

ABOUT LGS TREATMENTS KIT

Introduction & How to Use This Kit

Dear Friends,

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

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:



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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!

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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

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?

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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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