

The Ability Study

Tired of filling out questionnaires that are irrelevant to your child? Here is a chance to help researchers find the best, most useful, most relevant questions that will let parents and caregivers most accurately report on their children's abilities and challenges.

How Will the Study Help?

The Ability study focuses on how parents report information about what children adolescents and young adults with severe early life epilepsy **can** do. By participating in this study, you will be helping us develop one or more questionnaires that may be used in future studies of new therapies. This will allow scientists to better measure what your child can do now and how his or her abilities change over time.

Why Do We Need This?

Scientists and industry are developing novel therapies for many serious diseases that cause early-life epilepsies and related disorders. To test whether these new therapies work, we need good ways of showing whether a new drug makes a positive difference, not just for seizures but also for other important areas that are frequently affected in childhood epilepsies including mobility, hand use, communication, and behavior.

Who is Eligible?

Parents or primary caregivers of children aged 1 to 30 years-old who have a history of epilepsy and moderate to severe developmental impairments associated with Lennox-Gastaut or Dravet Syndrome or with variants in KCNQ2, KCNB1, PACS1, CHD2, or SCN2A. At this time, we are limited to inviting those living in the US, Puerto Rico and Canada.

What is Involved?

The study is done completely on-line. It covers many different areas in addition to seizures such as medical history, sleep, behavior, communication, gross and fine motor, eating and self-care. The entire survey may take 2 to 2 ½ hours to complete, but you can leave and come back as many times as you like. When you complete the full survey, you will receive a **\$150 Amazon gift card** to thank for your time and effort. You may also be invited to consider participating in an interview after you complete the survey to help the researchers better understand what you did and did not like about the questions. You will have the option to opt out if you do not want us to contact you.

How Do I Participate or Find Out More?

If you would like to learn more about the study please go to the following link: theability.study

If you have questions about the study, please email WhatIsEpilepsy@luriechildrens.org