### LENNOX-GASTAUT SYNDROME (LGS) KEY LEARNINGS FROM CAREGIVERS

#### November 2021

THE LGS

**COMMUNITY** IS

Innovative

Is silly Loves music

MY LGS KID Is cuddly Loves snuggling Is affectionate

Has a great sense of humor

Resilient

Caring & compassionate

Fiercely independent

Self-advocating

# 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.

# 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

Expressing anger physically, knocking things over

Vocalizing, moving head and hands when frustrated

Climbing everything, risking falls

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

#### BAD SEIZURE

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.

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

## MY KID'S CHALLENGING BEHAVIORS

Aggression

Banging head Biting

Requires constant visual-audio stimulation

Grabbing siblings by the hair

Hitting, flailing, throwing things

# MY KID'S UNGAFE BEHAVIORS

Putting things / in his mouth

— Running without sense of environment

Grabbing & pulling things down on herself

Seizure-related falls

### WEIGHING TREATMENTS VS. BEHAVIORS

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





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