Simons Searchlight Registry Update for SETBP1

December 2021

Participant Age at Most Recent Interview

Developmental & Behavioral Diagnoses

- Intellectual Disability/Development Delay: 16
- Autism: 3
- Language Impairment: 16
- ADHD: 7
- Anxiety: 1

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.

**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.

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

**Children with SETBP1 fall asleep in 23 minutes on average.**

**Medical issues related to sleep problems in children with SETBP1**

- Runny nose (1)
- Anxiety (1)
- Medication side effects (2)

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

- Parent lying in their bed until they fall asleep (1)
- Bedtime routine or ritual (5)

* Caregivers were able to select more than one answer.

---

**Thank you**

for contributing knowledge to Simons Searchlight!