

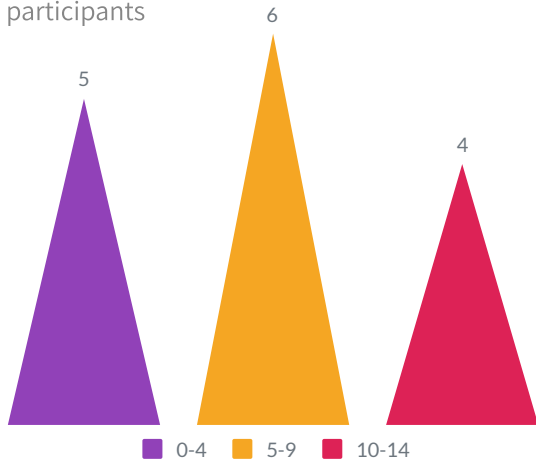
Simons Searchlight Registry Update SETBP1

June 2021

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

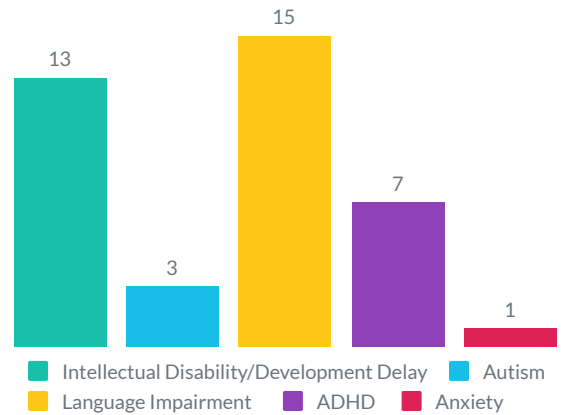
Ages in Years

15 participants



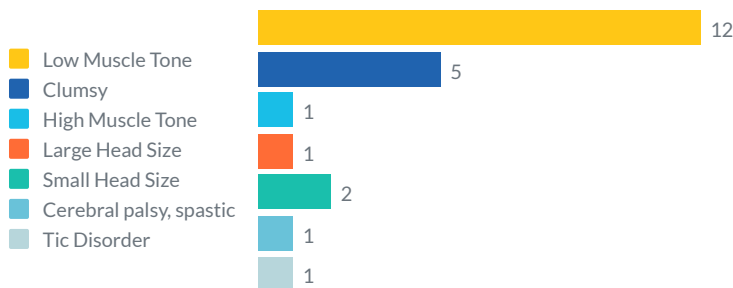
Developmental & Behavioral Diagnoses

15 participants



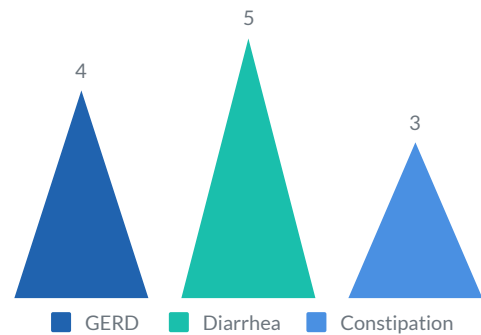
Neurological Problems

16 participants



Gastrointestinal Problems

16 participants



Notes:

- Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.
- Additional information is included on the 2021 quarter 1 registry report available on simonssearchlight.org/research/what-we-study/setbp1.
- Medical information presented does not include participants with Schinzel-Gideon Syndrome.
- Parts of this report were updated in October 2021 for accuracy.

Participation & Registration

This ever-growing database is made possible by the active participation of the SETBP1 community! Progress for individuals in your community with a SETBP1 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.

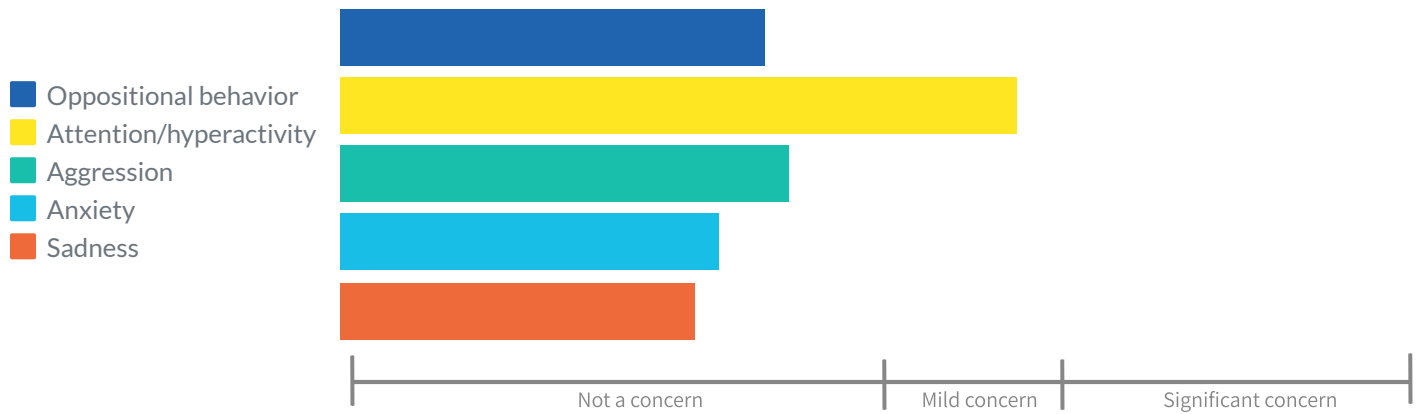


Information Spotlight: Child Behavior Checklist

“ 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 SETPB1. Individual caregivers may have indicated a lower or higher level of concern than indicated by the overall group.

Behavioral Concerns for ages 6-18 yrs



Top Behavioral Concerns

Ages 6-18 yrs

