Simons Searchlight Registry Update for HNRNPH2
December 2021

How to Participate
The information in this report is made possible by the active participation of the HNRNPH2 community! Progress for individuals in your community with a HNRNPH2 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.

**How to Participate**

1. Sign up online.
2. Provide your genetic lab report.
3. Share your important medical history.
4. Fill out surveys.
5. Provide a blood sample if you are interested.
6. Update us every year.

Participation is critical for advancing the understanding of HNRNPH2. Your contributions enable researchers to uncover new insights and findings.

**Participant Age at Most Recent Interview**

- **0-4 years**: 7
- **5-9 years**: 7
- **10-14 years**: 1
- **15-19 years**: 2
- **20-24 years**: 2
- **25+ years**: 1

**Developmental & Behavioral Diagnoses**

- **Intellectual Disability/Development Delay**: 20
- **Language Impairment**: 17
- **Autism**: 4
- **Anxiety**: 4

**Neurological Problems**

- **Tic Disorder**: 2
- **Movement Disorder**: 10
- **Small Head Size**: 18
- **Low Muscle Tone**: 6
- **High Muscle Tone**: 6
- **Clumsy**: 6
- **Cerebral Palsy**: 3
- **Cortical blindness**: 5
- **Seizures**: 2

**Gastrointestinal Problems**

- **GERD**: 7
- **Diarrhea**: 12
- **Constipation**: 2
- **Celiac Disease**: 1
- **Other**: 2

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.

**Participant Age at Most Recent Interview**

- **0-4 years**: 26
- **5-9 years**: 25
- **10-14 years**: 20
- **15-19 years**: 13
- **20-24 years**: 36
- **25+ years**: 18

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 20 participants with HNRNPH2.
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. 5 children with HNRNPH2 are represented.

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**Getting Enough Sleep**

Children with HNRNPH2 fall asleep in **12 minutes** on average.

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**Medical issues related to sleep problems in children with HNRNPH2**

- Seizures: 1
- GI symptoms: 1
- Anxiety: 1

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

- Medication: 1
- Bedtime routine or ritual: 4

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*Caregivers were able to select more than one answer.

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