Simons Searchlight Registry Update for 1q21.1 deletion
December 2021

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 participated in the online portion of the study.

How to Participate
The information in this report is made possible by the active participation of the 1q21.1 deletion community! Progress for individuals in your community with a 1q21.1 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.

Log in to see next steps
**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. 18 children with a 1q21.1 deletion are represented.

### Getting Enough Sleep

- **Always (5.56%)**
- **Usually (44.44%)**
- **Sometimes (22.22%)**
- **Rarely (22.22%)**
- **Never (5.56%)**

### Medical issues related to sleep problems in children with a 1q21.1 deletion*

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

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

- **Sound/white noise machine**
- **Sticker chart**
- **Parent lying in their bed until they fall asleep**
- **Medication**
- **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!