

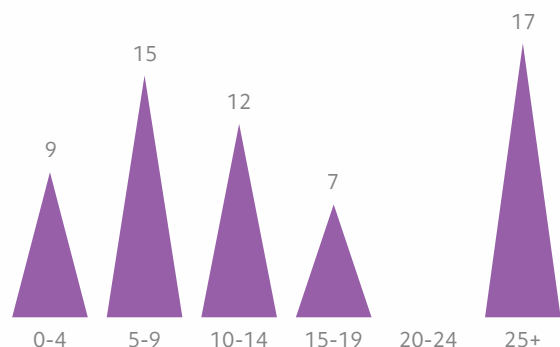
Simons Searchlight Registry Update 1q21.1 duplication

SIMONS
SEARCHLIGHT

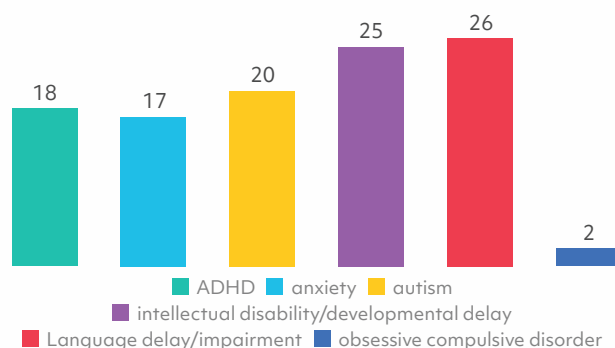
November, 2022

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 60 participants with 1q21.1 duplication.

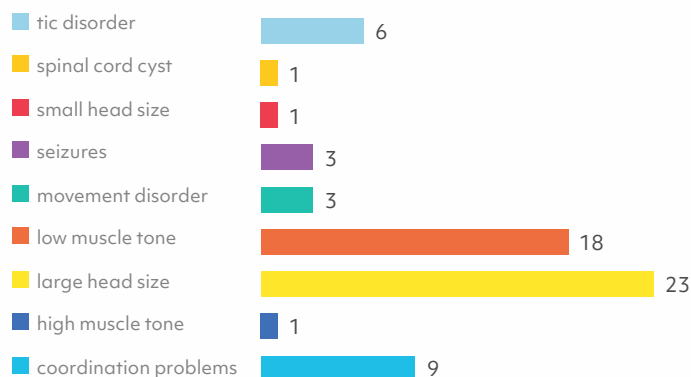
Ages in Years



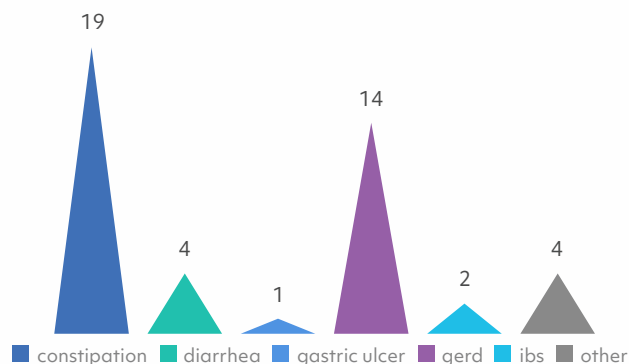
Developmental and Behavioral Conditions



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 1q21.1 duplication community! Progress for individuals in your community with 1q21.1 duplication 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



151

STEP 2

Provide your genetic lab report



89

STEP 3

Share your important medical history



63

STEP 4

Fill out surveys



77

STEP 5

Provide a blood sample if you are interested



20

STEP 6

Update us every year



Log in to see next steps