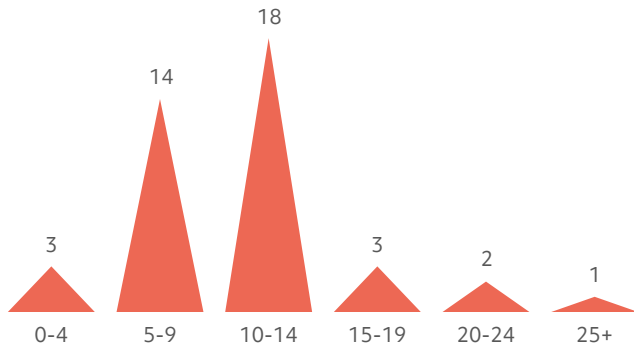


Simons Searchlight Registry Update SETBP1

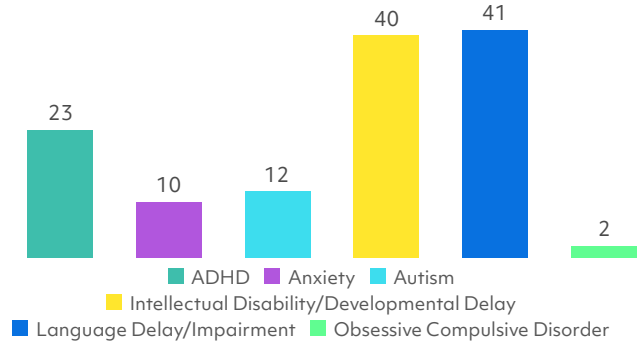
Data in these four graphs are from the medical history information collected in Simons Searchlight from 41 participants with SETBP1-related syndrome (SETBP1-related Disorder).

July 2026

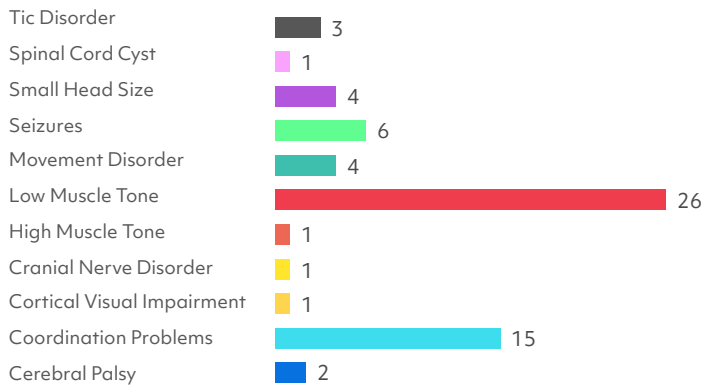
Ages in Years



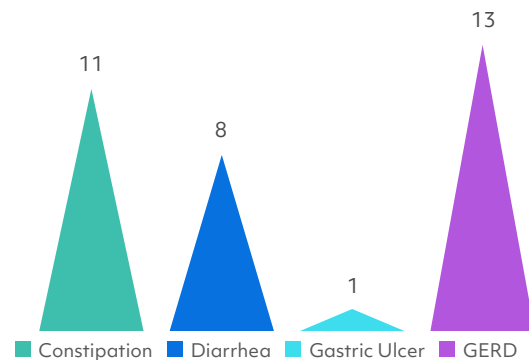
Developmental and Behavioral Conditions



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. Graphs include only individuals with pathogenic or likely pathogenic variants, and without additional variants.

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

119



STEP 2

Provide your
genetic
lab report

100



STEP 3

Share your
important
medical history

63



STEP 4

Fill out
surveys

77



STEP 5

Provide a blood
sample if you are
interested

24



STEP 6

Update us
every year

Log in to see
next steps