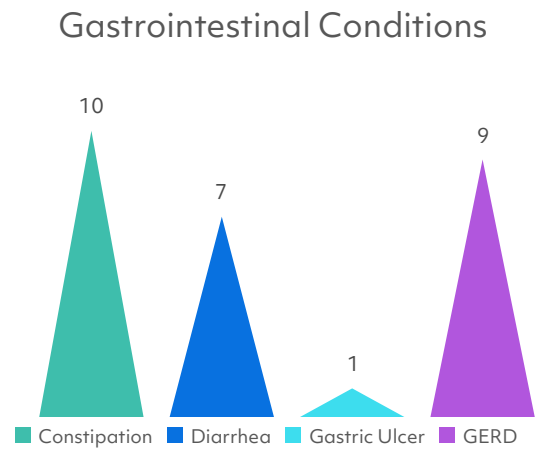
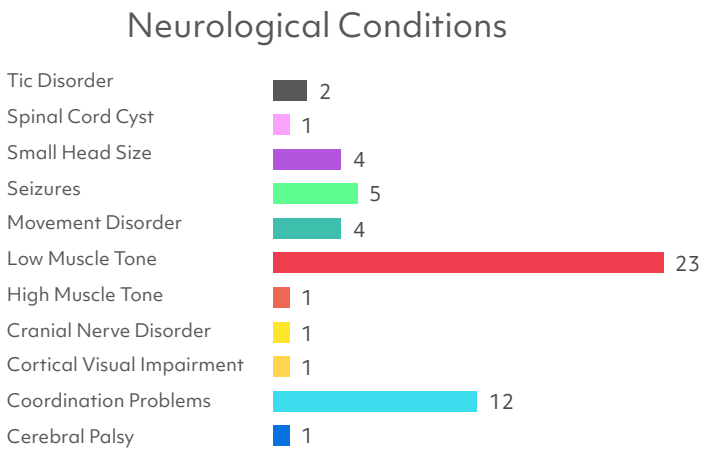
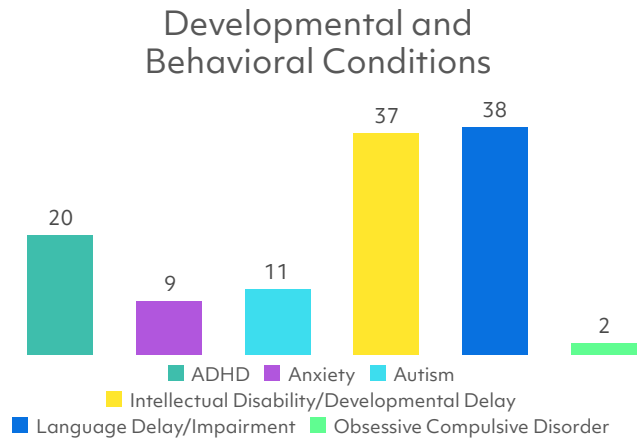
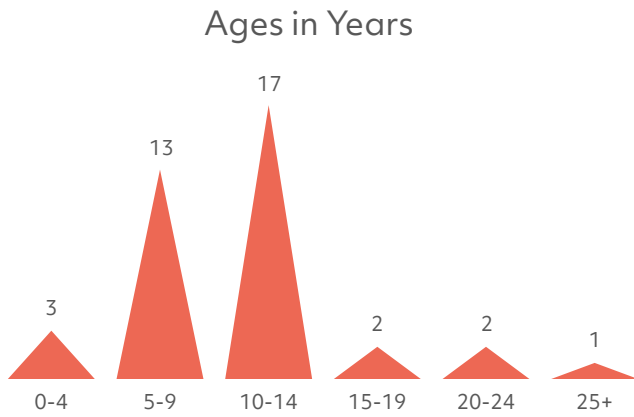


Simons Searchlight Registry Update SETBP1

Data in these four graphs are from the medical history information collected in Simons Searchlight from 38 participants with SETBP1-related syndrome (Schinzel-Giedion syndrome).

April 2026



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 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

118



STEP 2

Provide your genetic lab report

100



STEP 3

Share your important medical history

62



STEP 4

Fill out surveys

76



STEP 5

Provide a blood sample if you are interested

24



STEP 6

Update us every year

Log in to see next steps