

Nationwide Children's Hospital is recruiting *children diagnosed with CLN2 disease, a form of Batten Disease*, to participate in a study looking at cognitive and developmental outcomes over time.

Who can take part in this study?

We are recruiting individuals with CLN2 disease to participate in a study to look at cognitive and developmental outcomes over time in patients that are untreated and those that are receiving enzyme replacement therapy. The purpose of the study is to better understand the natural progression of the disease, as well as examine how best to measure developmental outcomes through clinical assessment to inform standard of care. Results from this study will provide a better understanding of CLN2 disease to guide assessment and treatment efforts.

What will happen during the study?

Participants that meet screening criteria will:

- Complete a battery of developmental assessments that include measures of early learning, language, and motor development.
- Caregivers will also complete a series rating forms regarding symptoms and behaviors they see
- Study participation will take 1-2 hours to complete for each visit. Families can participate up to 2 times per year.

Compensation

Participants will be reimbursed \$50 for their time for each visit completed.

Participation in research is completely voluntary

Contact Information

If you are interested in participating in this study or would like more information please contact Jessi Scherr, PhD at 614-355-7500 ext. 3-8230 or

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