Simons Searchlight Registry
Update 16p11.2 deletion
June 2021

Ages in Years

Developmental & Behavioral Diagnoses

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 172 participants with a 16p11.2 deletion.

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.
- Information on reported seizure types is included in the 2021 quarter 1 registry report available on simonssearchlight.org/16p11.2-deletion.
- Data in this report represent information collected in the online portion of the study.

Participation & Registration

This ever-growing database is made possible by the active participation of the 16p11.2 deletion community! Progress for individuals in your community with a 16p11.2 deletion 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.

427 215 172 185 91
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 a 16p11.2 deletion. 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

Behavioral Concerns for ages 6-18 yrs

- Oppositional behavior
- Attention/hyperactivity
- Aggression
- Anxiety
- Sadness

Top Behavioral Concerns
Ages 1.5-5 yrs

- Difficulty waiting
- Hyperactive
- Quickly frustrated
- Impatient

Top Behavioral Concerns
Ages 6-18 yrs

- Frequently distracted
- Obsessions
- Overeats
- Prefers to be alone than with people