Simons Searchlight Registry Update for 16p11.2 Deletion
December 2021

How to Participate
The information in this report is made possible by the active participation of the 16p11.2 deletion community! Progress for individuals in your community with a 16p11.2 deletion 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.

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**Participant Age at Most Recent Interview**

**Developmental & Behavioral Diagnoses**

**Neurological Problems**

**Gastrointestinal Problems**

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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 participated in the online portion of the study.

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Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 180 participants with a 16p11.2 deletion.
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. 90 children with a 16p11.2 deletion are represented.

### Getting Enough Sleep

- **Always** (22.22%)
- **Usually** (57.78%)
- **Sometimes** (13.33%)
- **Rarely** (5.56%)
- **Never** (1.11%)

### Medical issues related to sleep problems in children with a 16p11.2 deletion*

- **Pain**
- **Medication side effects**
- **GI symptoms**
- **Movement disorder**
- **Breathing problems**
- **Seizures**
- **Restless legs**
- **Sleep apnea/snoring**
- **Itchy skin**
- **Anxiety**
- **Runny nose**
- **Autonomic dysfunction**

### Children with a 16p11.2 deletion fall asleep in **21 minutes** on average

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

- **Visual schedule**
- **Witholding naps**
- **Bathroom break before bed**
- **Sound or white noise machine**
- **Medication**
- **Parent lying in their bed until they fall asleep**
- **Bedtime routine or ritual**

* Caregivers were able to select more than one answer

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**Thank you**
for contributing knowledge to Simons Searchlight!