Simons Searchlight Registry Update CTNNB1
September 2021

Ages in Years

- 0-4: 21
- 5-9: 7
- 10-14: 6
- 15+: 2

Developmental & Behavioral Diagnoses

- Intellectual Disability/Development Delay: 37
- Autism: 29
- Language Impairment: 7
- ADHD: 5
- OCD: 2
- Anxiety: 5

Neurological Problems

- Low Muscle Tone: 33
- Clumsy: 15
- High Muscle Tone: 21
- Small Head Size: 29
- Movement Disorder: 13
- Tic Disorder: 2
- Cerebral Palsy: 12

Gastrointestinal Problems

- GERD: 10
- Diarrhea: 2
- Constipation: 8

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/CTNNB1.

Participation & Registration

The information in this report is made possible by the active participation of the CTNNB1 community! Progress for individuals in your community with a CTNNB1 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 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.

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Information Spotlight: Sleep Concerns

The Children’s Sleep Habits Questionnaire is a survey used to understand sleep habits and possible sleep problems in children. All individuals were between 2 and 18 years of age. 31 children with CTNNB1 are represented.

Top Sleep Problems in CTNNB1

Trouble sleeping away
Wakes during the night
Others wake child
Seems tired

It is important to study sleep in children with rare neurodevelopmental disorders because these children are at higher risk for sleep problems, which can negatively impact their behavior and daily functioning.

- Alison Holbrook, PhD

Areas of Sleep Concern in CTNNB1*

- Daytime Sleepiness
- Breathing
- Parasomnias (e.g., sleepwalking)
- Night Wakings
- Sleep Anxiety
- Doesn’t Get Enough Sleep
- Delay Falling Asleep
- Bedtime Struggle

Overall Concern for Sleep Problems in CTNNB1

High likelihood of sleep problems (67.74%)
Low likelihood of sleep problems (32.26%)

*The bars in the graph show the number of children with a more significant problem in each aspect of sleep. Top Sleep Problems show the most frequently reported problem behaviors related to sleep. Areas of Sleep Concern are made up of several sleep problem behaviors that are similar in type. Top Sleep Problems may not result in increased concern for Areas of Sleep if similar behaviors are not also a problem.