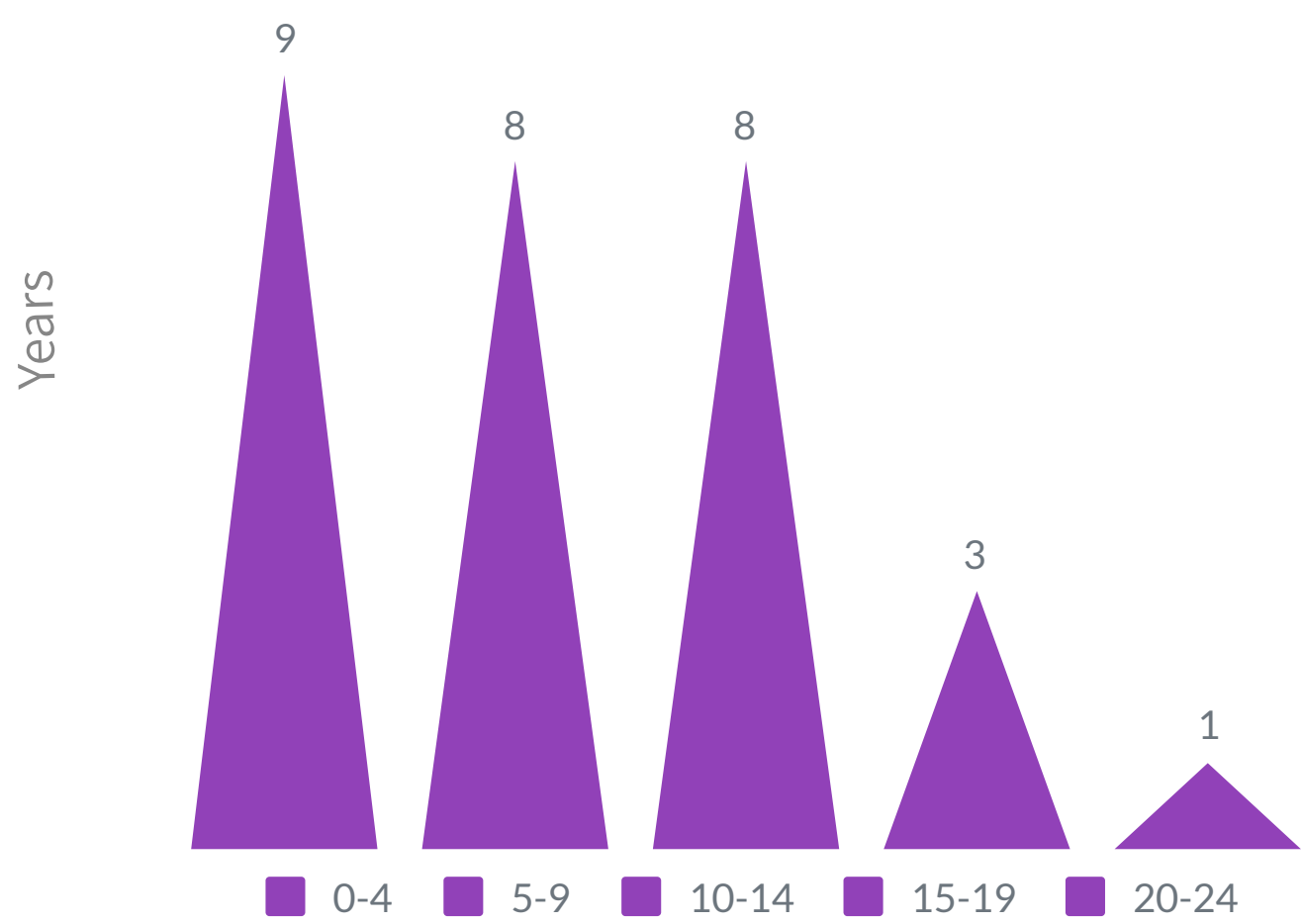


# Simons Searchlight Registry Update for Okur-Chung Neurodevelopmental Syndrome (OCNDS)

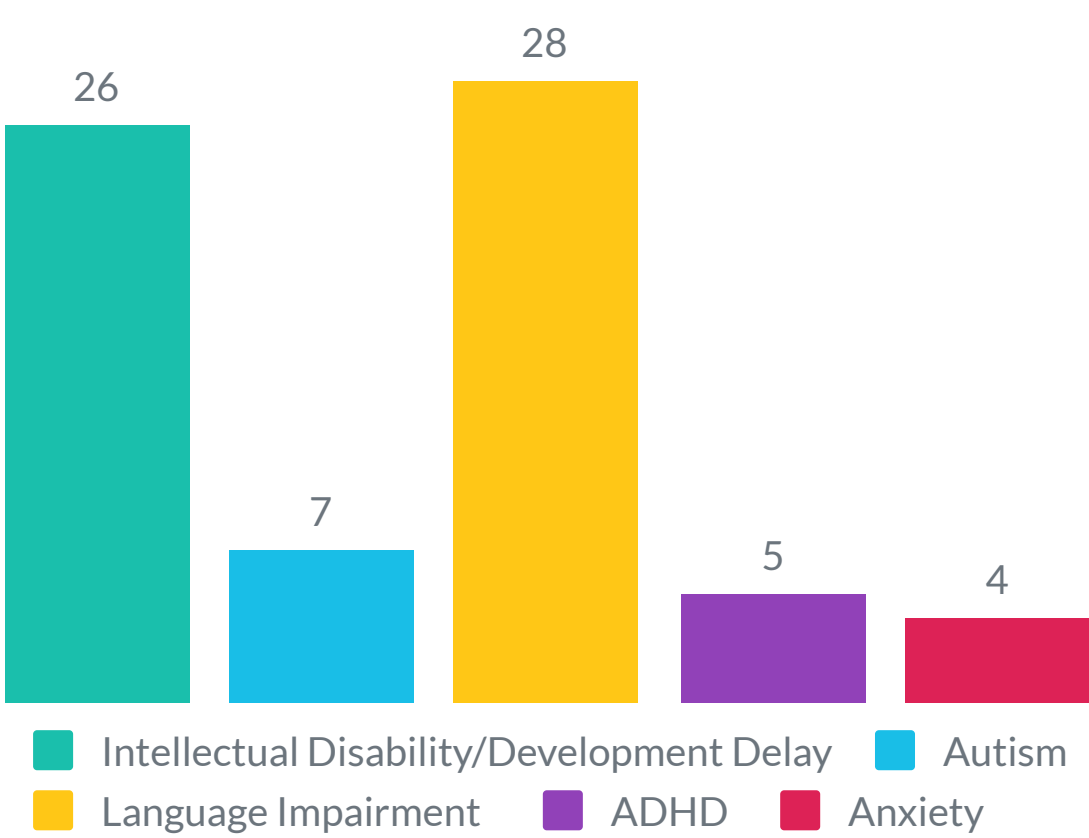
December 2021

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 29 participants with OCNDS.

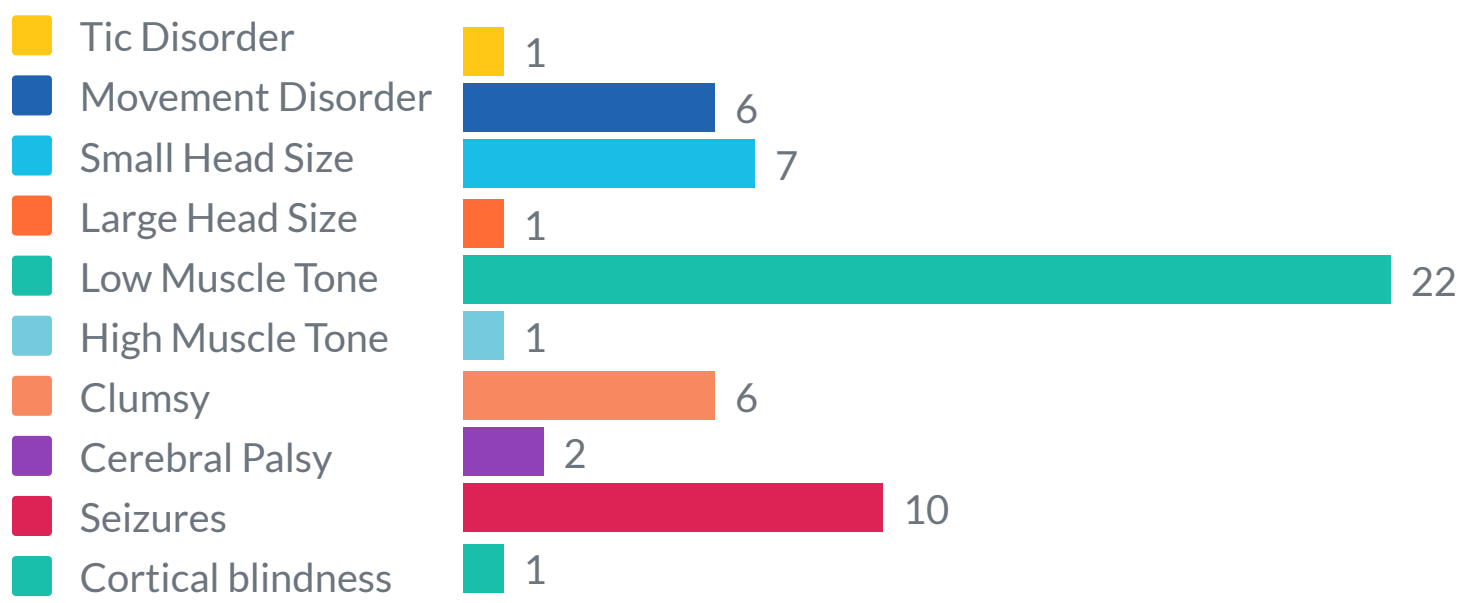
Participant Age at Most Recent Interview



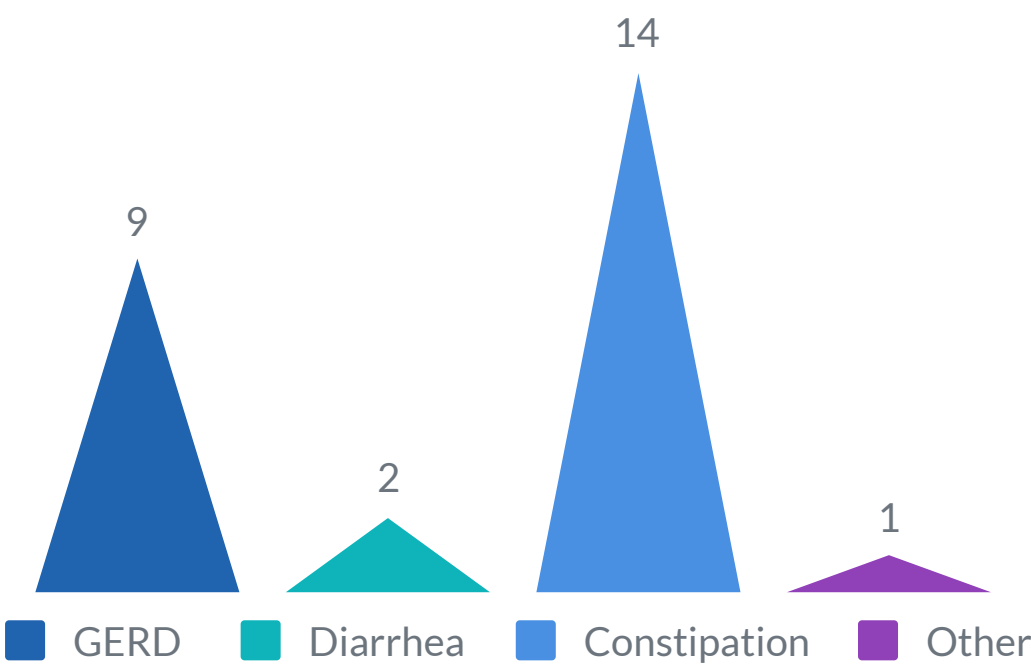
Developmental & Behavioral Diagnoses



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.

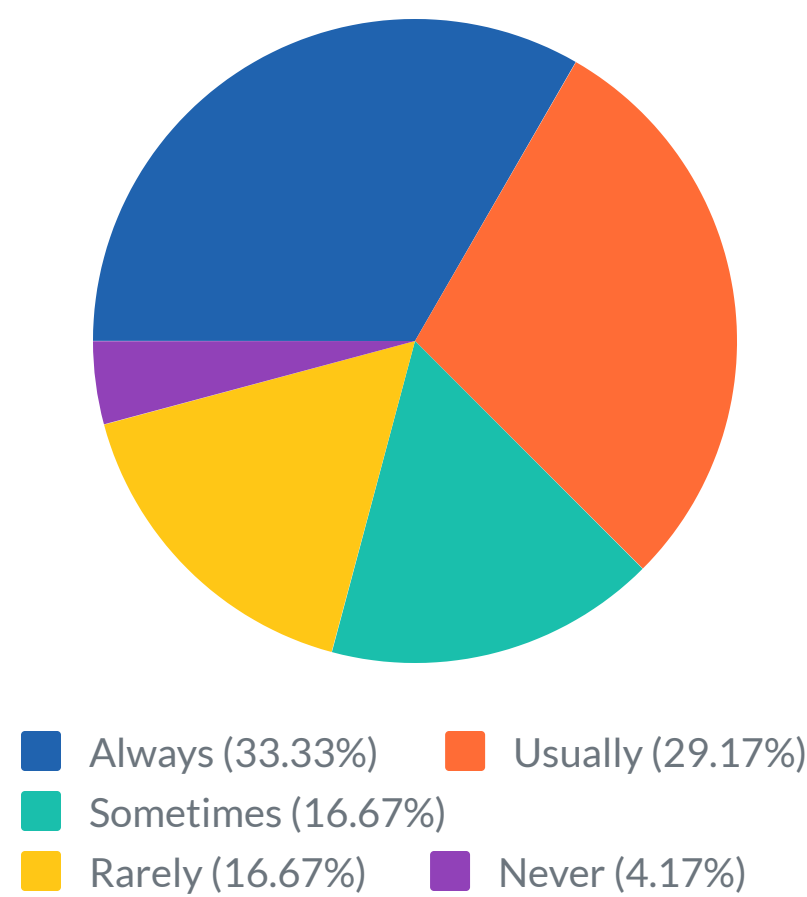
## How to Participate

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](https://simonssearchlight.org) dashboard today to check for new surveys and tasks. Your data could hold the clues geneticists need to find answers.



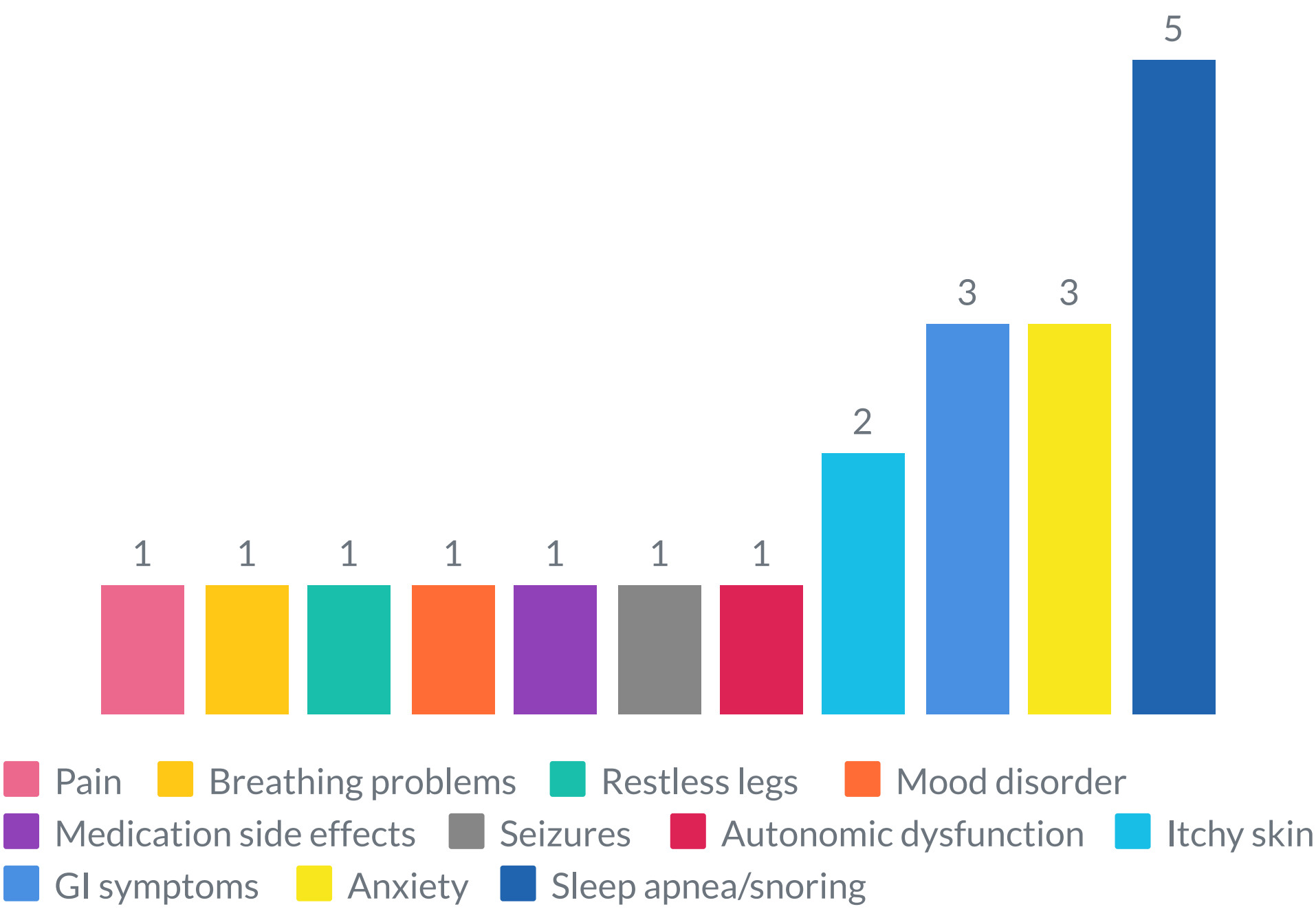
# Information Spotlight: Deeper Dive into Sleep

## Getting Enough Sleep



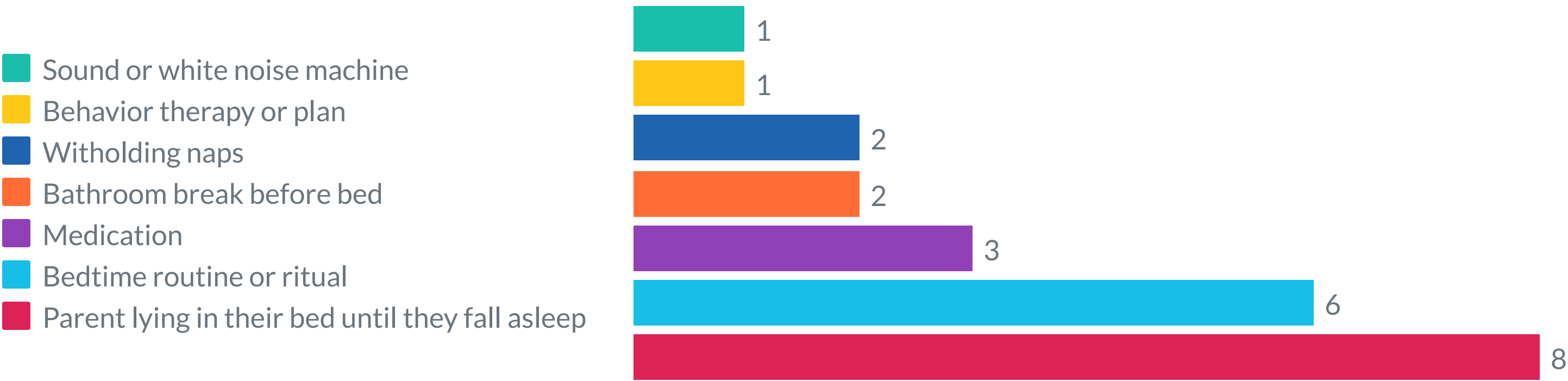
The **Simons Searchlight Sleep Supplement** is a custom survey. We worked with members of the Simons Searchlight community and sleep researchers to design these questions. It asks caregivers about children’s sleep habits and the impact of health issues on sleep behaviors. The survey looks at children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

## Medical issues related to sleep problems in children with OCNDS\*



Children with OCNDS fall asleep in **55 minutes** on average.

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



\* Caregivers were able to select more than one answer

**Thank you**

for contributing knowledge to Simons Searchlight!

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