LEARN ABOUT CLINICAL TRIALS IN LGS





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.





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)











LGS RNS



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.

