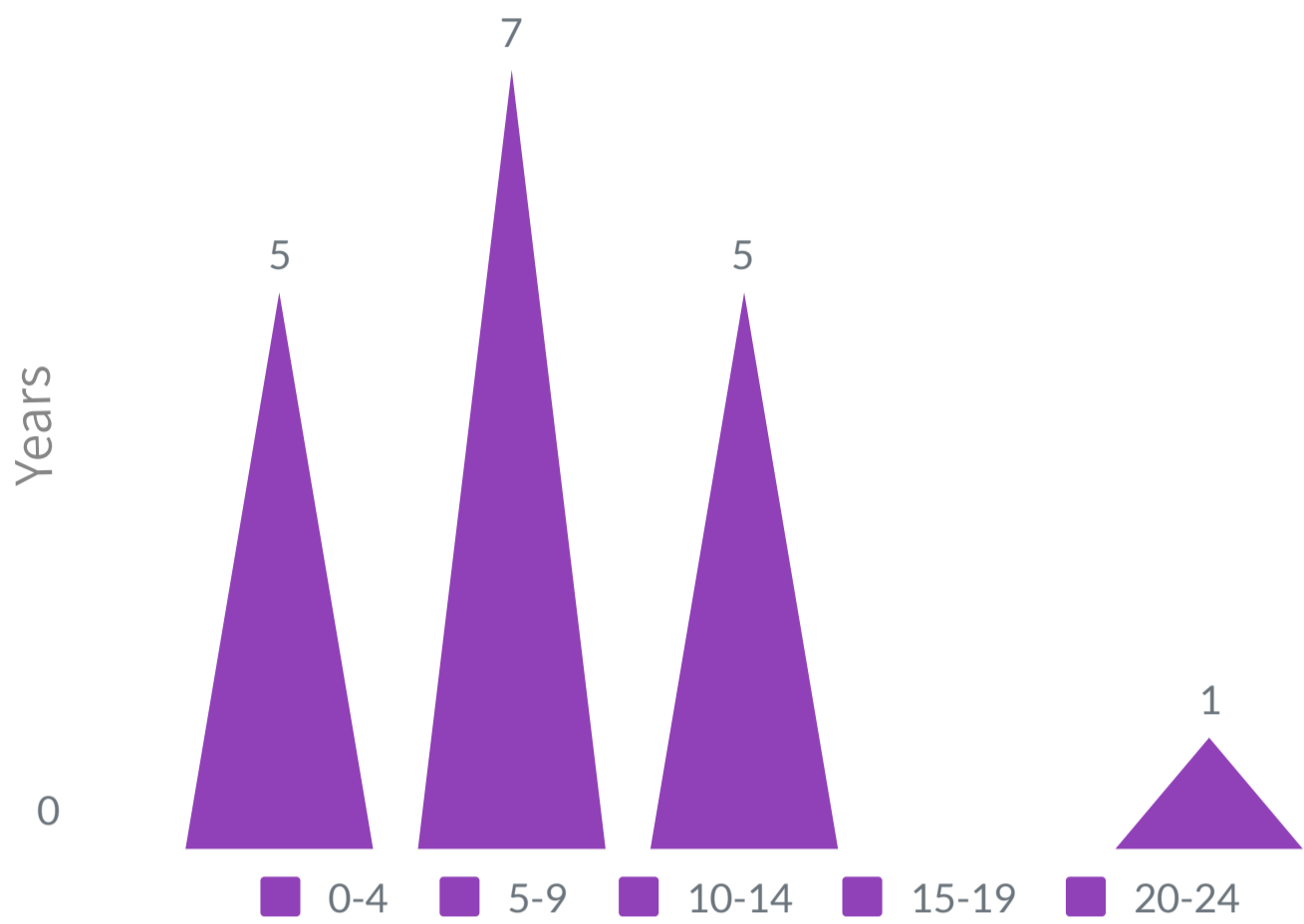


Simons Searchlight Registry Update for SETBP1

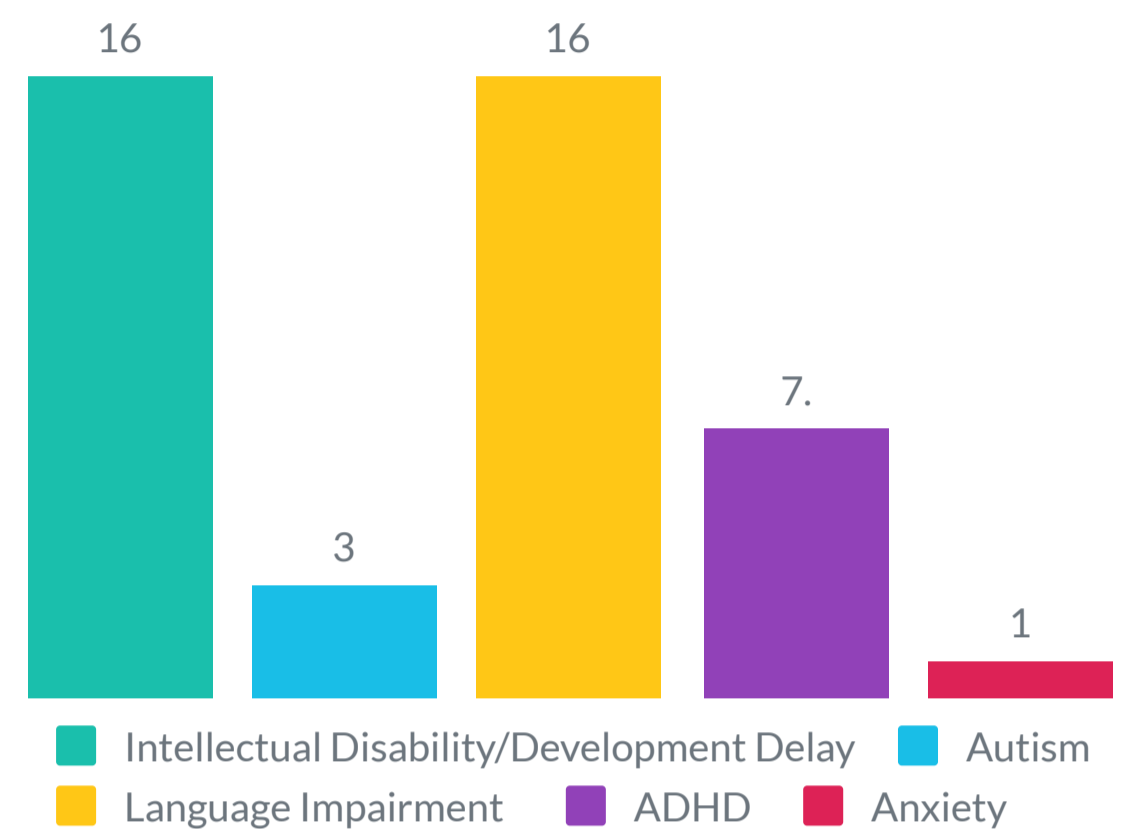
December 2021

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 18 participants with SETBP1.

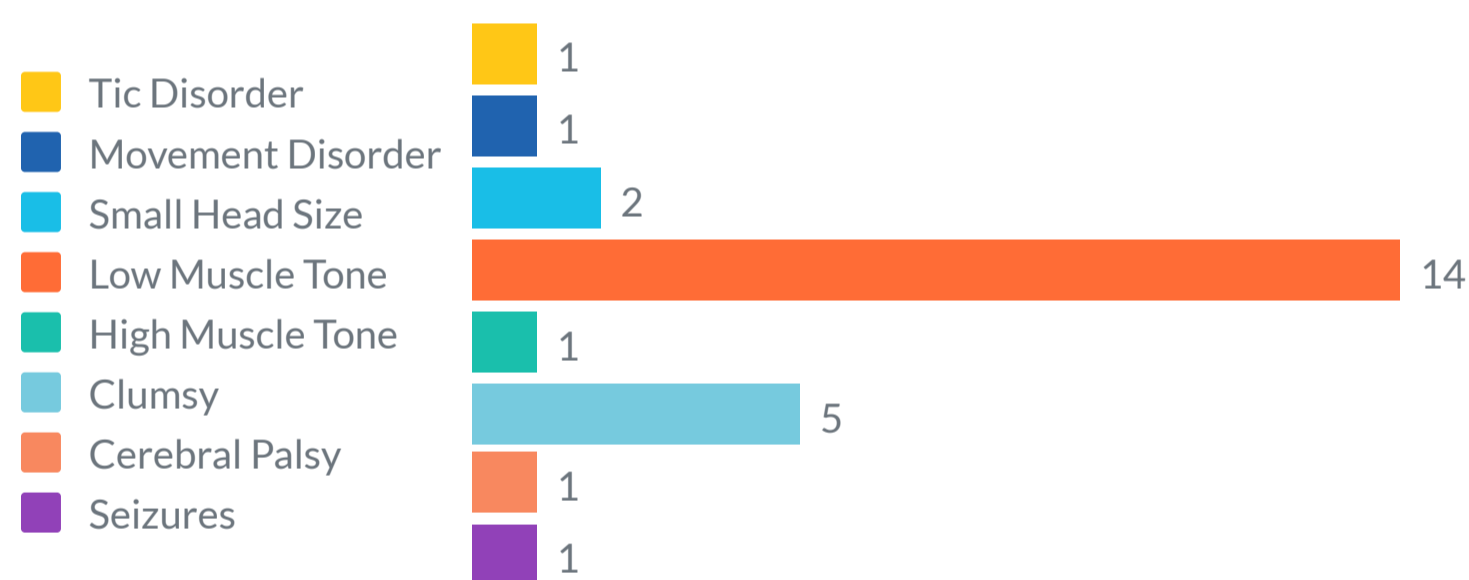
Participant Age at Most Recent Interview



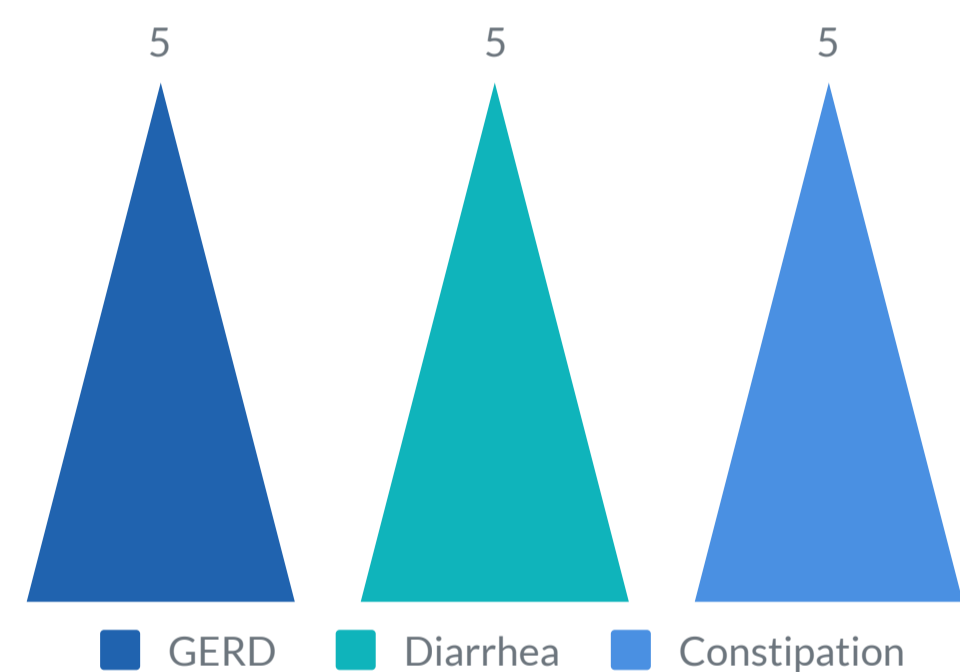
Developmental & Behavioral Diagnoses



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

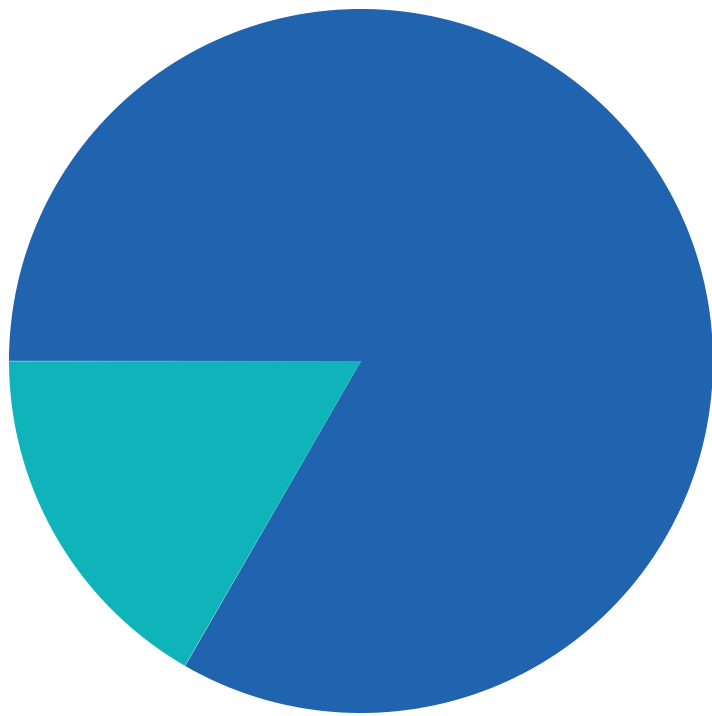
The information in this report is made possible by the active participation of the SETBP1 community! Progress for individuals in your community with a SETBP1 variant is shown below -- log in to your simonssearchlight.org dashboard today to check for new surveys and tasks. Your data could hold the clues geneticists need to find answers.



Information Spotlight: Deeper Dive into Sleep

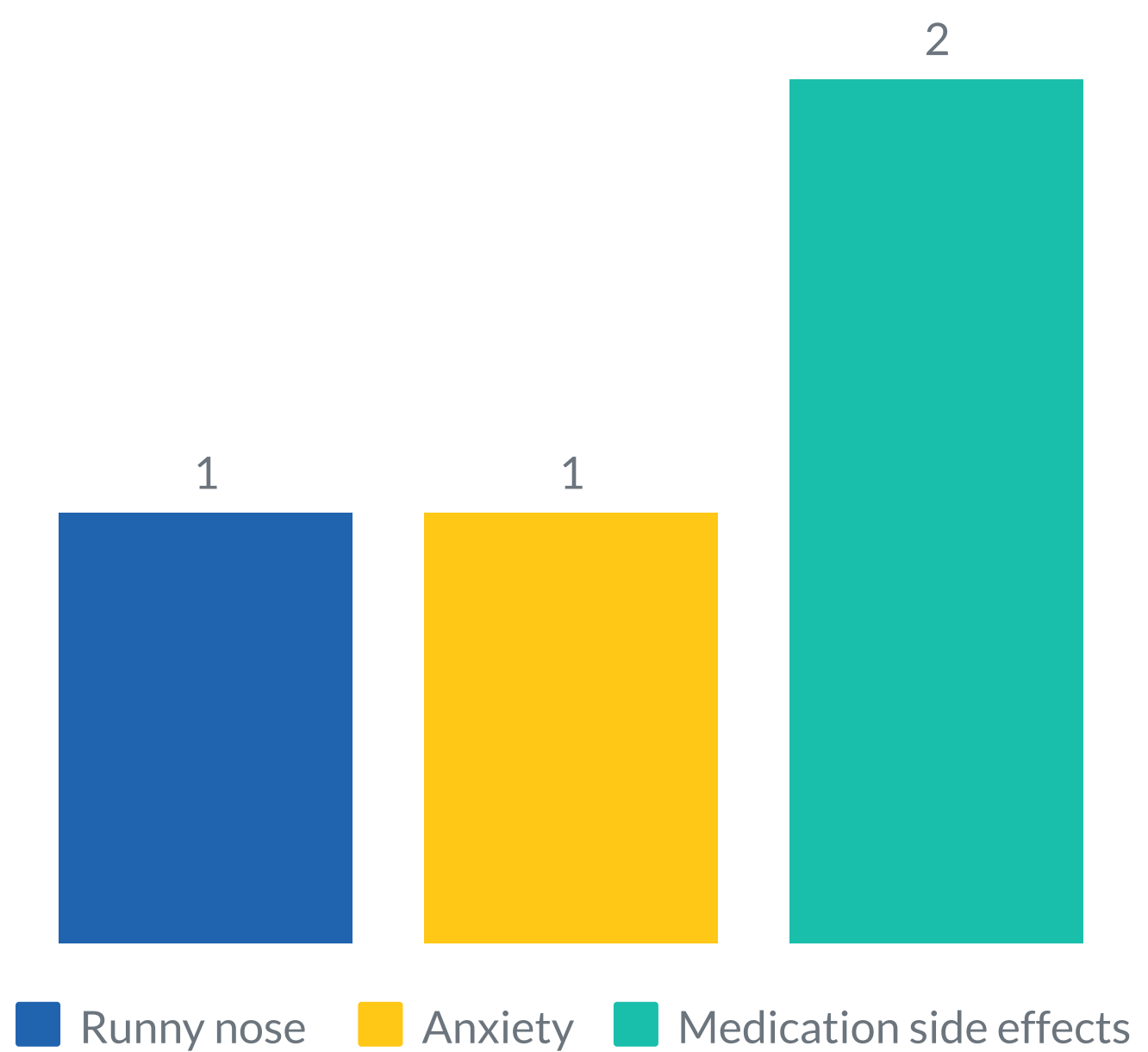
The Simons Searchlight Sleep Supplement is a custom survey. We worked with members of the Simons Searchlight community and sleep researchers to design these questions. It asks caregivers about children's sleep habits and the impact of health issues on sleep behaviors. The survey looks at children between ages 2 and 18 years of age. 6 children with SETBP1 are represented.

Getting Enough Sleep



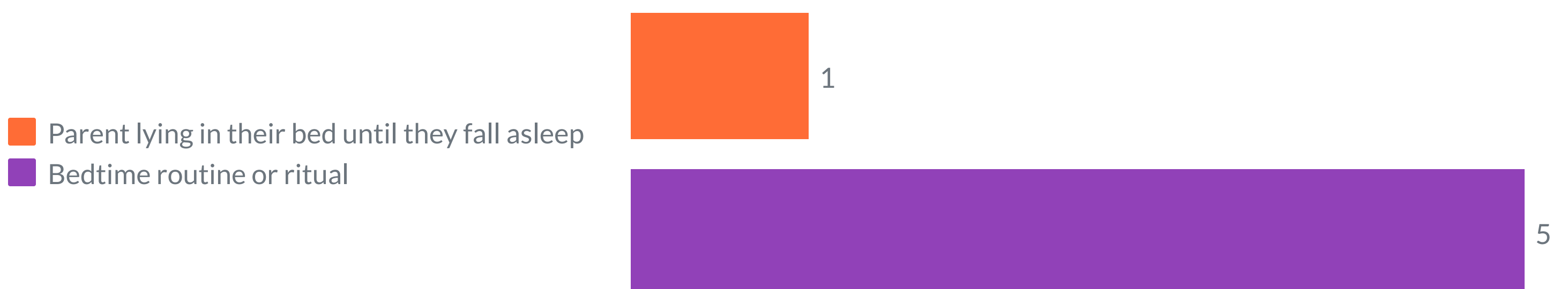
Usually (83.33%)
Sometimes (16.67%)

Medical issues related to sleep problems in children with SETBP1*



Children with SETBP1 fall asleep in **23 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!

SIMONS SEARCHLIGHT

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