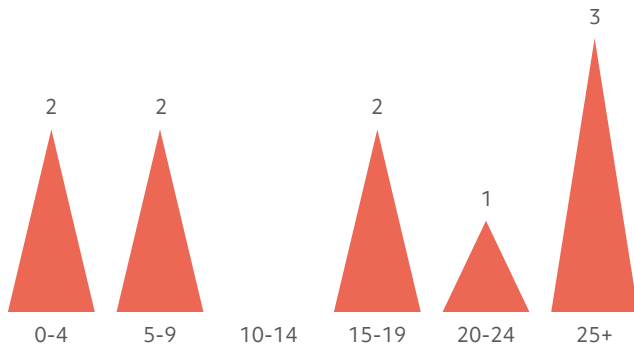


# Simons Searchlight Registry Update CSDE1

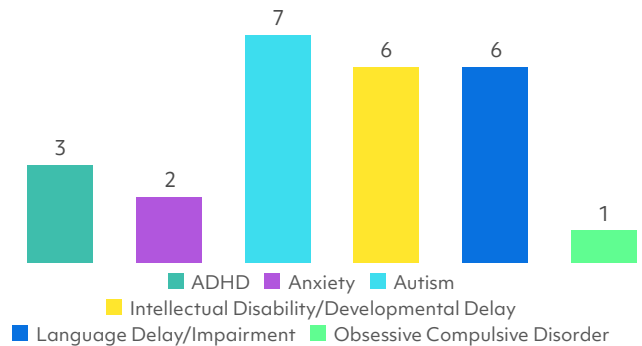
Data in these four graphs are from the medical history information collected in Simons Searchlight from 10 participants with CSDE1-related syndrome.

April 2026

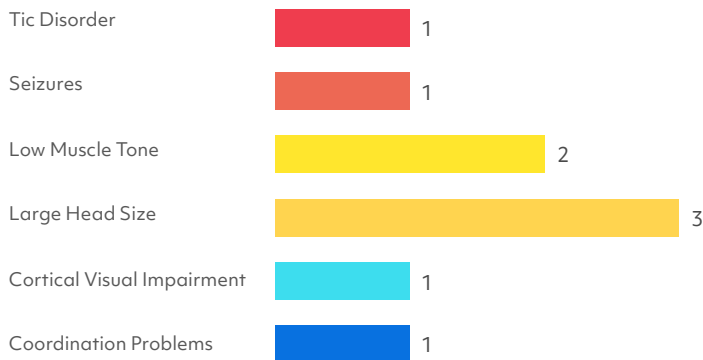
## Ages in Years



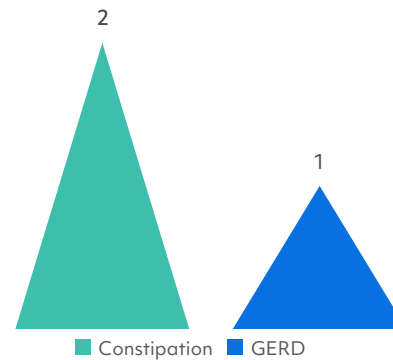
## Developmental and Behavioral Conditions



## 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 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 CSDE1 community! Progress for individuals in your community with CSDE1 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

19



### STEP 2

Provide your genetic lab report

19



### STEP 3

Share your important medical history

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### STEP 4

Fill out surveys

18



### STEP 5

Provide a blood sample if you are interested

5



### STEP 6

Update us every year

Log in to see next steps