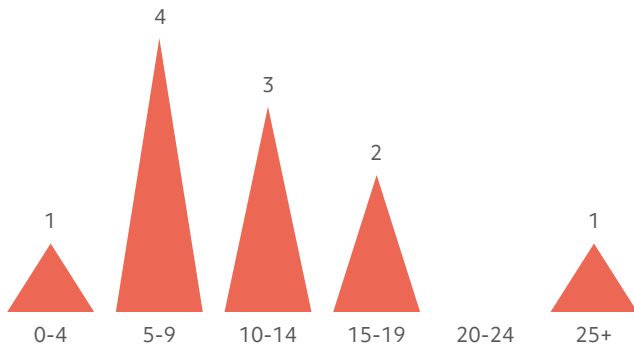# SIMONS SEARCHLIGHT

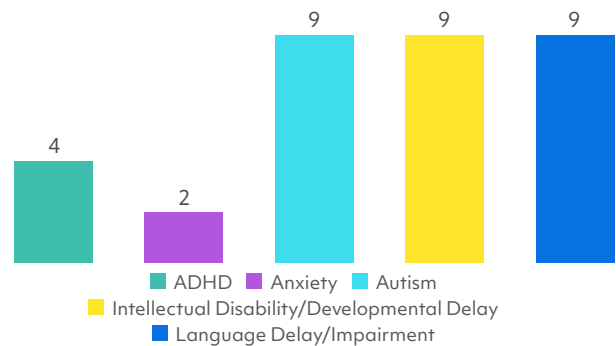# Simons Searchlight Registry Update **CHD2**

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 11 participants with CHD2.
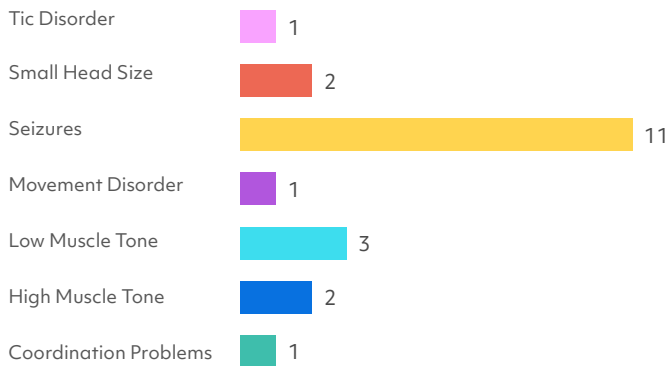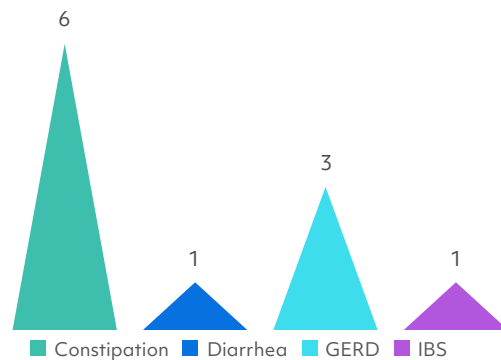
October 2023

Ages in Years

| 0-4 | 5-9 | 10-14 | 15-19 | 20-24 | 25+ |
| 1 | 4 | 3 | 2 | | 1 |

Developmental and Behavioral Conditions

- ADHD: 4
- Anxiety: 2
- Autism: 9
- Intellectual Disability/Developmental Delay: 9
- Language Delay/Impairment: 9

Neurological Conditions

- Tic Disorder: 1
- Small Head Size: 2
- Seizures: 11
- Movement Disorder: 1
- Low Muscle Tone: 3
- High Muscle Tone: 2
- Coordination Problems: 1

Gastrointestinal Conditions

- Constipation: 6
- Diarrhea: 1
- GERD: 3
- IBS: 1

NOTES: Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.

How to participate?

The information in this report is made possible by the active participation of the CHD2 community! Progress for individuals in your community with CHD2 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
30

STEP 2
Provide your genetic lab report
22

STEP 3
Share your important medical history
14

STEP 4
Fill out surveys
17

STEP 5
Provide a blood sample if you are interested
3

STEP 6
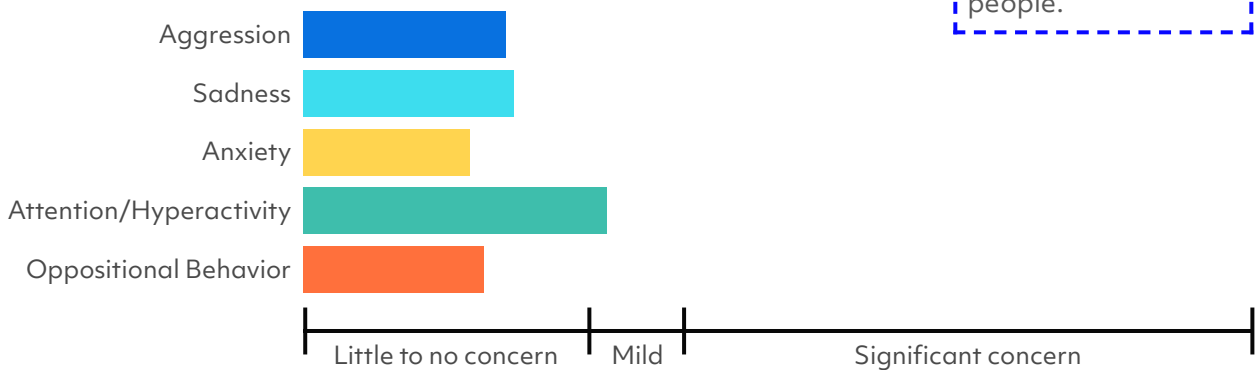Update us every year
Log in to see next steps

Information Spotlight:
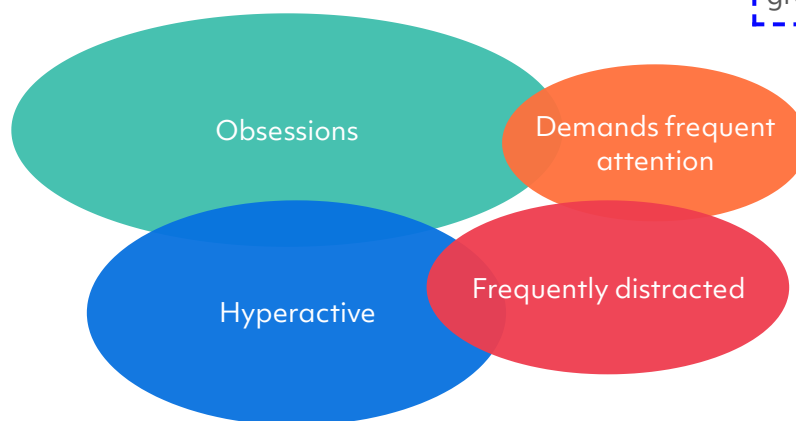## Child Behavior Checklist for Ages 6–18

The **Child Behavior Checklist (CBCL)** is a survey used for caregivers to share their concerns about their children's behaviors and emotions.

Caregivers completed the CBCL for Ages 6-18 (CBCL/6-18) for **10** children in the Simons Searchlight **CHD2** community.

Behavioral and Emotional Concerns
Ages 6-18 Years (10 individuals)

Tip: Longer bars mean more concerns reported by more people.

Aggression

Sadness

Anxiety

Attention/Hyperactivity

Oppositional Behavior

Little to no concern | Mild | Significant concern

Top Behavioral and Emotional Concerns
Ages 6-18 Years (10 individuals)

Tip: Bubbles show top 4 concerns reported in the group.

Obsessions

Demands frequent attention

Hyperactive

Frequently distracted

Kindly note that these summaries are from self-reported online research surveys and errors are possible. The behaviors and emotions shown may not apply to everyone, and individual caregiver perspectives and levels of concern may vary. Please contact us with any questions.