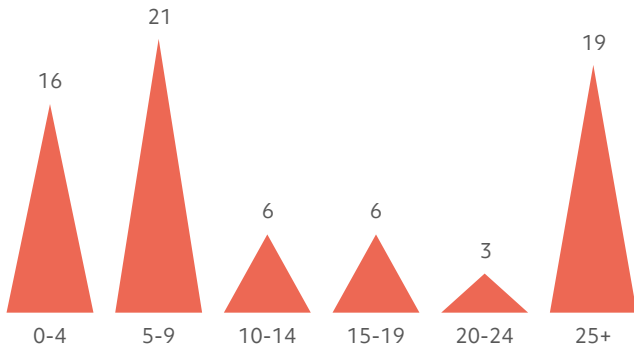


# Simons Searchlight Registry Update 1q21.1 deletion

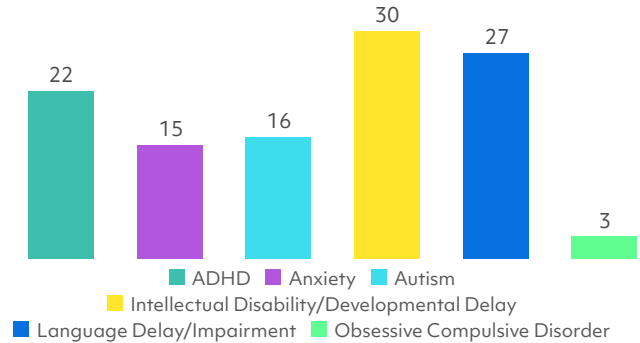
Data in these four graphs are from the medical history information collected in Simons Searchlight from 71 participants with 1q21.1 deletion syndrome.

April 2024

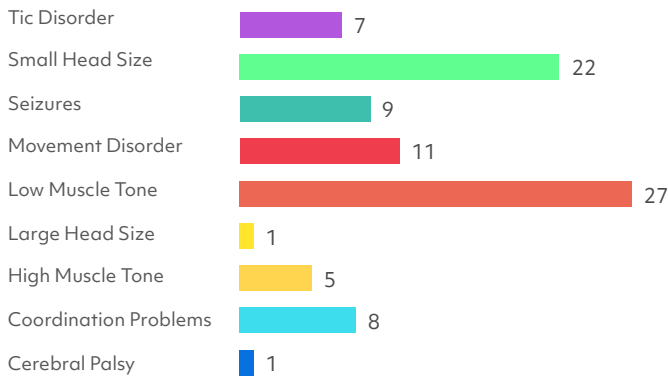
## Ages in Years



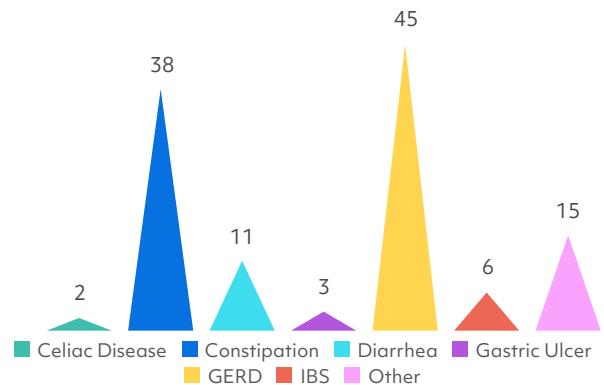
## Developmental and Behavioral Conditions



## 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.

## 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

148



### STEP 2

Provide your genetic lab report

91



### STEP 3

Share your important medical history

74



### STEP 4

Fill out surveys

71



### STEP 5

Provide a blood sample if you are interested

24



### STEP 6

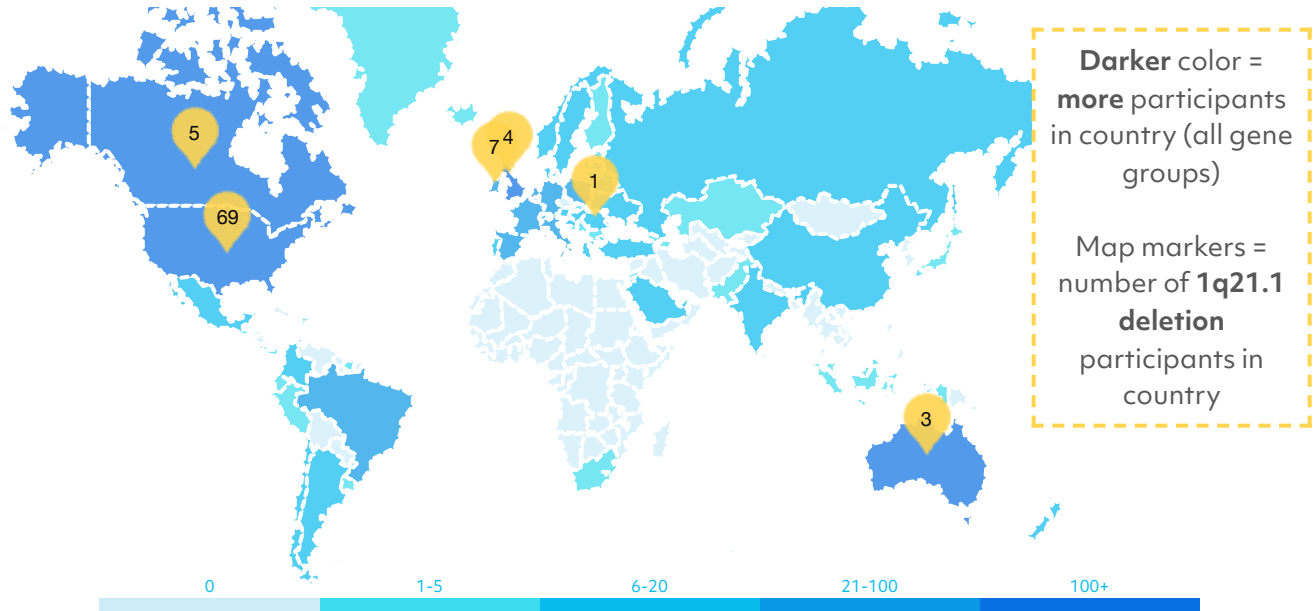
Update us every year

Log in to see next steps

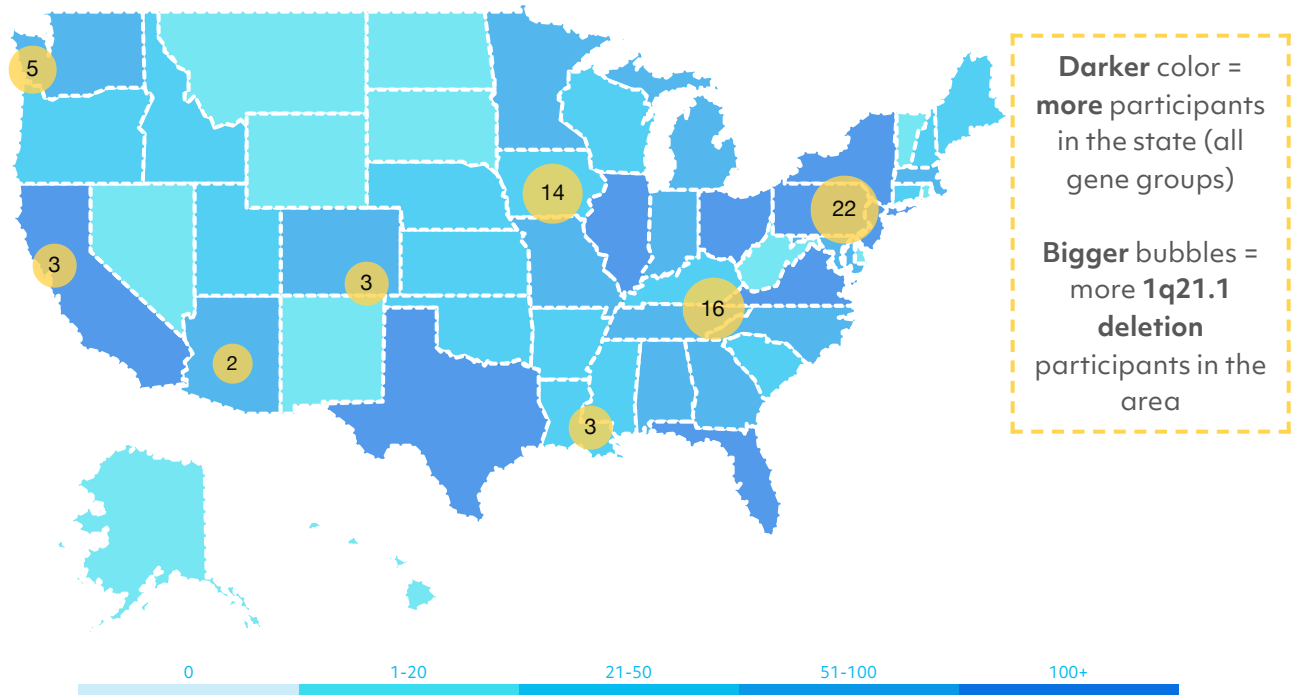
# Information Spotlight: Where in the world are Simons Searchlight families?



Simons Searchlight families live in **75** countries globally, including **89 1q21.1 deletion** participants in **6** countries.



Most Simons Searchlight families live in the United States. See where **69 1q21.1 deletion** participants live across the 50 states.



Thank you for participating in Simons Searchlight and helping us reach families worldwide!