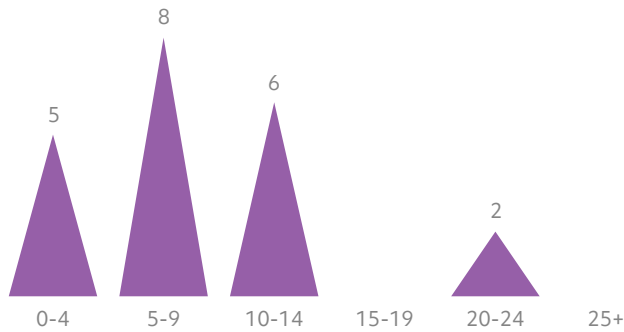


Simons Searchlight Registry Update SETBP1

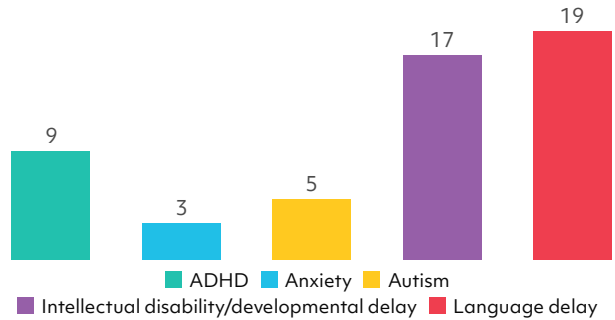
July, 2022

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 21 participants with SETBP1.

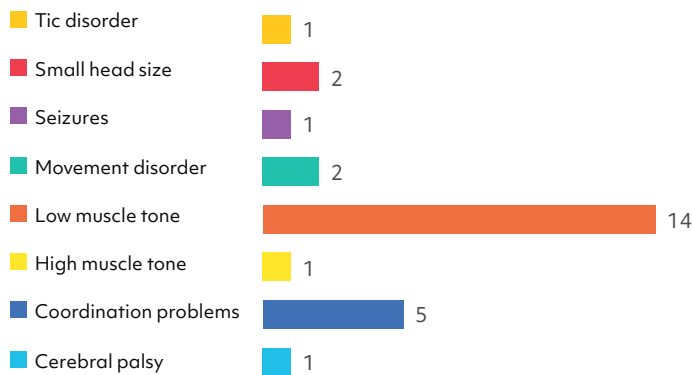
Ages in Years



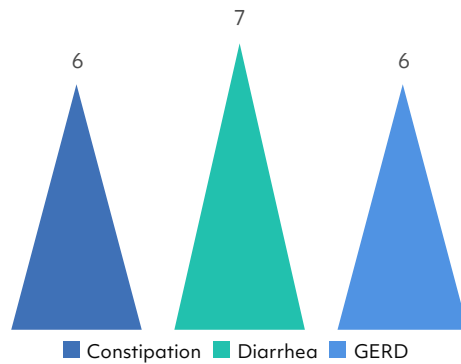
Developmental and Behavioral Conditions



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.

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



68

STEP 2

Provide your genetic lab report



54

STEP 3

Share your important medical history



32

STEP 4

Fill out surveys



43

STEP 5

Provide a blood sample if you are interested



11

STEP 6

Update us every year



Log in to see next steps