

Annual Family Survey

Please complete the survey below.

Thank you!

Seizure Types/Frequency

When was the last time your child had a seizure that caused stiffening and/or shaking of the body? (Examples: "grand mal," "tonic-clonic," "focal motor")

- Never/does not have this seizure type Today 1-6 days ago (up to 1 week) 1-4 weeks ago (up to 1 month) 5-12 weeks ago (1-3 months) 13-26 weeks ago (3-6 months) 6-12 months ago
 13-24 months ago More than 2 years ago Uncertain

During the last year, how frequent are seizures that cause stiffening and/or shaking of the body? (Examples: "grand mal," "tonic-clonic," "focal motor")

- Multiple per day but not every month Daily Weekly but not daily Monthly but not weekly At least once per year
 Less than once per year Uncertain Frequency not well defined

When was the last time your child had a seizure WITHOUT stiffening and/or shaking? (ex. Unresponsiveness, staring, drooling, such as "absence" or "focal with altered awareness")

- Never/does not have this seizure type Today 1-6 days ago (up to 1 week) 1-4 weeks ago (up to 1 month) 5-12 weeks ago (1-3 months) 13-26 weeks ago (3-6 months) 6-12 months ago
 13-24 months ago More than 2 years ago Uncertain

In the last year, how frequent are seizures WITHOUT stiffening and/or shaking? (ex. Unresponsiveness, staring, drooling, such as "absence" or "focal with altered awareness")?

- Multiple per day but not every month Daily Weekly but not daily Monthly but not weekly At least once per year
 Less than once per year Uncertain Frequency not well defined

Over the last year, has your child had seizures during sleep?

- Some at night or from sleep None at night or from sleep Unsure if they happen at night or from sleep

Seizure Emergencies

In the last year, has your child had any seizures lasting 5 minutes or longer?

Yes No Uncertain

How often did you give an emergency rescue medication?

I didn't give a rescue medicine Some of the time Every time

In the last year, how many times did you take your child to the emergency room/hospital because of seizures?

None Once Twice 3+ Uncertain

Has your doctor/provider ever discussed SUDEP (Sudden Unexplained Death in Epilepsy) with you?

Yes No Uncertain

Treatment Questions

Has your child continued to have seizures after trying three or more medications? (Do not include medications that were stopped in less than 3 months due to a side effect)

Yes No Uncertain

Which NEW treatments were tried in the last year? (2nd year on) multiple select

- Levetiracetam (Keppra) Oxcarbazepine (Trileptal) Valproic acid (Depakote) Lamotrigine (Lamictal) Zonisamide (Zonegran) Topiramate (Topemax) Lacosamide (Vimpat)
 Phenobarbital Clobazam (Onfi) Rufinamide (Banzel) Felbamate (Felbatol)
 Perampanel (Fycompa) Vigabatrin (Sabril) ACTH (Acthar) Oral steroid (e.g. prednisone, prednisolone) Cannabidiol-prescribed (Epidiolex) Cannabidiol-unprescribed Ketogenic diet
 Modified Atkins Diet Vagus Nerve Stimulator Deep Brain stimulation Epilepsy surgery (removed brain tissue) Corpus Callosotomy Other drug (free text if selected) None Uncertain

If other, what treatment(s)?

Quality of Life

Think about the child's usual routines. How often in the past 2 weeks have SEIZURES significantly changed these routines?

- Every day Most days (more than half) Some days (less than half) Never
 Uncertain

Think about the child's usual routines. How often in the past 2 weeks have SEIZURE MEDICATION SIDE EFFECTS significantly changed those routines?

- Every day Most days (more than half) Some days (less than half) Never
 Uncertain

If other, what new treatment(s)?

Which treatment provided your child the greatest benefit in the past year? (recurring surveys)

- Levetiracetam (Keppra) Oxcarbazepine (Trileptal) Valproic acid (Depakote) Lamotrigine (Lamictal) Zonisamide (Zonegran) Topiramate (Topemax) Lacosamide (Vimpat)
 Phenobarbital Clobazam (Onfi) Rufinamide (Banzel) Felbamate (Felbatol)
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 Modified Atkins Diet Vagus Nerve Stimulator Deep Brain stimulation Epilepsy surgery (removed brain tissue) Corpus Callosotomy Other drug (free text if selected) None Uncertain

Comorbidity Questions

Answer only if your child is 5 years or younger. Which best describes your child's development?

- My child is 6 years or older (too old for developmental delay diagnosis) Normal development (no delay)
 Borderline or possible mild delay Definite delay in one area (for example, isolated language delay, or delay in walking only) Definite delay in two or more areas (can include gross motor, fine motor, language, or social)

Have any of the following Psychiatric/behavioral/cognitive conditions been diagnosed? (may select more than one)

- ADD/ADHD Anxiety Autism/PDD Depression Learning disability Intellectual disability
 Language disorder Behavior disorder None of these apply

Have any of the following Neurologic conditions been diagnosed?

- Cerebral palsy Hearing impairment Migraines Movement disorder Sleep disorder
 Visual impairment (other than needing glasses for being nearsighted or farsighted) None of these apply

Does your child have any of the following medical needs?

- Feeding tube (G-tube, J-tube, or G/J-tube) Tracheostomy Assisted ventilation (CPAP, BiPap, or ventilator) VP (ventroperitoneal) shunt Communication device Wheelchair
 Hearing aid or cochlear implant Baclofen pump