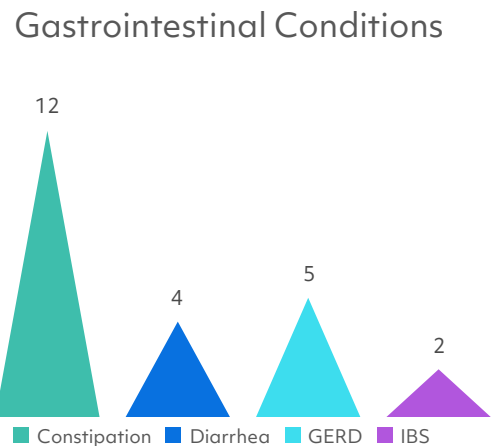
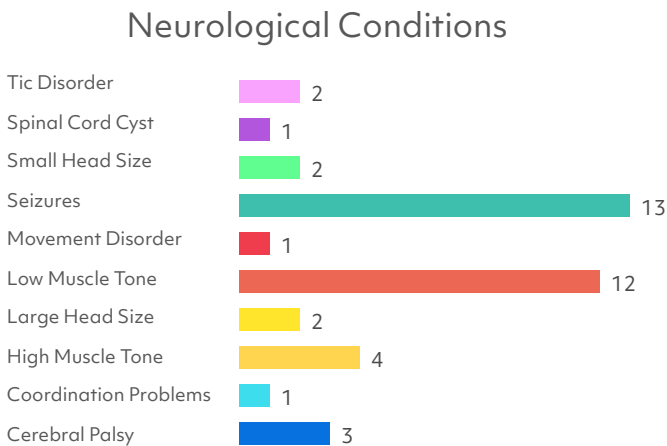
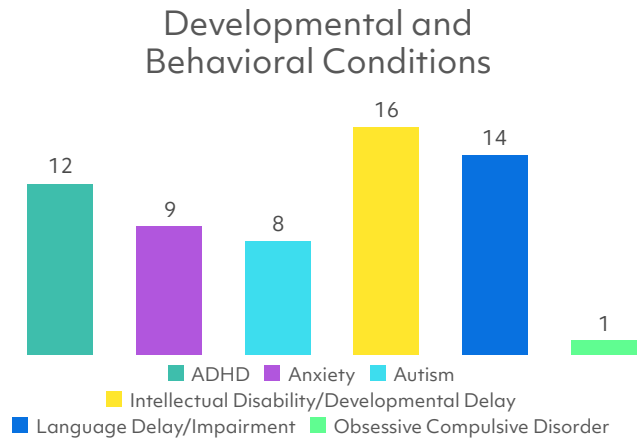
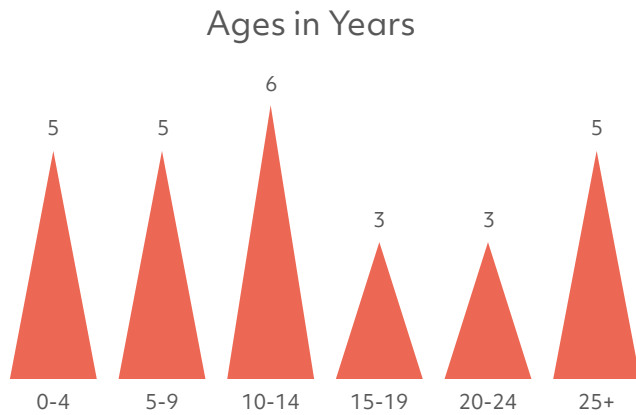


Simons Searchlight Registry Update 16p13.11 deletion

Data in these four graphs are from the medical history information collected in Simons Searchlight from 27 participants with 16p13.11 deletion syndrome.

July 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 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 16p13.11 deletion community! Progress for individuals in your community with 16p13.11 deletion 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

49



STEP 2

Provide your genetic lab report

39



STEP 3

Share your important medical history

27



STEP 4

Fill out surveys

30



STEP 5

Provide a blood sample if you are interested

3



STEP 6

Update us every year

Log in to see next steps