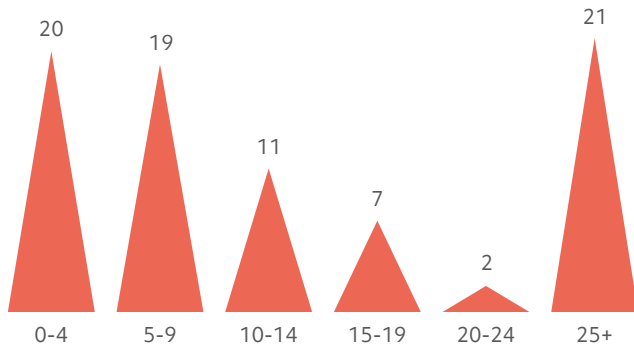


## Simons Searchlight Registry Update 1q21.1 deletion

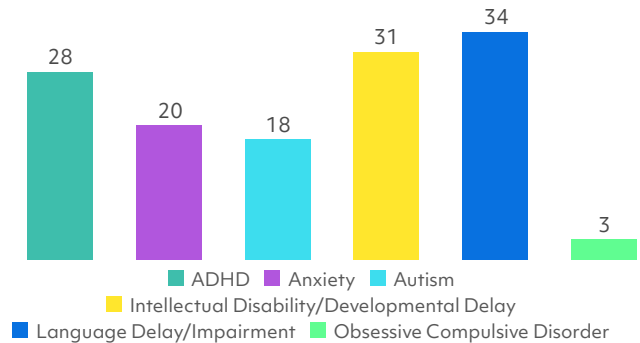
Data in these four graphs are from the medical history information collected in Simons Searchlight from 80 participants with 1q21.1 deletion syndrome.

July 2025

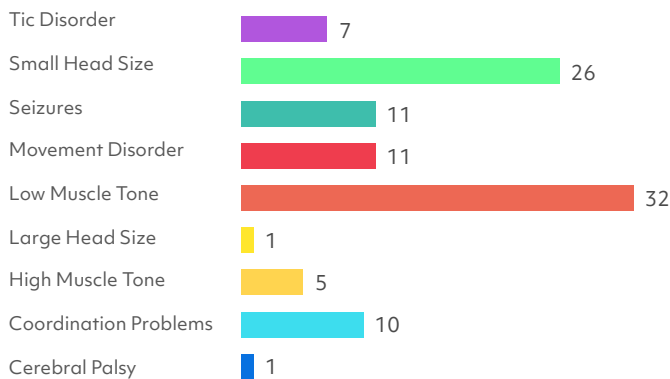
### Ages in Years



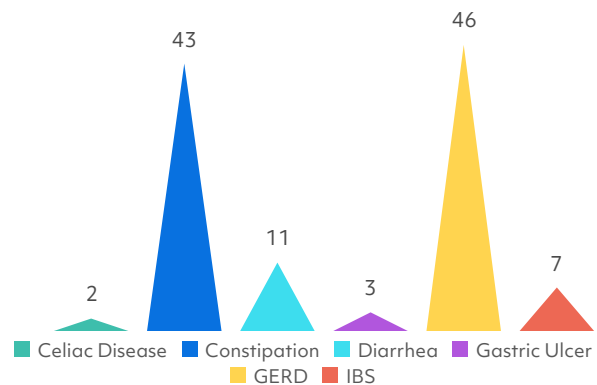
### Developmental and Behavioral Conditions



### 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 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 1q21.1 deletion community! Progress for individuals in your community with 1q21.1 deletion is shown below - log in to your [simonssearchlight.org](https://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

170



### STEP 2

Provide your  
genetic  
lab report

106



### STEP 3

Share your  
important  
medical history

83



### STEP 4

Fill out  
surveys

87



### STEP 5

Provide a blood  
sample if you are  
interested

25



### STEP 6

Update us  
every year

Log in to see  
next steps