Simons Searchlight Registry Update **CSNK2A1/OCNDS**

Data in these four graphs are from the medical history information collected in Simons Searchlight from 71 participants with CSNK2A1 (Okur-Chung Neurodevelopmental Syndrome, OCNDS).

**April 2024**

### Ages in Years

- 0-4: 18
- 5-9: 26
- 10-14: 14
- 15-19: 8
- 20-24: 3
- 25+: 2

### Developmental and Behavioral Conditions

- ADHD: 10
- Anxiety: 10
- Autism: 18
- Intellectual Disability/Developmental Delay: 64
- Language Delay/Impairment: 69

### Neurological Conditions

- Tic Disorder: 3
- Small Head Size: 16
- Seizures: 20
- Movement Disorder: 12
- Low Muscle Tone: 50
- Large Head Size: 1
- High Muscle Tone: 2
- Cortical Visual Impairment: 2
- Coordination Problems: 10
- Cerebral Palsy: 2

### Gastrointestinal Conditions

- Celiac Disease: 37
- Constipation: 5
- Diarrhea: 15
- GERD: 1
- IBS: 5

**NOTES:** Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.

**How to participate?**

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

- **STEP 1**
  - Sign up online
  - 129

- **STEP 2**
  - Provide your genetic lab report
  - 105

- **STEP 3**
  - Share your important medical history
  - 79

- **STEP 4**
  - Fill out surveys
  - 92

- **STEP 5**
  - Provide a blood sample if you are interested
  - 24

- **STEP 6**
  - Update us every year
  - Log in to see next steps
Information Spotlight:
Where in the world are Simons Searchlight families?

Simons Searchlight families live in 75 countries globally, including 105 CSNK2A1/OCNDS participants in 20 countries.

Most Simons Searchlight families live in the United States. See where 47 CSNK2A1/OCNDS participants live across the 50 states.

Thank you for participating in Simons Searchlight and helping us reach families worldwide!