Simons Searchlight Registry Update CTNNB1

Ages in Years

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

Developmental & Behavioral Diagnoses

- Intellectual Disability/Developmental Delay: 29
- Language Impairment: 6
- Autism: 5
- ADHD: 2
- OCD: 4

Neurological Problems

- Low Muscle Tone: 33
- Clumsy: 15
- High Muscle Tone: 21
- Small Head Size: 13
- Movement Disorder: 2
- Tic Disorder: 12
- Cerebral Palsy: 10

Gastrointestinal Problems

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

Notes:
- Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.
- Additional data is included on the 2021 quarter 1 registry report available on simonssearchlight.org/CTNNB1.

Participation & Registration

This ever-growing database 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 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
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 CTNNB1. 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

Not a concern | Mid concern | Significant concern

Behavioral Concerns for ages 6-18 yrs

Oppositional behavior
Attention/hyperactivity
Aggression
Anxiety
Sadness

Not a concern | Mid concern | Significant concern

**Top Behavioral Concerns**

**Ages 1.5-5 yrs**
- Chews on non-food items
- Quickly moves from one activity to the next
- Quickly frustrated
- Difficulty waiting

**Top Behavioral Concerns**

**Ages 6-18 yrs**
- Anxious
- Frequently distracted
- Sudden mood swings
- Specific fears (e.g. animals, places, situations)