Simons Searchlight Registry Update for CHAMP1

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 pathogenic or likely pathogenic variant.

How to Participate

The information in this report is made possible by the active participation of the CHAMP1 community! Progress for individuals in your community with a CHAMP1 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.
Information Spotlight: **Deeper Dive into Sleep**

**Getting Enough Sleep**

- Usually (71.43%)
- Sometimes (14.29%)
- Rarely (14.29%)

**Medical issues related to sleep problems in children with CHAMP1***

- GI symptoms
- Runny nose
- Anxiety
- Restless legs
- Itchy skin

*Caregivers were able to select more than one answer.

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

- Bedtime routine or ritual: 4
- Medication: 1
- Sound or white noise machine: 1

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**Children with CHAMP1 fall asleep in 47 minutes on average.**

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**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. 7 children with CHAMP1 are represented.

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*Thank you* for contributing knowledge to Simons Searchlight!