Simons Searchlight Registry
Update for Distal 16p11.2 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 participate in the online portion of the study.

How to Participate

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

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. 11 children with a distal 16p11.2 deletion are represented.

**Getting Enough Sleep**

- Always (9.09%)
- Usually (36.36%)
- Sometimes (27.27%)
- Rarely (18.18%)
- Never (9.09%)

**Children with a distal 16p11.2 deletion fall asleep in 50 minutes on average.**

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

- Pain
- Movement disorder
- Medication side effects
- Seizures
- Autonomic dysfunction
- Breathing problems
- Restless legs
- Sleep apnea/snoring
- GI symptoms

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

- Medication
- Parent lying in their bed until they fall asleep
- Bedtime routine or ritual

*Caregivers were able to select more than one answer.

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