Simons Searchlight Registry Update for Okur-Chung Neurodevelopmental Syndrome (OCNDS)

December 2021

How to Participate

The information in this report is made possible by the active participation of the OCNDS community! Progress for individuals in your community with a CSNK2A1 variant is shown below -- log in to your simonssearchlight.org dashboard today to check for new surveys and tasks. Your data could hold the clues geneticists need to find answers.

**Participant Age at Most Recent Interview**

**Developmental & Behavioral Diagnoses**

**Neurological Problems**

**Gastrointestinal Problems**

**Notes:**
- Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.
- Graphs show data as of the last medical history interview completed on participants who have a pathogenic or likely pathogenic variant.

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**How to Participate**

**STEP 1** Sign up online.

**STEP 2** Provide your genetic lab report.

**STEP 3** Share your important medical history.

**STEP 4** Fill out surveys.

**STEP 5** Provide a blood sample if you are interested.

**STEP 6** Update us every year.

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**Participant Age at Most Recent Interview**

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Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 29 participants with OCNDS.
Information Spotlight: **Deeper Dive into Sleep**

The Simons Searchlight Sleep Supplement is a custom survey. We worked with members of the Simons Searchlight community and sleep researchers to design these questions. It asks caregivers about children’s sleep habits and the impact of health issues on sleep behaviors. The survey looks at children between ages 2 and 18 years of age. 24 children with OCNDs are represented.

### Getting Enough Sleep

- **Always** (33.33%)
- **Usually** (29.17%)
- **Sometimes** (16.67%)
- **Rarely** (16.67%)
- **Never** (4.17%)

### Medical issues related to sleep problems in children with OCNDs*

- **Pain**
- **Breathing problems**
- **Restless legs**
- **Mood disorder**
- **Medication side effects**
- **Seizures**
- **Autonomic dysfunction**
- **Itchy skin**
- **GI symptoms**
- **Anxiety**
- **Sleep apnea/snoring**

* Caregivers were able to select more than one answer

### Best Ways to Help Sleep: Community Recommendations*

- **Sound or white noise machine**
- **Behavior therapy or plan**
- **Witholding naps**
- **Bathroom break before bed**
- **Medication**
- **Bedtime routine or ritual**
- **Parent lying in their bed until they fall asleep**

* Caregivers were able to select more than one answer