

Lennox Gastaut Syndrome

The Natural History Project

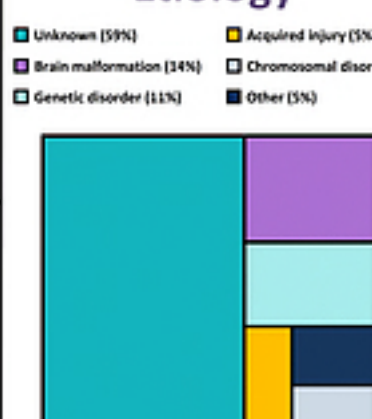
37 Parents from the USA, Australia, and the Netherlands participated



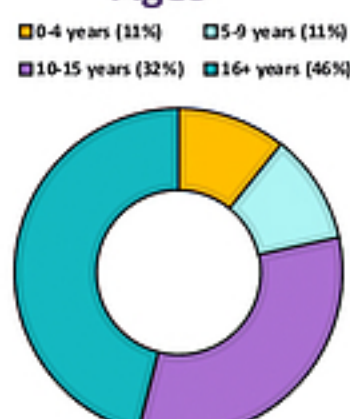
Gender

43% ♀ **57%** ♂

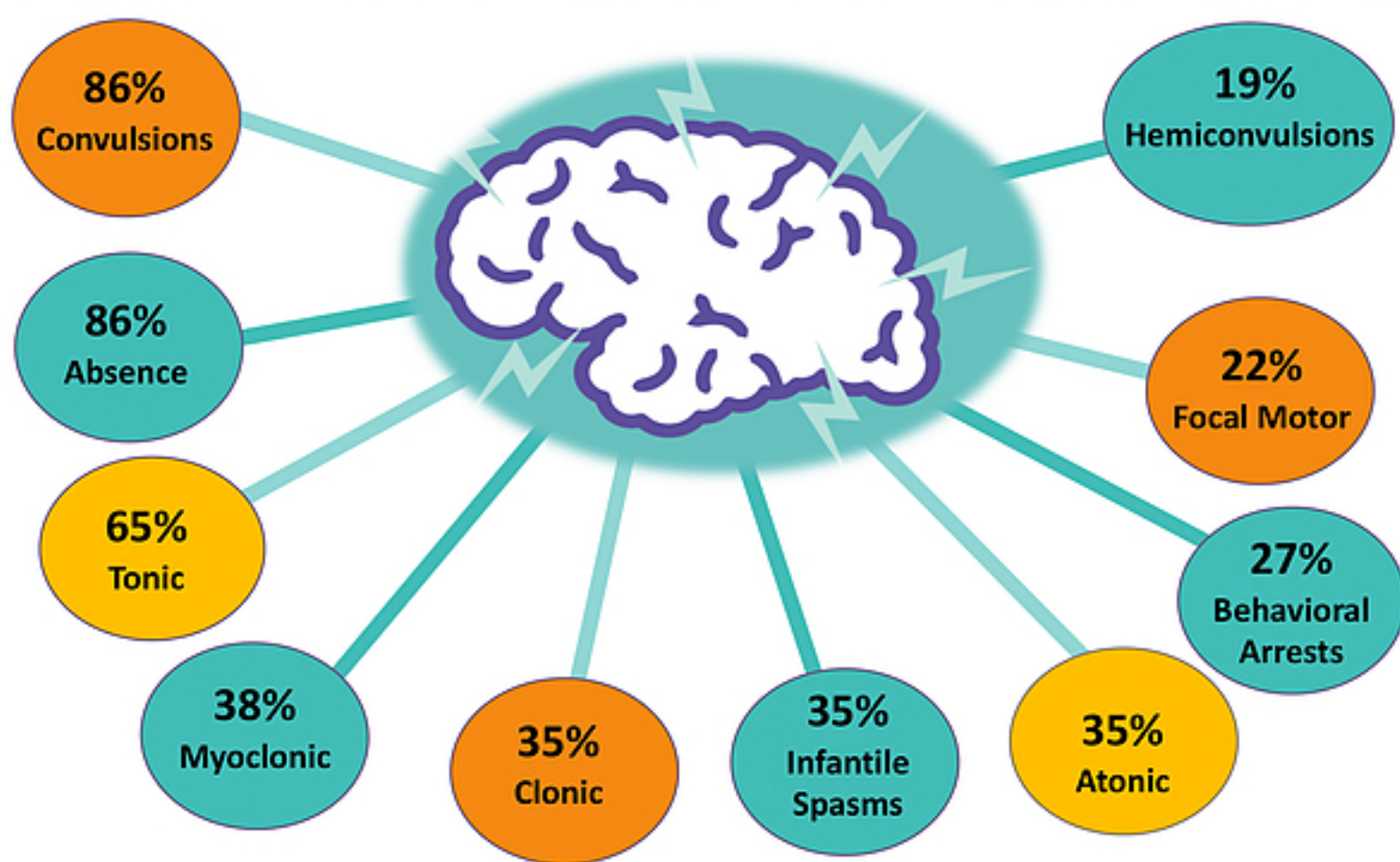
Etiology



Ages



SEIZURE TYPES



97% had seizures recently*

75% had seizures every day in the past week

58% had triggers for their seizures including:

- **Hyperthermia (24%)**
- **Excitement (19%)**
- **Bright/Flashing Lights (19%)**

*In the past 6 months



81% of parents monitor their child's sleep

- **75%** reported seizures ≥ 3 nights a week
- **39%** reported their child waking up ≥ 3 nights a week (not due to seizures)
- **39%** reported child restlessness ≥ 3 nights a week



Seizure Emergencies

*In the past 6 months



82% have ever had prolonged seizures (≥ 10 min) of any type



32% had a prolonged seizure in the past 6 months

- **24%** had a seizure lasting >30 minutes



51% recently* used rescue medications

- **53%** needed a 2nd rescue dose at least 1/2 the time
- **24%** needed a 2nd dose every time

45% recently* used bridge medications



30% recently* went to an ED or were hospitalized for seizures at least once

15% Convulsive
24% Non-convulsive
9% Myoclonic
9% Other

Children having different prolonged seizure types*

FUNCTIONAL ABILITIES



31% require a wheeled mobility device



46% have significant visual impairment



25% typically do not use hands to manipulate objects



50% do not speak words



42% are completely dependent on a caregiver for feeding



54% inconsistently or rarely communicate even with people they know (e.g. family)

ACTIVITIES OF DAILY LIVING[†]



13% dress themselves



38% use spoon and fork



4% brush their own teeth



29% wash and dry their hands



29% drink from a cup



46% use a touchscreen device



46% scribble or draw with a crayon or pencil



30% have simple academic skills



17% are completely independent for toilet use



58% walk independently without an aid

FAMILY IMPACT



52% experience substantial financial challenges



82% say life feels like a rollercoaster



78% report moderate to severe fatigue

HEALTHCARE TEAM



In the past year

Types of Therapists Seen:

74% Speech
70% Occupational
57% Physical

17% Behavioral
9% Psychologist
9% Developmental

Types of Specialists Seen:

96% Neurologist
43% Special Needs Dentist
43% Orthopedist
30% Neurosurgeon
26% Ophthalmologist

17% Dermatologist
17% Dietician
17% Gastroenterologist
9% Cardiologist
9% Geneticist



6 – Median # of different specialist and therapists involved in care
64% Of children have a therapy appointment at least 2x per week
43% Of parents feel care is not well coordinated across specialists



* Throughout, "Recently" refers to the past 6 months

[†] Participants who can do the task independently or with occasional verbal prompts and reminders

The survey was designed in and administered through CLIRINX, Dublin Ireland



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