the treatment of status epilepticus. These medications are sprays that are administered into the nose. There are currently two FDA-approved nasal medications: intranasal midazolam (Nayzilam<sup>®</sup>) and intranasal diazepam (Valtoco<sup>®</sup>). There are several potential benefits to nasal medications, including ease of usage, safety for the person administering the medication, and avoidance of potential embarrassment for adolescents and adults that may otherwise require rectal medication. However, nasal medications may not be a good option for everyone.

## When Should Rescue Medications Be Used For Seizure Clusters Or Status Epilepticus?

Every person with LGS and epilepsy should develop a Seizure Action Plan (SAP) with his or her medical provider that details the indications for use of a seizure rescue medication and which medication should be used. This plan should be implemented as soon as possible once a seizure cluster or status epilepticus (seizure greater than 5 minutes) is identified. The plan should be written down and be available for anyone who might be with the individual when they experience a seizure. For those known to have frequent seizure clusters or status epilepticus, a plan should also be available for emergency medical personnel. Most schools and daycare providers require a written Seizure Action Plan for all children with epilepsy that details the types of seizures they have, what should be done if they have a seizure, and when rescue medications should be given.

# SEIZURE ACTION PLAN (SAP)

## Create Yours Today!

- Work with your medical provider to determine when a seizure rescue medication should be used and which medication you will use.

The image shows a sample of the 'Acute Seizure Action Plan' form. It is a multi-section document with a purple border. At the top, it has fields for 'Name', 'Birth date', 'Today's date', 'Care partner phone numbers', 'Provider name/facility', and 'Provider phone numbers'. Below this is the 'Usual Seizure Pattern' section, which includes 'Triggers', 'Pattern of seizures', 'Allergies', and 'What the seizures normally look like'. The 'look like' section has checkboxes for 'Absence seizure (also called petit mal)', 'Tonic seizure', and 'Clonic seizure', each with a corresponding illustration. The 'Care' section is divided into 'Standard Care Needed' and 'Provide Rescue Treatment'. 'Standard Care Needed' includes 'Time the seizure', 'Keep person safe', 'Don't restrict', 'Stay with person', and 'Keep a record'. 'Provide Rescue Treatment' includes 'Specific instructions' and 'Other'. The 'Call for Emergency Help' section has checkboxes for 'Seizure longer than minutes', 'Unusual seizure', and 'Injury/blue lips', and fields for 'Call Healthcare Provider if:' and 'Call for Emergency Help if:'. At the bottom, there is a 'Healthcare Provider Authorization' section with a signature line and a date field.

## Seizure Action Plan Template

Use this handy template to create your own SAP today!



***Don't forget to share this Plan with other caregivers!***

RESCUE MEDICATIONS  
VIDEO  
DEMONSTRATIONS



NEED A SAP FORM  
WITH MORE SPACE TO  
WRITE?



NEED ANOTHER COPY  
OF THIS PAGE





# Acute Seizure Action Plan

Name: _____	Birth date: _____	Today's date: _____
Care partner phone numbers: _____	Provider name/facility: _____	Provider phone numbers: _____



## Usual Seizure Pattern

**Triggers:** \_\_\_\_\_

**Pattern of seizures:** \_\_\_\_\_

**Allergies:** \_\_\_\_\_

**What the seizures normally look like (Check all that apply)**

<p>Head May Drop Loss of Muscle Control Slump or Fall Forward</p> <p><input type="checkbox"/> Atonic seizure (also called drop)</p>	<p>Occurs Through the Entire Brain Blank Stare</p> <p><input type="checkbox"/> Absence seizure (also called petit mal)</p>	<p>Blink Rapidly Roll Their Eyes Can Be Confused With Daydreaming</p> <p><input type="checkbox"/> Tonic seizure</p>	<p>Stiff Body Incontinence Back Arched Epileptic Cry</p> <p><input type="checkbox"/> Clonic seizure</p>	<p>Occurs in Specific Lobe of the Brain Blank Stare</p> <p><input type="checkbox"/> Focal impaired awareness seizure (also called complex partial)</p>	<p><b>Describe:</b> _____</p> <p>_____</p> <p>_____</p> <p>_____</p>
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**NOTES:** \_\_\_\_\_

## Care

**Standard Care Needed**

If this happens, \_\_\_\_\_ provide standard care

<p>Time the seizure</p> <p>NOTES: _____</p>	<p>Keep person safe</p> <p>NOTES: _____</p>	<p>Don't restrict</p> <p>NOTES: _____</p>	<p>Stay with person</p> <p>NOTES: _____</p>	<p>Keep a record</p> <p>NOTES: _____</p>
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**Provide Rescue Treatment**

If this happens, \_\_\_\_\_ provide standard care (above) **and** rescue treatment

<p><input type="checkbox"/> Rectum</p>	<p><input type="checkbox"/> Nose</p>	<p><input type="checkbox"/> Mouth</p>	<p><b>Specific Instructions:</b> _____</p> <p>_____</p> <p><input type="checkbox"/> Other: _____</p>
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**Call for Emergency Help**

If any of these happen,

<p><input type="checkbox"/> Seizure longer than _____ minutes</p>	<p><input type="checkbox"/> Unusual seizure</p>	<p><input type="checkbox"/> Injury/Blue lips</p>	<p><input type="checkbox"/> Other: _____</p> <p>_____</p> <p>_____</p> <p>_____</p>
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**Get help now**

<p>Call Healthcare Provider if: _____</p> <p>Call for Emergency Help if: _____</p>	
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**NOTES:** \_\_\_\_\_

## Healthcare Provider Authorization

Signature: \_\_\_\_\_ Provider Printed Name: \_\_\_\_\_ Date: \_\_\_\_\_ For use from: \_\_\_\_\_ to: \_\_\_\_\_

**Don't forget to share this with other caregivers!**

# Seizure First Aid

How to help someone having a seizure

**01**

## **STAY WITH THE PERSON UNTIL THEY ARE AWAKE AND ALERT AFTER THE SEIZURE**

- Remain calm and check for medical ID
- Time the seizure and write it down in your seizure log
- Video the seizure if want to share with the doctor

**02**

## **KEEP THE PERSON SAFE**

- Move them away from harm

**03**

## **TURN THE PERSON ONTO THEIR SIDE IF THEY ARE NOT AWAKE AND AWARE**

- Keep airway clear
- Loosen any tight clothes around their neck
- Put something small and soft under their head

**04**

## **CALL 911 IF...**

- Seizure lasts longer than 5 minutes
- Person does not return to their usual state
- Person is injured, pregnant, or sick
- First time seizure or repeated seizures
- Person has difficulty breathing
- The seizure occurs in water

**05**

## **DO NOT...**

- ✗ Restrain them
- ✗ Put any objects in their mouth
- ✓ Rescue meds can be given if prescribed by a health care professional

**BEFORE YOUR NEXT SEIZURE:**

CREATE A SEIZURE ACTION PLAN (SAP) WITH YOUR DOCTOR.  
SHARE YOUR SAP WITH ALL CAREGIVERS.

ON DEMAND SEIZURE  
FIRST AID TRAINING  
FOR EVERYONE YOU  
KNOW!



BE SURE TO COMPLETE REVERSE SIDE



Name: \_\_\_\_\_  
Phone: \_\_\_\_\_  
Relationship: \_\_\_\_\_  
City: \_\_\_\_\_  
State: \_\_\_\_\_

In Case of Emergency, Please Notify:

# Emergency Medical Information

Street: \_\_\_\_\_  
City: \_\_\_\_\_  
State: \_\_\_\_\_  
Zip: \_\_\_\_\_  
Phone: \_\_\_\_\_



Name: \_\_\_\_\_  
Date Completed: \_\_\_\_\_  
Updated: \_\_\_\_\_

Keep Copies of this Card Handy for Paramedics and Hospital Staff

FOLD HERE - PLACE ON REFRIGERATOR - FOLD HERE

## Current Medical Information

Name of Doctor: \_\_\_\_\_ Phone #: \_\_\_\_\_

Name of Doctor: \_\_\_\_\_ Phone #: \_\_\_\_\_

Currently Being Treated For:

\_\_\_\_\_  
\_\_\_\_\_

## Current Medications:

Medication	Dosage	Taken How Often? (Frequency)	Taken to treat what condition?	Located where in your home?

\* Attach & date a separate page for additional medications or to record updates.

Allergies to Medications: \_\_\_\_\_

Pharmacy Name: \_\_\_\_\_ Phone: \_\_\_\_\_



## Basic Information

Name: \_\_\_\_\_

Male: \_\_\_\_\_ Female: \_\_\_\_\_ Height: \_\_\_\_\_ Weight: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Marital Status: \_\_\_\_\_

Hair Color: \_\_\_\_\_ Eye Color: \_\_\_\_\_ Blood Type: \_\_\_\_\_ Religion: \_\_\_\_\_

Primary Language Spoken: \_\_\_\_\_ Other Language(s): \_\_\_\_\_

\_\_\_\_\_ Glasses \_\_\_\_\_ Contact Lenses \_\_\_\_\_ False Teeth/Bridge

Hearing Aid: \_\_\_\_\_ Left \_\_\_\_\_ Right Deaf: \_\_\_\_\_ Left \_\_\_\_\_ Right

Blind: \_\_\_\_\_ Left \_\_\_\_\_ Right Artificial Eye: \_\_\_\_\_ Left \_\_\_\_\_ Right

Artificial Limbs or Prosthetic Devices: \_\_\_\_\_

Pacemaker Model #: \_\_\_\_\_ Defibrillator Model #: \_\_\_\_\_

Identifying Marks (i.e., birthmarks, tattoos, etc.): \_\_\_\_\_

Normal Blood Pressure: \_\_\_\_\_ / \_\_\_\_\_ Smoker? \_\_\_\_\_

## Medical History

Check Conditions that you have been treated for:

<input type="checkbox"/> Allergies	<input type="checkbox"/> Blood Pressure	<input type="checkbox"/> Epilepsy	<input type="checkbox"/> Insulin	<input type="checkbox"/> Stroke
<input type="checkbox"/> Anemia	<input type="checkbox"/> Cancer	<input type="checkbox"/> Glaucoma	<input type="checkbox"/> Jaundice	<input type="checkbox"/> Tuberculosis
<input type="checkbox"/> Arthritis	<input type="checkbox"/> Dementia	<input type="checkbox"/> Hay Fever	<input type="checkbox"/> Parkinson's Disease	
<input type="checkbox"/> Asthma	<input type="checkbox"/> Diabetes	<input type="checkbox"/> Heart Condition	<input type="checkbox"/> Sinus	

## Hospital Information

Hospital Preference: \_\_\_\_\_ City: \_\_\_\_\_ State: \_\_\_\_\_

Last Hospitalization: \_\_\_\_\_ Hospital: \_\_\_\_\_ Date: \_\_\_\_\_ Treated For: \_\_\_\_\_

\_\_\_\_\_ Living Will If yes, location of Living Will: \_\_\_\_\_

\_\_\_\_\_ Do Not Resuscitate (DNR) Order Location of DNR: \_\_\_\_\_ Organ Donor: \_\_\_\_\_

## Medical Insurance Coverage

Medicare #: \_\_\_\_\_ Medicaid #: \_\_\_\_\_

Other Policy #: \_\_\_\_\_

Need Another Copy? Download at [www.MedicalCareAlert.com/EMS](http://www.MedicalCareAlert.com/EMS)  
or call Customer Service 1-877-913-3680



Keep Copies of this Card Handy for Paramedics and Hospital Staff



# MORE IMPORTANT INFO ABOUT SEIZURES

## Seizure Types

We at the LGS Foundation believe it is important for families living with LGS to be able to recognize different seizure types. However, there is a lack of detailed, accurate information on the internet as to what seizure types may look like. This brought us to create this video library of what seizures may look like. Thank you to the families who shared these heartbreaking videos with us so we may educate others. And thank you to the physicians who have reviewed these videos to help us best determine the seizure types represented.

### Seizure Type Videos



## Seizure Safety

Safety Is A Constant Concern For Those With LGS

Children and adults with LGS have frequent seizures and are at high risk of injury. Furthermore, they may not have the ability to sense danger, may wander off from their home or school, and may place themselves in potentially dangerous situations if not properly supervised. Always consider potential safety issues ahead of time to keep the person with LGS safe.

### More on Seizure Safety



## Keeping an Online Seizure Diary

Keep a seizure diary where you record seizures along with other relevant information, such as dietary changes, the timing of medication intake of both anticonvulsants and other drugs, the amount and quality of sleep, etc. This is a useful tool when working with your neurologist and may assist in identifying seizure triggers. Seizure Tracker is an online tool that is free and easy to use and allows you to print reports and graphs that can be shared with medical professionals.

**Seizure Tracker®**  
be aware. track it.



GET THE SEIZURE  
TRACKER APP



## Seizure Detection Devices

While no device has been proven to prevent epilepsy-related mortality (including SUDEP), the Danny Did Foundation (DDF) is devoted to seeking out seizure detection and seizure prediction devices - as well as other technologies - that are designed to enable intervention by a caregiver. Intervention is believed to reduce the risks that accompany epilepsy. Check out the latest from our friends at Danny Did. LGS Foundation and Danny Did also partner to provide grants to families to get seizure detection devices.



DANNY DID  
FOUNDATION  
HAS GREAT INFO  
& GRANTS



## Durable Medical Equipment

Those with LGS often need medical equipment or supplies. These include seizure safety helmets, manual or power wheelchairs, assistive communications devices, special beds, special seating, gait trainers, standers, lifts, etc. Insurance often covers some or all of the costs for these medically necessary items. See some useful links below:



**About Medical  
Equipment & Supplies**



**Daily Living  
Aids\***



**Special Needs  
Equipment\***



**Danmar Products  
Helmets\***

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LENNOX-GASTAUT SYNDROME



# IMPORTANT INFO ABOUT SUDEP

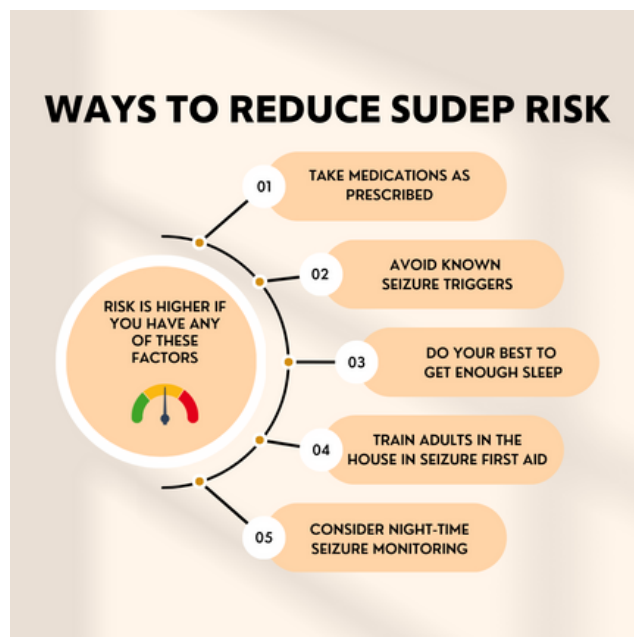
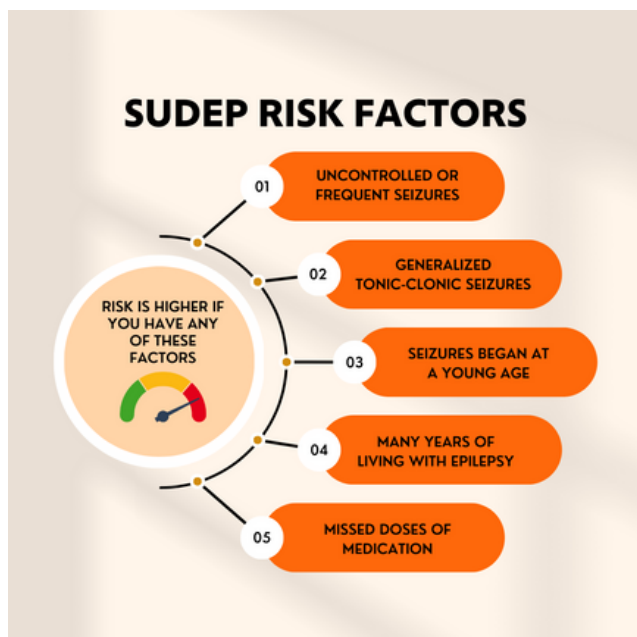
## Learn About Sudden Unexpected Death in Epilepsy (SUDEP)

While this information may be frightening for a family to read, the LGS Foundation is committed to making sure that families have the knowledge they need to do what they can to prevent complications and death from seizures. There may be some things families can do to avoid situations and modify risks. The LGS Foundation recommends that families of those diagnosed with LGS be given information about SUDEP from their physician and ways to reduce the risk. People with LGS are 14x more likely to die prematurely. SUDEP is a major cause.

Mortality due to epilepsy is a significant concern for the families of those with LGS. Seizures can sometimes be fatal for a number of reasons. Some children with LGS may lose their lives due to accidents, status epilepticus, or illness. Another concern for our community is SUDEP or Sudden Unexpected Death in Epilepsy. It is defined as the "Sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in patients with epilepsy, with or without evidence for a seizure and excluding documented status epilepticus, in which postmortem examination does not reveal a toxicologic or anatomic cause for death." (Nashef, 1997).

There are several risk factors for SUDEP, and research suggests there are ways to reduce the risk.

**Get More Info  
on SUDEP**



<https://www.cdc.gov/epilepsy/about/sudep>



**5 Things You Should  
Know About SUDEP**



**Video: Mortality  
& SUDEP in LGS**



**Why is it important  
to talk about SUDEP?**



**Partners Against  
Mortality in Epilepsy**



**North American  
SUDEP Registry**

**For Our Bereaved Families  
We Are Here For You**



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# LEARN ABOUT CLINICAL TRIALS IN LGS



## Clinical Trials

Scan for more  
info on LGS  
clinical trials



### What Is A Clinical Trial?

Clinical trials are research studies performed in those with a medical condition like LGS. They scientifically evaluate a medical or surgical intervention. They are the primary way that researchers find out if a new treatment, like a new drug, diet, or medical device is safe and effective in reducing seizures in those with LGS.

Without volunteers, clinical trials cannot exist and we would not be able to find new treatments for LGS and seizures. Families who participate in clinical trials are on the cutting edge of helping us to find better treatments and cures. The reason we have treatments for LGS today is due to the fact that LGS families participated in past trials. We are forever grateful for their contribution.

### Why are Clinical Trials Important?

Research is our best hope for advancing treatments and eventually finding a cure for LGS and associated epilepsies. Research is not just the responsibility of scientists and doctors. It is important that patients participate to whatever extent they are able.

Patients can participate in research in several ways, including 1) sharing their information with scientists through patient registries so researchers can understand how LGS affects individuals; and 2) volunteering for clinical studies or trials to help doctors understand how treatments affect patients.

Clinical studies seek to answer questions such as:

- Does this investigational drug or treatment work?
- Does it work better than another treatment already available?
- Does it cause any side effects?
- Are there any other benefits that could improve patient quality of life?

Since 2011, thanks to community engagement and study participation, 7 new medications have received approval from the FDA for the treatment of LGS.

### Should I Participate in a Clinical Trial?

People participate in clinical trials for a variety of reasons. Healthy volunteers say they participate to help others and to contribute to moving science forward. Participants with an illness or disease also participate to help others, but also to possibly receive the newest treatment and to have the additional care and attention from the clinical trial staff.

Clinical trials offer hope for many people and an opportunity to help researchers find better treatments for others in the future.



LEARN MORE  
HERE

### Current Clinical Trials for Seizures in LGS (Medication, Rescue Therapies, and Neuromodulation)

- The SKYWAY Study for Soticlestat (a medicine to treat seizures in LGS)
- The PACIFIC Study for LP365 (a medicine to treat seizures in LGS)
- The STARS Study for Staccato Alprazolam (a medicine in an inhaler device for prolonged seizures)
- The STELLINA Study for Valtoco (a nasal spray for seizure clusters being studied in children 2-5 years old)
- The LGS Clinical Study for RNS (RNS, also known as Responsive Neurostimulation, study for seizures in LGS)
- The CARISBAMATE Study (Carisbamate is a medicine to treat seizures in LGS)

SKYWAY  
STUDY



PACIFIC  
STUDY



STARS  
STUDY



STELLINA  
STUDY



LGS RNS  
STUDY



CARISBAMATE  
STUDY



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**LGS FOUNDATION**  
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# DIET THERAPY FOR SEIZURES

## Dietary Therapy

Dietary therapies can help control various types of seizures in both children and adults when medicines alone don't work. There are four major dietary therapies used today for epilepsy. They are all low in carbohydrates (like sugar, pasta, and bread) and high in fat (like butter, oils, bacon, and avocados).



## Types of Diets to Treat Seizures

- Ketogenic Diet (KD)
- Medium-Chain Triglyceride (MCT) Diet
- Modified Atkins Diet (MAD)
- Low Glycemic Index Diet (LGID)

### Ketogenic Diet

The Keto Diet is very high in fat and very low in protein and carbohydrates. It is designed to make the body burn fat instead of carbohydrates as the main source of energy. The body will go into ketosis as a sign that fat is being burned, and this can be detected in the urine of those on the diet. This diet is often restricted to a small number of calories each day and strict amounts of fat, proteins, and carbohydrates.

More about Keto



### Medium-Chain Triglyceride (MCT) Diet

The MCT Diet is often used to supplement the Keto Diet by adding a specific type of fat called MCT. MCTs are smaller than most fats and easier to digest. They get absorbed into the blood quickly and turn the oil into usable energy. This diet adds MCT oil to supplement the fats consumed during the Keto Diet.

More about MCT



### Modified Atkins Diet (MAD)

This diet, like the Keto Diet, is very high in fat and very low in protein and carbohydrates. It is less restrictive than the Keto Diet and allows for more calories and a wider variety of foods. With the MAD, foods are not weighed and measured as in the Keto Diet, and the amounts of fats, proteins, and carbohydrates are less restricted.

More about MAD



### Low Glycemic Index Diet (LGID)

The LGID is an alternative to the Keto Diet and limits the type of carbohydrates a person can eat. This diet focuses on eating carbohydrates with a Low Glycemic Index, a measurement of how a food raises blood sugar. Low Glycemic Index foods (e.g., whole grain breads and berries) do not raise blood sugar as dramatically as those with a High Glycemic Index (e.g., candy and chips).

More about LGID



MORE GREAT  
RESOURCES



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# NEUROMODULATION



## Types of Neuromodulation to Treat Seizures

- VNS (Vagus Nerve Stimulation)
- RNS Therapy (Responsive Neurostimulation)
- DBS Therapy (Deep Brain Stimulation)

## What is Neuromodulation?

Neuromodulation is a type of technology that acts directly upon nerves. A device is implanted in a person and it delivers electrical impulses to alter nerve activity. The most common types of neuromodulation used in LGS are Vagus Nerve Stimulation (VNS), Responsive Neurostimulation (RNS), and Deep Brain Stimulation (DBS). All of these require some type of surgery to implant the device.

## What is Vagus Nerve Stimulation (VNS)?

How does the brain control heart rate, digestion, sweating, speech, chewing, and the gag reflex? Though these functions seem unrelated, they're all controlled by the vagus nerve – a long fiber that connects the brain to the throat, heart, and digestive system.

Stimulating this nerve — using an implanted device that controls the vagus nerve much like an artificial pacemaker controls the heart — can suppress seizures after they start and can reduce seizure frequency by 45 to 80 percent. VNS devices stimulate this nerve by sending mild electrical impulses to it, which are then carried up to the brain to the areas where seizures begin. This technique, known as vagal nerve stimulation (VNS), is most effective in people with atonic and focal seizures. The device tends to be least effective in individuals who experience generalized tonic-clonic and complex partial seizures.



LEARN MORE  
HERE

## What is Responsive Neurostimulation (RNS)?

In responsive neurostimulation, a small battery-powered device called a neurostimulator is implanted in the patient's skull. The neurostimulator is connected to thin wires, called leads, which the surgeon places in the area or areas of the brain where the patient's seizures originate. The neurostimulator monitors the brain's electrical activity. When brain activity that could lead to a seizure is detected, the neurostimulator delivers a pulse of electrical stimulation through the leads. The electrical pulse may stop the seizure before it begins.



## What is Deep Brain Stimulation (DBS)?

DBS is an FDA-approved seizure treatment that stimulates deep brain structures with an implanted neurostimulator device. The device is implanted during brain surgery.

Common areas targeted by DBS include:

- Centromedian nucleus of the thalamus (CM) stimulation is more effective for patients with generalized epilepsy than focal epilepsy. This procedure can reduce seizures by 70-80 percent in people with tonic-clonic and absence seizures, but outcomes are harder to predict in people with focal seizures or frontal lobe epilepsy.
- Anterior nucleus of the thalamus (ANT) stimulation can control seizures that begin in the temporal lobe, and the effects are relatively long-lasting. Some people experience depression and memory impairment after ANT stimulation, however. This procedure has been approved for use in Europe, but not the United States.
- Hippocampal deep brain stimulation can reduce seizure frequency by 50-60 percent in people with temporal lobe epilepsy. People with normal MRI findings have better seizure outcomes after this type of stimulation than those with hippocampal injuries. Benefits are greatest when both, rather than one, side of the hippocampus are stimulated. Memory decline has not been reported.



# EPILEPSY SURGERY



## Epilepsy Surgery

Epilepsy Brain Surgery is any type of brain surgery where parts of the brain are removed, disconnected, destroyed, or stimulated to stop seizures. Numerous types of surgery exist. The most common brain surgeries used in LGS are Corpus Callosotomy and surgery to implant Neuromodulation devices.

## Epilepsy Surgery Types

### Curative Surgery Types

The purpose of these procedures is to stop seizures completely. A small number of those with LGS may qualify for these types of surgery. Resections are surgeries that remove part of the brain, while a disconnection is a procedure that disconnects part of the brain while leaving the rest of the brain intact. Other surgeries may destroy a small or large part of the brain with heat (laser), radiation, or by preventing blood flow. They include:

- Laser Ablation
- Lesionectomy
- Lobectomy
- Hemispherectomy
- Amygdalohippocampectomy
- Hippocampal Transection
- Posterior Quadrant Resection or Disconnection

Scan for more  
info on  
Epilepsy  
Surgery

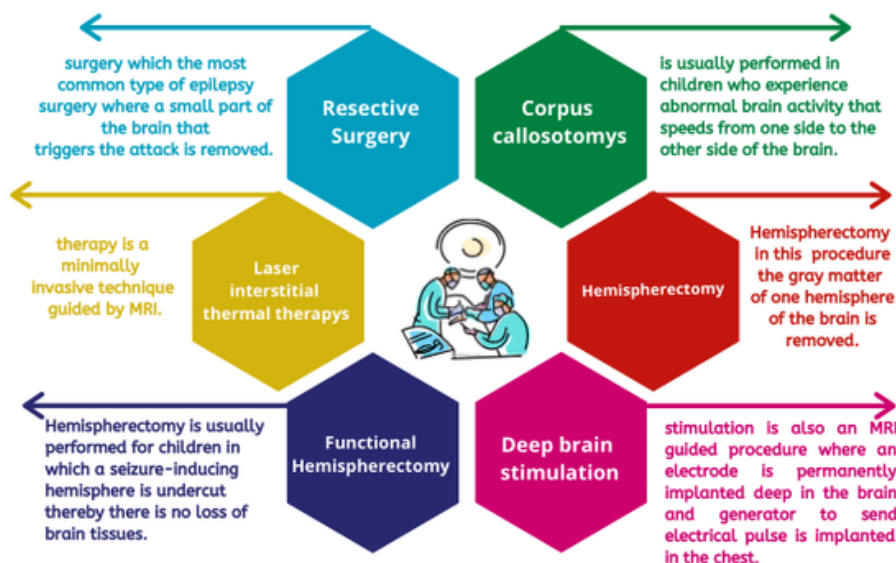


### Palliative Surgery Types

There are other procedures that are not intended to stop the seizures completely but instead aim to stop the seizures after they begin or reduce the number of seizures. These are known as palliative procedures. They include:

- Corpus Callosotomy
- Multiple Subpial Transection

## Types of Epilepsy Surgery



#becauseyourhealthmatters



Check out our friends at  
the Pediatric Epilepsy  
Surgery Alliance for more  
info



# ALTERNATIVE THERAPY



## Complementary and Alternative Therapy

Complementary and alternative therapies are products or practices together with standard medical care. These include practices such as massage, acupuncture, chiropractic, homeopathy, naturopathy, and others.

Complementary approaches or treatments mean that treatments are used together with traditional Western medicine.

Alternative approaches or treatments are used instead of traditional Western medicine.

Traditional Western medicine develops treatments using a scientific approach to answer questions such as: why treatments work, how well they work, whom they work for, what side effects may occur, and how the benefits compare to the risks. The results of testing are published in scientific journals. Most treatments need to receive approval from the Food and Drug Administration or a relevant federal advisory group before they can be marketed and used by the general public.

The list of alternative therapies changes over time as new approaches emerge. Others are proven safe and effective and become part of conventional health care. In epilepsy, for instance, the ketogenic diet began as an alternative therapy but has been scientifically tested and is now considered a conventional therapy for some people with epilepsy.

## Alternative Therapies Sometimes Used by Those with LGS

 <b>Biological Approaches</b>	 <b>Manipulative &amp; Body-Based</b>	 <b>Mind-Body Approaches</b>	 <b>Alternative Medical Systems</b>	 <b>Energy Therapies</b>
Diets Herbs Vitamins	Massage Chiropractic Osteopathy	Yoga Spirituality Relaxation	Homeopathy Naturopathy Ayurveda	Reiki Magnets Qigong

Complementary and alternative medicine: assessing the evidence for immunological benefits. Goldrosen & Straus, 2004



LEARN MORE  
AT  
EPILEPSY.COM



BE AN  
INFORMED  
CONSUMER

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# GENETICS AND LGS



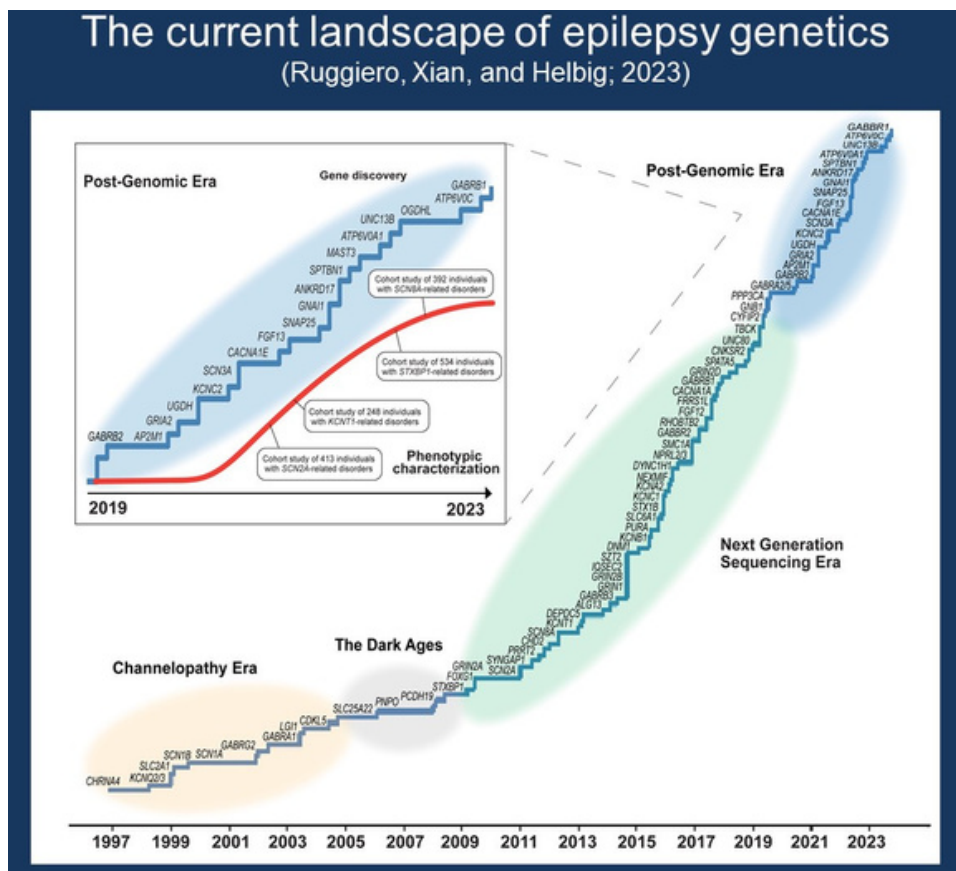
**Half of all seizure disorders that eventually evolve into LGS are genetic. Find out if yours is.**

## Why Is Genetic Testing in LGS Important?

For everyone with LGS, the LGS is secondary to some initial cause (etiology) of early-life seizures (e.g., LGS secondary to CDKL5 mutations). In half of LGS cases, the cause of seizures is genetic. Genetic testing may:

- Help identify the cause of a person's seizures that evolved into LGS.
- Lead to more information about the diagnosis and long-term outcome for the person with LGS.
- Help guide the selection of anti-seizure medications. For example, there is evidence that some medications may work better to control seizures in people with a genetic diagnosis. There is also evidence that some medications may not work well or may cause side effects in people with certain genetic disorders.
- Help better inform other family members of their own risk of epilepsy, as well as their chances of having a child with epilepsy.
- Make it possible for individuals and families to access other resources such as medications, gene therapy, special support services, etc.
- Lead to participation in research studies specific to genetic diagnosis.
- Help an individual or family end what is often referred to as the “diagnostic odyssey” or the search for an answer to what caused the seizures to start.

Note: We do not know what causes seizures in LGS, but the LGS Foundation is dedicated to advancing research to understand this!



**Genes in Epilepsy**



**Genes in LGS**



LEARN MORE FROM TWO POSTS FROM ILAE ABOUT GENES IN EPILEPSY AND LGS



**Genetic Testing in LGS**



**Learn About Genetic Testing in LGS**

**American Academy of Pediatrics**  
DEDICATED TO THE HEALTH OF ALL CHILDREN®



**Genetic Testing Overview**

**GeneDx**



**What You Need to Know About Genetic Testing\***

**Ambry Genetics®**



**Considering Genetic Testing? Start here.\***

**INVITAE**



**Your Health Starts in Your Genes\***

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\*LGS Foundation does not endorse this company or any products, links provided for information purposes only.

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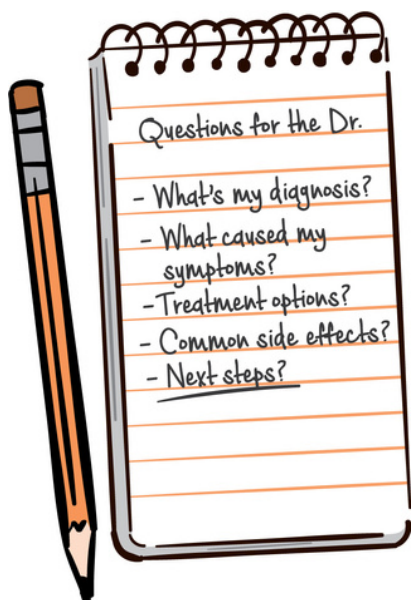
# MAKING THE MOST OF YOUR DOCTOR VISIT

## Preparing for Your Doctor's Visit

You may feel overwhelmed by concern, fear, and anxiety at a doctor's appointment. This is normal. Caregivers are often unable to recall much of what the doctor said. However, it is important to understand the specifics of your loved one's diagnosis.

### Keep these tips in mind:

- Don't be afraid to ask questions to learn about the needs of your loved one. Bring a list of questions with you.
- Bring photos or videos of your loved one's symptoms.
- Take another family member or support person with you.
- If you need translation, interpretation, or other communication support, make this known when scheduling your appointment.
- Ask for any written information about the diagnosis (including medical details). Read this when you get home.
- Ask the doctor to explain the information to other family members. This will allow you to talk about it more at home.
- Ask for information about how the diagnosis will affect your loved one and your day-to-day lives. Ask about services that can help.
- Arrange for the next appointment with your loved one's neurologist. This will allow you to ask further questions once you have digested the information.
- Take time to process the information given to you.



## 5 WAYS to Make the Most of Your DOCTOR VISIT

Being able to **talk with your doctor** is important, especially if you have **health problems** or **concerns**.



**Use these TIPS** to make the most of your doctor visit.

- 1 Prepare for your visit.**  
Be ready to ask three or four questions. Share your symptoms, medicines or vitamins, health habits, and any major life changes.



- 2 Take notes or ask for written materials.**  
Don't be afraid to ask the doctor to repeat or clarify important information.



- 3 Make decisions with your doctor that meet your needs.**  
Discuss risks, benefits, and costs of tests and treatments. Ask about other options and preventive things you can do.



- 4 Be sure you are getting the message.**  
If you have trouble hearing, ask your doctor to face you when talking and to speak louder and more clearly.



- 5 Tell the doctor if you feel rushed, worried, or uncomfortable.**  
You can offer to return for a second visit or follow up by phone or email.



Learn more about communicating with your doctor:

<https://www.nia.nih.gov/health/doctor-patient-communication>

**NIH** National Institute on Aging

# FIND A DOCTOR OR LGS COMPREHENSIVE CARE CENTER

## What is a Neurologist?

Neurologists are doctors who specialize in treating diseases of the brain and spinal cord. To become a neurologist in the United States, one must graduate from medical school, then complete a neurology residency for four years.

## What is an Epileptologist?

Epileptologists are neurologists who specialize in caring for those with epilepsy. To become an Epileptologist, one must first become a neurologist and then complete an additional one or two years of epilepsy subspecialty training.

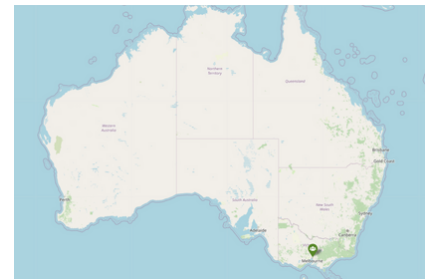
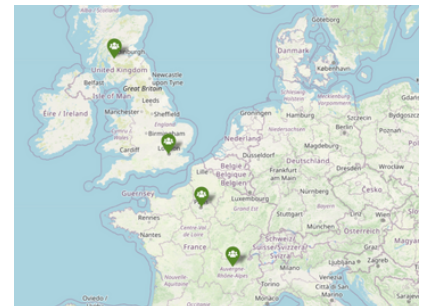
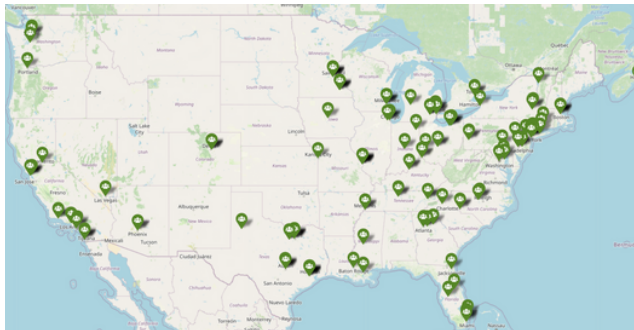
## Find a Doctor

Are you looking for a doctor who knows about LGS?

Check out our list.

Professionals listed on this site have treated patients with Lennox-Gastaut Syndrome and/or related disorders. Many have been recommended by LGS families in our community of support.

Find or Recommend  
a Doctor



## Find an LGS Comprehensive Care Center

Individuals with Lennox-Gastaut Syndrome have complex and lifelong neurological and medical needs that are unique. Often, a local care team is not familiar with LGS or may not have had another patient with this diagnosis. A visit to a Comprehensive Care Center will benefit the patient and family, allowing them to connect with knowledgeable experts and form a bridge to their local care provider when complex issues arise.

To qualify as an LGS Comprehensive Care Center, the center is expected to:

- Offer a multidisciplinary approach for the treatment of Lennox-Gastaut Syndrome
- Have a high concentration of expertise and related resources centered on LGS
- Demonstrate a strong knowledge base and familiarity with LGS
- Commit to furthering clinical knowledge of LGS through collaboration with others, including the LGS Foundation
- Have involvement in studies and/or clinical trials for Lennox-Gastaut Syndrome and are knowledgeable about new treatments and cutting-edge research

Find or Recommend  
a Center



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# Doctor Visits

Date:		Time:		
Doctor:	Location:	Contact Info:		
Reason(s) for Visit		Questions / Symptoms		
<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>		<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>		
Doctor's Comments / Notes				
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Age:	Weight:	Height:	Blood Pressure:	Heart Rate:
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Next Appointment:				

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# MEETING A NEW NEUROLOGIST OR EPILEPTOLOGIST

Are you meeting a new doctor soon? It's important to bring the right information with you when you do.

This toolkit from our friends at the Child Neurology Foundation might help.

In English:










## Child Neurologist New Visit Toolkit

### What your new neurologist needs to know

**DIRECTIONS:** We encourage you to fill out this form prior to your first visit with a neurologist or when visiting a new neurologist. We recommend you print this form out and bring it to the visit with you as well as keep an electronic or paper copy for yourself. It will be a valuable resource to track your child's journey and ensure the best quality of care.

**SECTIONS ON THIS FORM INCLUDE:**

 New Visit Highlights	 Testing & Treatment Summary	 Medication Summary
 Symptoms Summary	 Service Summary	 Seizure Summary
 Prenatal/Birth History		

*Please note, you may not have all this information, and that is OK. Simply provide what information you can.*

Giving your neurologist essential information helps them effectively diagnose and treat your child. Often there are symptoms you do not realize are significant and may be related to your child's condition. We hope this tool helps you and your neurologist collaborate successfully during your visit.

### Additional items to bring to your visit

**IF YOU HAVE ANY OF THE FOLLOWING ITEMS, THEY MAY BE HELPFUL.**

1. A copy of visit notes from your last medical visit related to this condition.
2. Videos of any relevant seizures, movements, behaviors etc.
3. Bring a copy of related test results (labs, genetic tests, imaging etc), if you have electronic copies bring those as well.
4. Copy of most recent neuropsychologist/academic assessment.

### Tips and tricks for your visit


1. **Bring a notebook and pen** so you can take notes.
2. When describing symptoms, **be as specific as possible** and don't exaggerate or downplay symptoms.
3. If your child is able, **encourage them to share their concerns and questions during the visit.** This will help your child feel involved in the process and gives them skills to advocate for themselves.
4. **Invite another adult** to help take notes, offer support, and care for the child so you can focus on the conversation with the doctor.
5. **Don't be afraid to ask a question** if you are confused by what the doctor is saying. You may want to repeat answers back to ensure you've captured everything.
6. Be sure to ask when/if you should **schedule your next visit.**
7. If you are having tests done, if they can't give you results immediately, **ask when you should expect to get the results,** and ensure you authorize sharing results with other members of your child's care team.
8. Before you leave, **make sure you discussed your top concerns and got answers to your top 3 questions.** If the doctor does not have time to answer them during the visit, ask if a nurse can help, or if you should schedule a follow up visit or phone call.
9. **Doctors prefer summaries over specifics.** If they need more details they will ask, so having your information organized can help make answering those questions easier. Consider putting everything into a binder and group visit summaries, test results, treatment summary and medication history in separate sections. If possible, keep in chronological order, with the most recent information first.

Download Toolkit

Get the Toolkit.  
It's available in  
English and  
Spanish!



In Spanish:










## Kit de herramientas para nueva visita con el neurólogo infantil

### ¿Qué necesita conocer su nuevo neurólogo?

**INSTRUCCIONES:** Le aconsejamos que rellene este formulario antes de su primera visita con el neurólogo o cuando visite a un nuevo neurólogo. Le recomendamos que imprima este formulario y lo traiga con usted a la visita, así como también que guarde para usted una copia electrónica o en papel. Este será un recurso valioso para seguir la trayectoria de su niño y para garantizar la mejor calidad de la atención.

**LAS SECCIONES EN ESTE FORMULARIO INCLUYEN:**

 Lo más destacado de la nueva visita	 Resumen de las pruebas y el tratamiento	 Resumen de los medicamentos
 Resumen de los sistemas	 Resumen del servicio	 Resumen de la convulsión
 Historial prenatal/nacimiento		

*Por favor, tenga en cuenta que es posible que usted no tenga toda esta información, y eso está bien. Solo proporcione la información que usted pueda.*

Al suministrarle la información esencial a su neurólogo le ayuda a diagnosticar y tratar con efectividad a su niño. A menudo hay síntomas que usted no considera significativos y que pueden estar relacionados con la afección de su niño. Esperamos que esta herramienta le ayude a usted y a su neurólogo para colaborar exitosamente durante su visita.

### Materiales adicionales que debe traer a su visita

**SI TIENE CUALQUIERA DE LOS SIGUIENTES MATERIALES, PUEDEN SER DE AYUDA.**

1. Una copia de las notas de la última visita médica relacionada con esta afección.
2. Videos de las convulsiones, movimientos, conductas, etc., de importancia.
3. Traiga consigo una copia de los resultados de las pruebas relacionadas con este estado de salud (pruebas de laboratorio, genéticas, imágenes, etc.), si tiene copias electrónicas también trágalas.
4. Copia de las evaluaciones neuropsicológicas/académicas más recientes.

### Consejos y tácticas para su visita

1. Traiga consigo una libreta y un bolígrafo para que pueda tomar notas.
2. Cuando describa los síntomas, sea lo más específico posible y no exagere ni reste importancia a los mismos.
3. Si su niño puede hacerlo, **ánimelo a que comparta sus preocupaciones y preguntas durante la visita.** Esto ayudará a que su niño se sienta involucrado en el proceso y le dará habilidades para defenderse por sí mismo.
4. Invite a otro adulto a que le ayude a tomar notas, le ofrezca apoyo y cuide del niño para que usted pueda centrarse en la conversación con el médico.
5. No tenga temor de hacer preguntas si está confundido por lo que le está diciendo el doctor. Es posible que quiera repetir las respuestas para asegurarse de que ha captado todo.
6. Asegúrese de preguntar cuándo/ si debe programar su próxima visita.
7. Si se hacen pruebas, y no le pueden dar los resultados inmediatamente, pregunte cuándo debe esperar recibirlos y asegúrese de dar la autorización para compartir los resultados con otros miembros del equipo de atención de su niño.
8. Antes de marcharse, asegúrese de haber hablado sobre sus principales preocupaciones y de haber obtenido respuestas a sus tres (3) preguntas principales. Si el médico no tiene tiempo para responder las preguntas durante la visita, pregúntele si una enfermera puede ayudarlo o si debe programar una visita o una llamada telefónica de seguimiento.
9. Los médicos prefieren los resúmenes en lugar de los detalles, pero si ellos necesitan más detalles se los pedirán, por lo que tener su información organizada puede facilitar las respuestas a esas preguntas. Considere la posibilidad de poner todo en una carpeta y agrupar los resúmenes de las visitas, los resultados de las pruebas, el resumen del tratamiento y la historia clínica de los medicamentos recetados en secciones separadas. Si es posible, mantenga todo en orden cronológico, con la información más reciente primero.

Download Toolkit

Works great for  
adults with LGS,  
too!

# HOW TO NAVIGATE INSURANCE DENIALS

## I just received an insurance denial. What happens now?

Receiving a coverage denial notice for yourself or your loved one can be stressful, frustrating, time-consuming, and complicated. The first step in managing the denial process is to understand the reason for the denial so you can take steps to try to appeal and resolve it. To help navigate the process, below are some tips on denials, appeals, and where to find more information.

What are some common reasons for denials?

- Review the Explanation of Benefits (EOB), a document from your insurance company that provides information about your claims, or the denial letter to identify the reasoning behind the denial. If you are unsure of the reason for denial, contact your insurance company or healthcare team for an explanation.
- Some common reasons medications are denied include:
  - There may have been a processing error: examples include a missing authorization code, the paperwork was not filed in a timely manner, or payment was not received.
  - There are limits on the amount of medication (dose, quantity, or intervals between doses) you can receive.
  - The insurance company has a medication formulary (a list of medications that it covers) that prefers you use a generic or biosimilar medication rather than the prescribed brand name medication.
  - The medication is non-formulary, meaning it is not covered by your insurance plan.
  - A pre-authorization is required by your insurance company prior to receiving the medication.
  - The insurance company requires you to try and fail another medication(s) first before providing coverage for your prescribed treatment. This is also known as step therapy or fail first.

### Appealing a Denial

- When you file an appeal, you are asking your insurance company to reconsider its decision of denying coverage for a specific medication, treatment, or service. Depending on your insurance plan, there may be a deadline for filing an appeal, so pay attention to timelines for submission. Most of the time, your doctor's office will handle submitting an appeal, but patients have the option to submit an appeal letter as well. Contact your healthcare team for support when writing your appeal letter, as they may have templates or helpful information to include. After you submit, follow up with your insurance company and confirm they received your appeal letter and that the appeal is being processed.
- Helpful tips when writing an appeal letter:
  - When writing your appeal letter, clearly state the purpose is to appeal a decision. Include the policy number, claim number, date of service, and your completed contact information (home address, best phone number, and email address). Be as concise as possible, and include only facts related to the denial reason. Check for spelling and grammar errors. You want to include a letter(s) from your healthcare team documenting your personal LGS journey and showing medical necessity for the denied medication, treatment, or service, as well as copies of any relevant medical records.
  - When sending your letter, be sure to include any of the items below as supportive documentation:
    - A copy of the denial letter or Explanation of Benefits (EOB).
    - A copy of any bills received (if applicable).
    - A copy of the completed appeal form from the insurance company.
    - If needed, an 'Appointment of Representative' Form which allows you to name someone to make medical decisions for you.
    - Letter of medical necessity from your healthcare team and any other supportive letters.
    - Relevant medical records related to the denial.
    - Supportive peer-reviewed journal articles.
- Remember:
  - File appeals in a timely fashion and pay attention to deadlines - there are often short windows during which an appeal can be filed after a claim is denied.
  - Keep all copies of correspondence from your doctor's office and the insurance company.
  - Keep a record of all names/titles of everyone you speak to and any case or authorization numbers.
  - Only send copies of documents and keep all originals on file for reference.