



Issues that Impact Families in the LGS Community

INTERNATIONAL
LGS FOUNDATION
FAMILY & PROFESSIONAL CONFERENCE



LENNOX-GASTAUT SYNDROME (LGS) KEY LEARNINGS FROM CAREGIVERS

November 2021

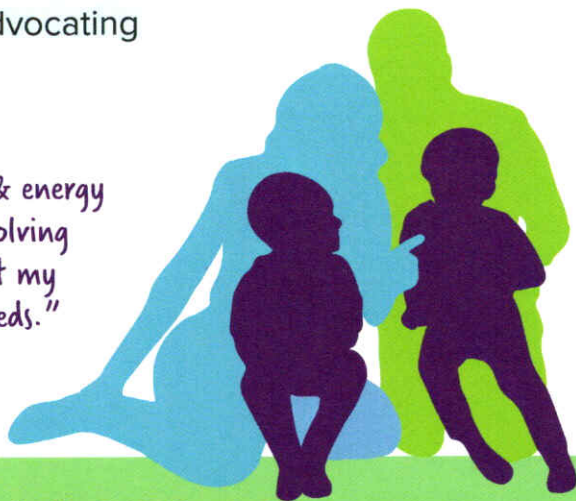
MY **LGS** KID

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

THE LGS **COMMUNITY** IS

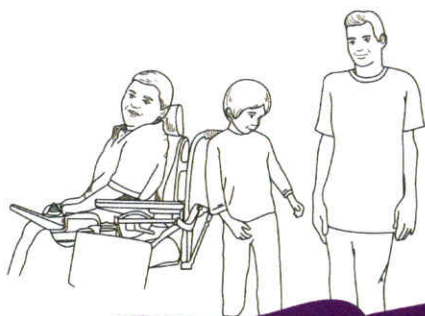
- Resilient
- Caring & compassionate
- Fiercely independent
- Self-advocating
- Innovative

"Most of my time & energy go to constantly evolving the routine to meet my child's changing needs."



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.



A GOOD DAY IS WHEN...

- He has fewer seizures.
- She can participate in her therapies.
- She's attentive in homeschool.
- He's in a good mood with good energy.
- It's a school day; she loves school.
- It's a day that follows the routine.

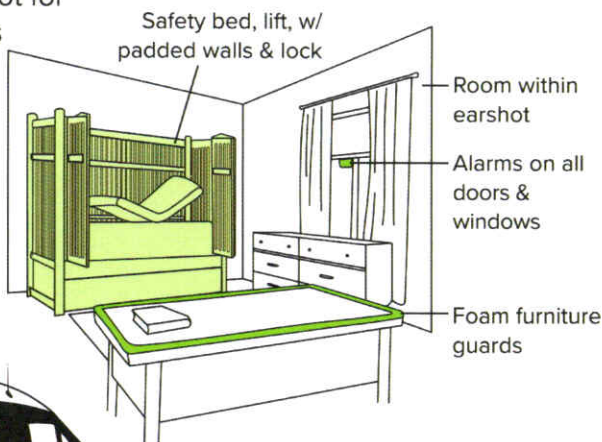
"Don't ignore those with special needs because you're not sure how to communicate with them. Be patient and put effort into communicating, so they feel seen and included."

SAFETY MODIFICATIONS

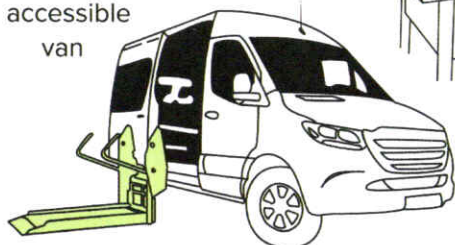
- Monitoring vitals
- Pureeing food
- Thickening liquids
- Using a harness in the car
- Bringing a foldable cot for adult diaper changes
- Using backseat & in-home cameras



Tent w/ a lock

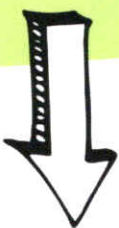
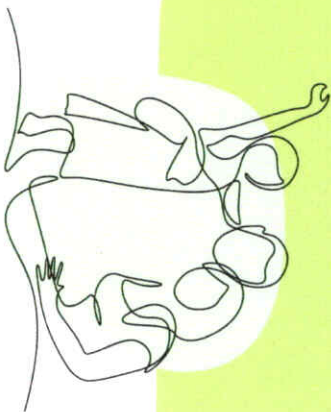


Wheelchair-accessible van



Seizure watch

What do you adore
about your child that
most people don't see
or understand?



silly

JGYYOUS

HUMOROUS

MUSICAL artistic

BLESSING

unique LOVING

HEART

KEY CHALLENGES

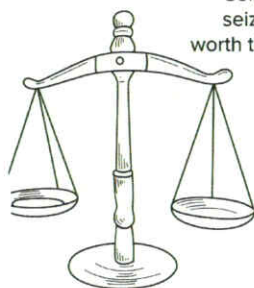
- No respite care
- Care coordination, logistics
- Emotional burden, isolation (difficulty traveling, missed social opportunities)
- Equipment (bed, lift, chair, brace)
- Family dynamics
- Fear (a bad seizure, SUDEP, guardianship)
- Finding the right pediatric & adult HCPs
- Financial strain (high costs,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

MY KID'S CHALLENGING BEHAVIORS

- Expressing anger physically, knocking things over
- Vocalizing, moving head and hands when frustrated
- Hitting, flailing, throwing things
- Aggression
- Biting
- Banging head
- Requires constant visual-audio stimulation
- Grabbing siblings by the hair

WEIGHING TREATMENTS VS. BEHAVIORS

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



MY KID'S UNSAFE BEHAVIORS

- Putting things in his mouth
- Running without sense of environment
- Grabbing & pulling things down on herself
- Seizure-related falls
- Climbing everything, risking falls

A BAD SEIZURE

For us it's the length. More than a couple of minutes and you're going to see regression in abilities.

Drop and tonic-clonic seizures are the scariest.

The worst is when she has a seizure cluster, and we can't stop it with meds or the magnet.

ZOGENIX

Now a part of UCB

UCB welcomes Zogenix, Inc. to UCB. ©2022 UCB, Inc, Smyrna, GA 30080

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Source: Zogenix-sponsored LGS Advocacy Advisory Board
with Eight Caregivers, Nov. 11, 2021.