LGS FOUNDATION®
LENNOX-GASTAUT SYNDROME

Celebrating more than 15 years of service improving the lives of individuals impacted by LGS through advancing research, awareness, education, and family support.

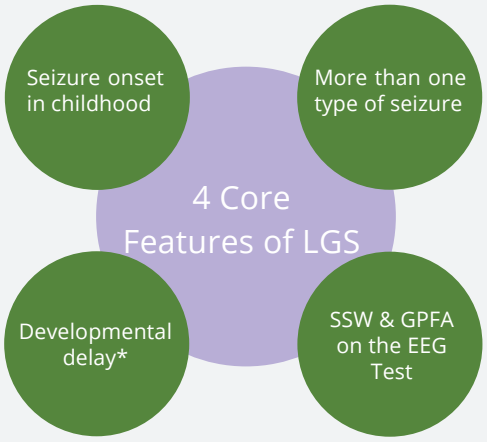
www.LGSFoundation.org

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.

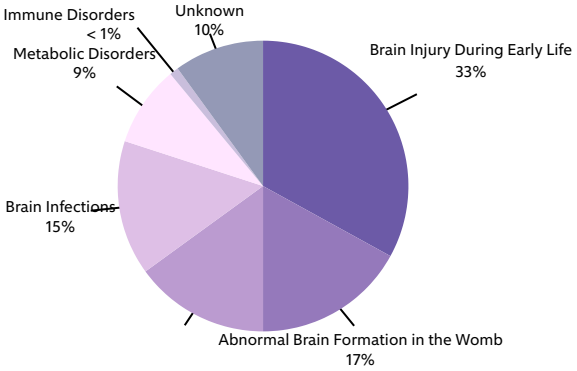
In LGS:

- Seizures usually begin in the pre-school years.
- More than one seizure type is always present.
- Tonic seizures are present in nearly all with LGS at some point.
- Seizures are nearly always treatment-resistant.
- Many LGS Associated Disorders exist including issues with sleep, behavior, movement, feeding, toileting, communication, and others.
- Slow spike and wave (SSW) and Generalized Paroxysmal Fast Activity (GPFA) are seen on the EEG. These are hallmarks of LGS.
- SSW and GPFA usually emerge between ages 3-5 years but can begin later in childhood.
- SSW and GPFA occur between seizures and can worsen seizures, development, and behavior problems.



*Developmental delay is not required to make the LGS diagnosis and 30% of kids are typically developing at diagnosis.

What causes seizures in LGS?



Some genes and genomic regions that cause seizures that can evolve into LGS:

ALG13	GNAO1	PCDH19SLC35A2
ARX	GRIN1	PIGASPTAN1
CACNA2D2	GRIN2A	PLCB1ST3GAL3
CLN1/2/5	GRINBB	PPP3CASTXBP1
CDKL5	HNRNPU	PTENTBD1D24
DNM1	KCNT1	SCA2TCF4
DOCK7	KCNQ2	SCN1ATSC1/2
FLNA	MAGI2	SCN2AWWOX
FOXG1 Dup	MEF2C	SCN8ADup 15q
GABRA1	NEDDL4	SETBP122q Del
GABRB3	NDP	SIK1Trisomy 21
GLI3	NRXN1	SLC25A22
		and many more . . .

- In LGS, the brain is affected at a critical time in its development. Seizures and developmental problems result.
- There are many causes of seizures that can evolve into LGS. In most but not all cases, a cause can be found. Finding it can take extensive testing. In some cases, more than one cause is found.
- Knowing the cause of seizures can help identify an effective treatment in some cases.
- Most with LGS may have abnormal brain imaging seen on the MRI test, but some have normal brain imaging prior to developing LGS.
- LGS can also develop from other epilepsy syndromes such as West, Ohtahara, EIEE, Hypothalamic Hamartoma, Infantile Spasms, etc.

Who has LGS?

1-2%
of people with epilepsy

3-4%
of children with epilepsy

48,000
childen 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 in LGS 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.
- Over 95% with LGS are intellectually disabled.
- Up to 70% with LGS will no longer show slow spike-and-wave (<3Hz) on EEG in adulthood.
- Over 50% suffer behavioral issues including hyperactivity, sleep disturbances, rage attacks, aggression, and autistic features.
- Those with LGS are 14 times more likely to die prematurely. Premature death in LGS is often due to SUDEP*, aspiration pneumonia, seizures, injury, or the underlying brain disorder.

The LGS Foundation is committed to finding a cure for this devastating disorder!

Arzimanoglou A, et al. Epileptic Disord. 2011;13(Suppl 1):S3-S13.
Berg AT, et al. Epilepsia, 2018;59(11).
Bourgeois BF, et al. Epilepsia, 2014;55(Suppl 4).
Cross JH, et al. Front Neurol. 2017;8:505.
Goldsmith IL, et al. Epilepsia, 2000;41(4).
LGS Foundation Caregiver Concerns Survey 2018.
McTague A, et al. Lancet Neurol. 2016;15(3).

*SUDEP – Sudden Unexpected Death in Epilepsy.