

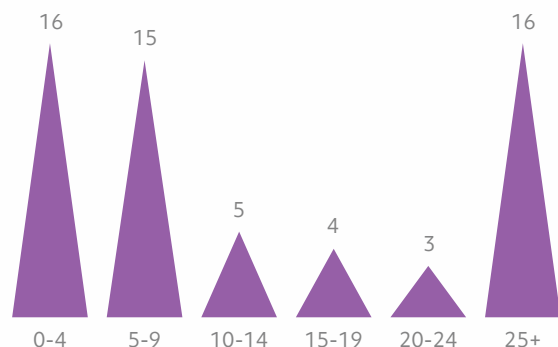
# Simons Searchlight Registry Update 1q21.1 deletion

SIMONS  
SEARCHLIGHT

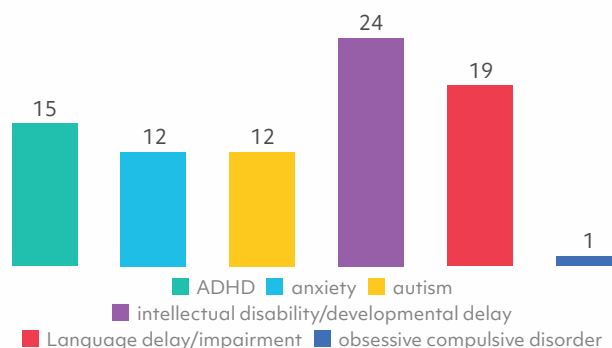
November, 2022

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 59 participants with 1q21.1 deletion.

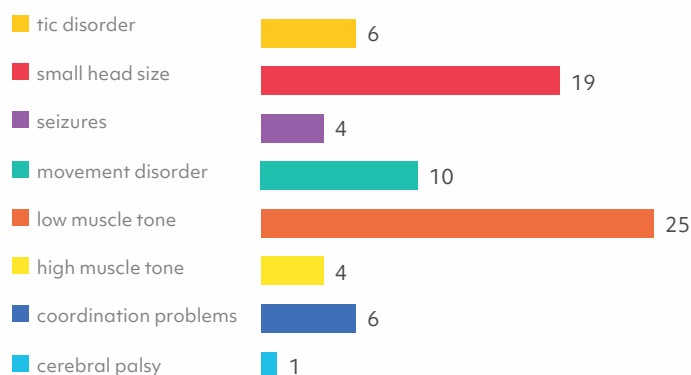
## Ages in Years



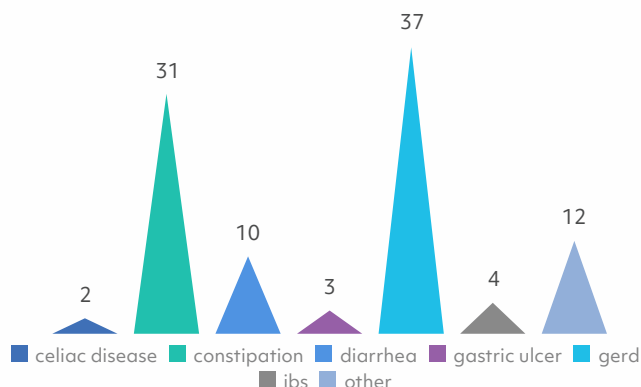
## Developmental and Behavioral Conditions



## 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 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



140

### STEP 2

Provide your genetic lab report



83

### STEP 3

Share your important medical history



60

### STEP 4

Fill out surveys



67

### STEP 5

Provide a blood sample if you are interested



21

### STEP 6

Update us every year



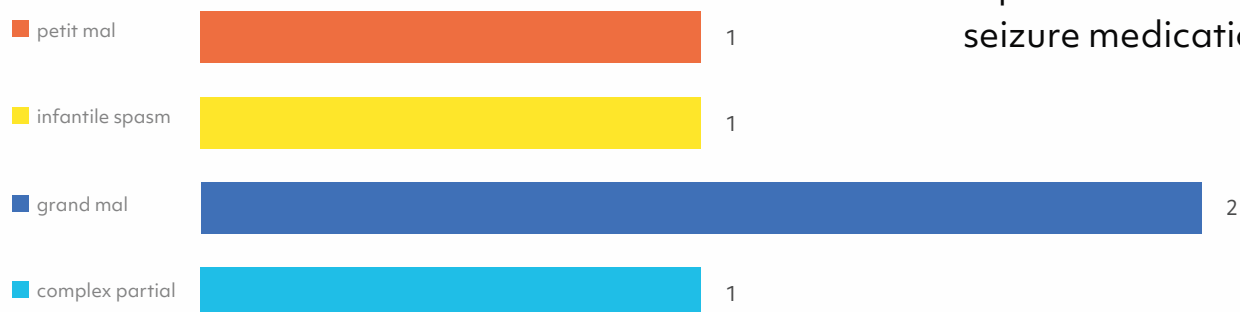
Log in to see next steps

# Information Spotlight for 1q21.1 deletion: Seizures

SIMONS  
SEARCHLIGHT

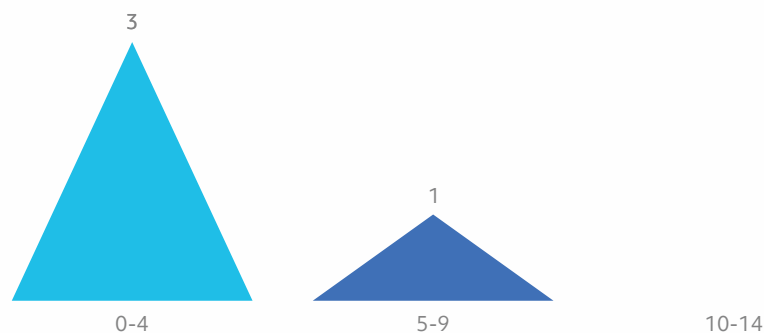
## Types of Seizures reported in the Medical History Interview

3% of individuals with 1q21.1 deletion are taking seizure medication.



## A look at the Seizure History Survey

### Age that Seizure First Started



9 report experiencing seizures.

- Some individuals may not have provided an age of onset.



**Thank you**

for contributing knowledge  
to Simons Searchlight!