Simons Searchlight Registry Update for SYNGAP1

December 2021

Participants’ 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 SYNGAP1 community! Progress for individuals in your community with a SYNGAP1 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.

**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.

Log in to see next steps.
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. 14 children with SYNGAP1 are represented.

**Children with SYNGAP1 fall asleep in 30 minutes on average.**

**Medical issues related to sleep problems in children with SYNGAP1**

- Runny nose: 1
- Pain: 1
- GI symptoms: 2
- Mood disorder: 2
- Medication side effects: 2
- Sleep apnea/snoring: 3
- Restless legs: 3
- Anxiety: 7

Best Ways to Help Sleep: Community Recommendations

- Parent lying in their bed until they fall asleep: 2
- Bedtime routine or ritual: 2
- Medication: 3
- Sound/white noise machine: 3

*Caregivers were able to select more than one answer.

Thank you for contributing knowledge to Simons Searchlight!