Simons Searchlight Registry Update for SCN2A

Participant Age at Most Recent Interview

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 94 participants with SCN2A.

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 SCN2A community! Progress for individuals in your community with a SCN2A 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**

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. 37 children with SCN2A are represented.

**Getting Enough Sleep**

- Always (8.11%)
- Usually (35.14%)
- Sometimes (32.43%)
- Rarely (21.62%)
- Never (2.7%)

**Children with SCN2A fall asleep in 43 minutes on average.**

**Medical issues related to sleep problems in children with SCN2A***

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

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

- Discipline
- Bathroom break before bed
- Sound/whit noise machine
- Parent lying in their bed until they fall asleep
- Withholding naps
- Bedtime routine or ritual
- Medication

* Caregivers were able to select more than one answer

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