



## What is the study about?

The SCN2A Clinical Trial Readiness Study being led by Dr. Anne Berg at **Ann & Robert H. Lurie Children's Hospital of Chicago**, has been designed by an extensive team of parents, providers, scientists and pharmaceutical representatives to identify the nature and range of the many challenges affecting young people with SCN2A-DEE. The purpose of this study is to provide information that will help researchers determine the performance of specific measures over time in children with SCN2A-DEE. If eligible, your participation will be spread out over a 12 month period. There will be four opportunities to claim \$50 gift cards as a way to thank you for your time.

## How will the study help?

The information that comes from this project will be used to inform parents and educate providers about what to expect in a child with SCN2A-DEE. This study will also provide information on the reliability of specific measurements over a short period of time and the rate at which they change over time in an individual child. The data from this study will provide the basis for designing efficient therapeutic trials to test new treatments for SCN2A-DEE and can be used for advocacy with policy makers.

## How do I participate?

If you chose to participate, you will complete an online consent form and then fill out a screening questionnaire through a secure, online portal. If you are eligible, the SCN2A CTRS team will contact you to invite you to participate. If you do not meet eligibility for the full CTRS, you will be invited to participate in a shorter, one time survey.

## How is this different from other SCN2A data collections?

The SCN2A CTRS uses FDA validated instruments that are specifically designed to measure change in children with SCN2A DEE. This is critical as these measurements will be used to determine if a new therapeutic is successful or not. Other SCN2A data collections will compliment this study as they are looking at different aspects such as long term changes, medical records, and how SCN2A measures up to other genetic disorders. The best news is that once enrolled in the SCN2A CTRS, your data will be owned by YOU and you can share it with whom you choose.

To learn more about the study and to begin your registration and consent process, please go to the following link: <https://scn2a.study/>

If you have questions about the study, please email [WhatIsEpilepsy@luriechildrens.org](mailto:WhatIsEpilepsy@luriechildrens.org)