Simons Searchlight Registry Update CSNK2A1 (Okur-Chung Syndrome)

June 2021

Ages in Years

- 0-4: 7
- 5-9: 9
- 10-14: 7
- 15-19: 3
- 20-24: 1

Developmental & Behavioral Diagnoses

- Intellectual Disability/Development Delay: 23
- Autism: 25
- ADHD: 6
- Anxiety: 5
- Language Impairment: 4

Neurological Problems

- Low Muscle Tone: 21
- Clumsy: 6
- Large Head Size: 1
- Small Head Size: 7
- Movement Disorder: 6
- Tic Disorder: 1
- Cerebral Palsy: 2
- Seizures: 10

Gastrointestinal Problems

- GERD: 9
- Diarrhea: 2
- Constipation: 14
- Other: 1

Notes:
- Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.
- Information on reported seizure types is included on the 2021 quarter 1 registry report available on [simonssearchlight.org/CSNK2A1](http://simonssearchlight.org/CSNK2A1).

Participation & Registration

This ever-growing database 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](http://simonssearchlight.org) dashboard today to check for new surveys and other priority tasks. Your unique data could hold the clues scientists need to make progress and find answers.

**STEP 1**
Sign up online.

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

**STEP 3**
Schedule medical history phone call with a genetic counselor.

**STEP 4**
Fill out surveys.

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

**STEP 6**
We follow up with you over time.

Log in to see next steps
Information Spotlight: Child Behavior Checklist

The Child Behavior Checklist (CBCL) is a survey used to understand behavioral and emotional concerns in children.

The bars in the graphs show the overall level of concern reported by Simons Searchlight caregivers who completed the CBCL survey about their children with OCNS. Individual caregivers may have indicated a lower or higher level of concern than indicated by the overall group.

### Behavioral Concerns for ages 1.5-5yrs

- **Oppositional behavior**
- **Attention/hyperactivity**
- **Aggression**
- **Anxiety**
- **Sadness**

*Not a concern | Mild concern | Significant concern*

### Behavioral Concerns for ages 6-18 yrs

- **Oppositional behavior**
- **Attention/hyperactivity**
- **Aggression**
- **Anxiety**
- **Sadness**

*Not a concern | Mild concern | Significant concern*

### Top Behavioral Concerns

**Ages 1.5-5 yrs**
- Demands must be met immediately
- Afraid to try new things
- Easily frustrated
- Specific fears (e.g., animals, places, situations)

**Ages 6-18 yrs**
- Can't sit still, restless, hyperactive
- Inattentive or easily distracted
- Demands a lot of attention
- Temper tantrums or hot temper