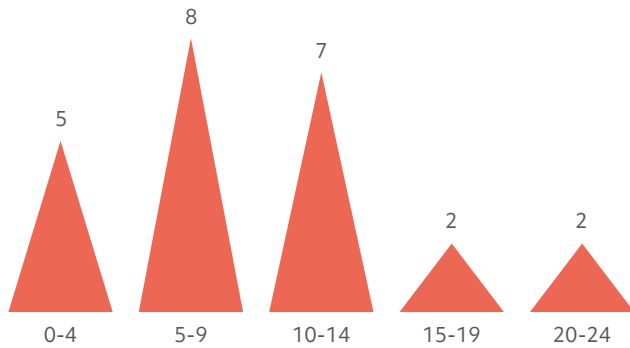


Simons Searchlight Registry Update SETBP1

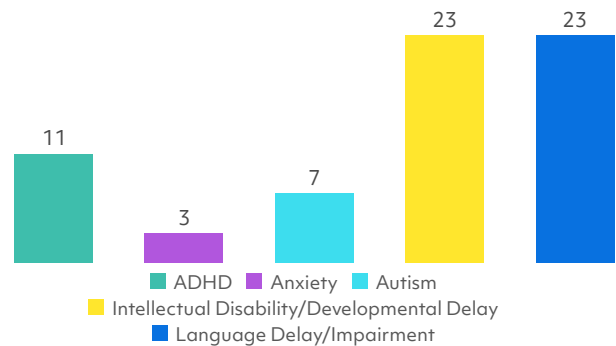
Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 24 participants with SETBP1.

October 2023

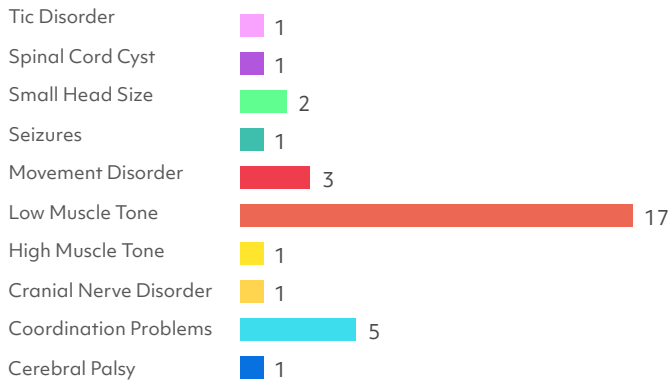
Ages in Years



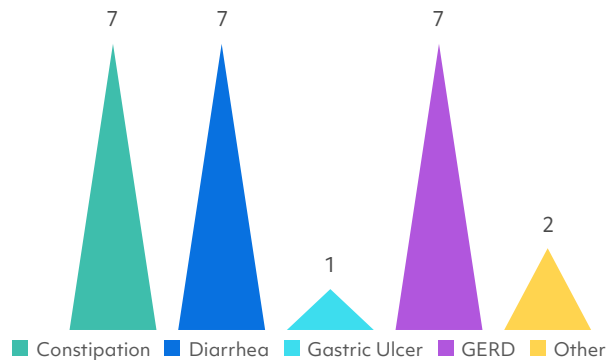
Developmental and Behavioral Conditions



Neurological Conditions



Gastrointestinal Conditions



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 SETBP1 community! Progress for individuals in your community with SETBP1 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

84



STEP 2

Provide your genetic lab report

68



STEP 3

Share your important medical history

40



STEP 4

Fill out surveys

47



STEP 5

Provide a blood sample if you are interested

18



STEP 6

Update us every year

Log in to see next steps

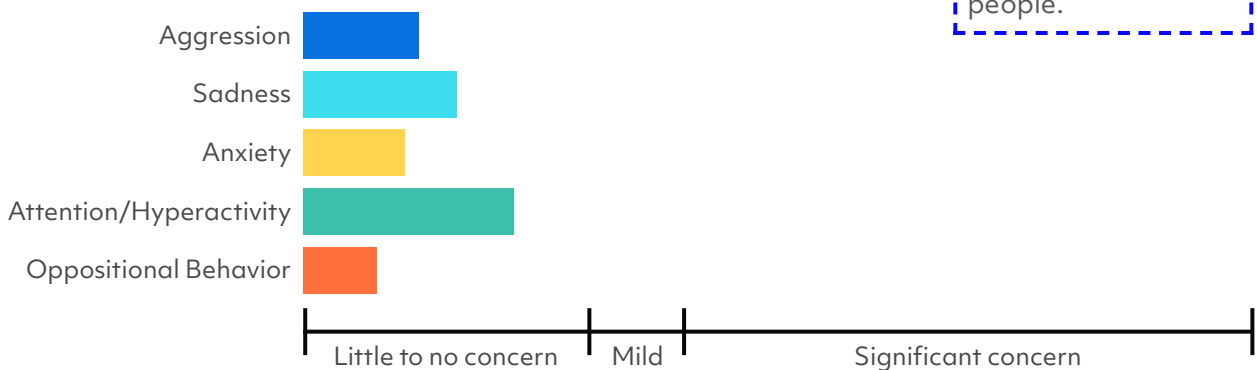
Information Spotlight: Child Behavior Checklist for Ages 1.5–5



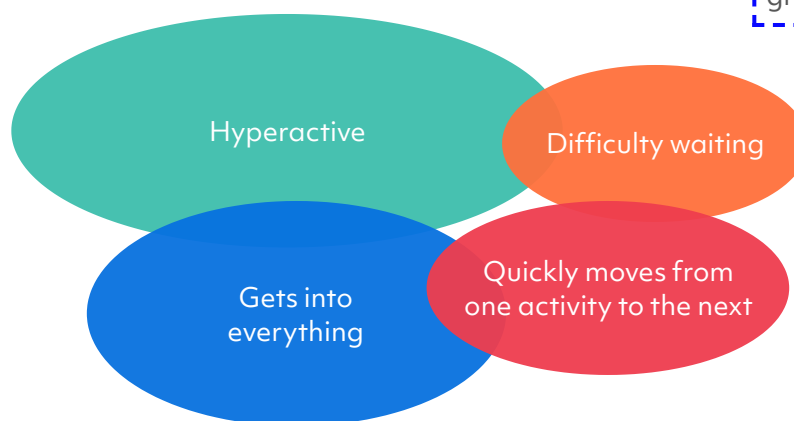
The **Child Behavior Checklist (CBCL)** is a survey used for caregivers to share their concerns about their children's behaviors and emotions.

Caregivers completed the CBCL for Ages 1.5-5 (CBCL/1.5-5) for **9** children in the Simons Searchlight **SETBP1** community.

Behavioral and Emotional Concerns Ages 1.5-5 Years (9 individuals)



Top Behavioral and Emotional Concerns Ages 1.5-5 Years (9 individuals)



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.

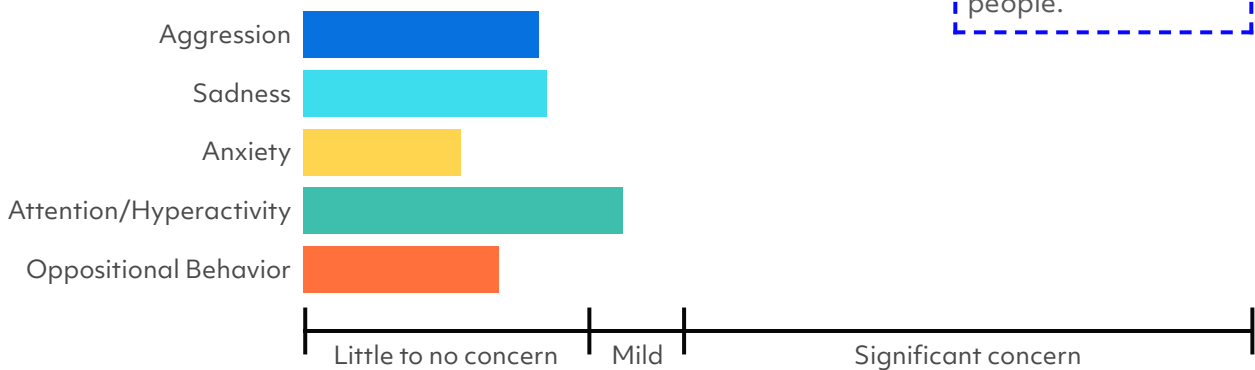
Information Spotlight: Child Behavior Checklist for Ages 6–18



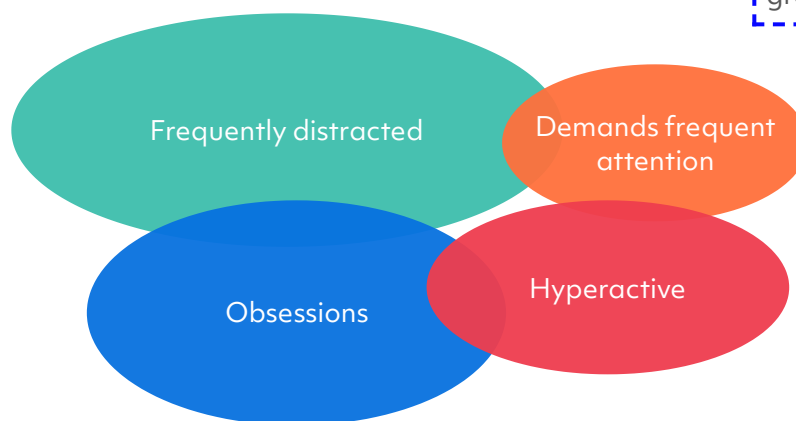
The **Child Behavior Checklist (CBCL)** is a survey used for caregivers to share their concerns about their children's behaviors and emotions.

Caregivers completed the CBCL for Ages 6-18 (CBCL/6-18) for **15** children in the Simons Searchlight **SETBP1** community.

Behavioral and Emotional Concerns Ages 6-18 Years (15 individuals)



Top Behavioral and Emotional Concerns Ages 6-18 Years (15 individuals)



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.