Simons Searchlight Registry Update HNRNPH2

June 2021

Ages in Years

- 0-4: 7
- 5-9: 7
- 10-14: 2
- 15-19: 3
- 20+: 1

Developmental & Behavioral Diagnoses

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

Neurological Problems

- Low Muscle Tone: 18
- Clumsy: 6
- High Muscle Tone: 2
- Small Head Size: 10
- Movement Disorder: 6
- Tic Disorder: 2
- Cerebral Palsy: 2
- Cortical Blindness: 1
- Cyst in the Spinal Cord: 1
- Seizures: 4

Gastrointestinal Problems

- GERD: 7
- Diarrhea: 2
- Gastric Ulcer: 1
g - Constipation: 1
- Celiac Disease: 3
- Other: 1

Notes:
- Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.
- Information on reported seizure types is included on the 2021 quarter 1 registry report available on simonssearchlight.org/gene/HNRNPH2.

Participation & Registration

This ever-growing database is made possible by the active participation of the HNRNPH2 community! Progress for individuals in your community with an HNRNPH2 variant is shown below -- log in to your simonssearchlight.org dashboard today to check for new surveys and other priority tasks. Your unique data could hold the clues scientists need to make progress and find answers.

**STEP 1**
Sign up online.

**STEP 2**
Provide your clinical lab report.

**STEP 3**
Schedule medical history phone call with a genetic counselor.

**STEP 4**
Fill out surveys.

**STEP 5**
Provide a blood sample if you are interested.

**STEP 6**
We follow up with you over time.

Log in to see next steps.

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 20 participants with HNRNPH2.
Information Spotlight: Child Behavior Checklist

The Child Behavior Checklist (CBCL) is a survey used to understand behavioral and emotional concerns in children.

The bars in the graphs show the overall level of concern reported by Simons Searchlight caregivers who completed the CBCL survey about their children with HNRNPH2. Individual caregivers may have indicated a lower or higher level of concern than indicated by the overall group.

Behavioral Concerns for ages 1.5-5yrs

Oppositional behavior
Attention/hyperactivity
Aggression
Anxiety
Sadness

Top Behavioral Concerns
Ages 1.5-5 yrs

- Chews on non-food items
- Scared to attempt new things
- Quickly frustrated
- Sudden mood swings