

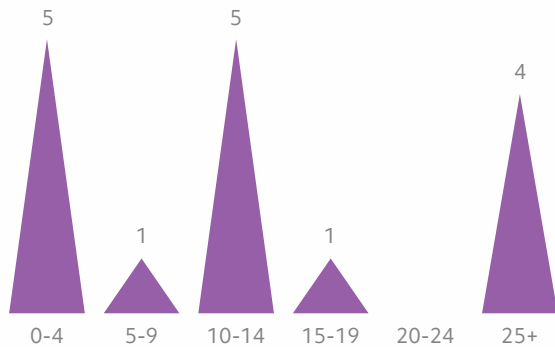
# Simons Searchlight Registry Update DISTAL 16p11.2 deletion

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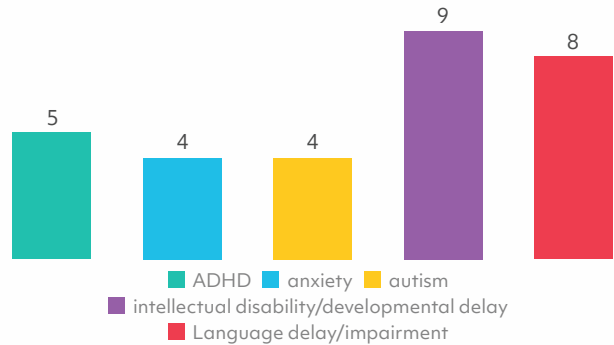
November, 2022

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 16 participants with DISTAL 16p11.2 deletion.

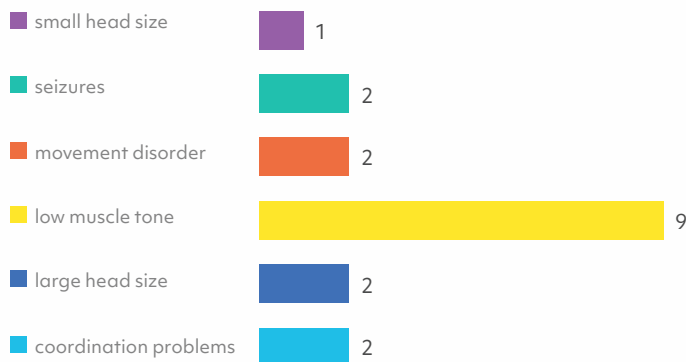
## Ages in Years



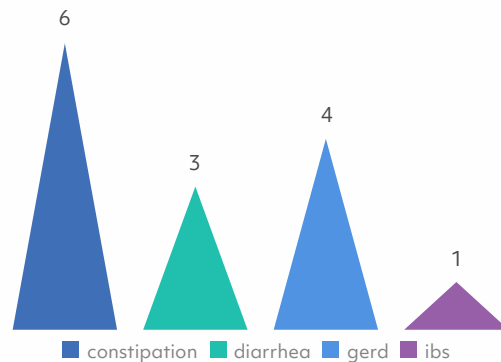
## Developmental and Behavioral Conditions



## 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 DISTAL 16p11.2 deletion community! Progress for individuals in your community with DISTAL 16p11.2 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



66

### STEP 2

Provide your genetic lab report



62

### STEP 3

Share your important medical history



17

### STEP 4

Fill out surveys



40

### STEP 5

Provide a blood sample if you are interested



5

### STEP 6

Update us every year

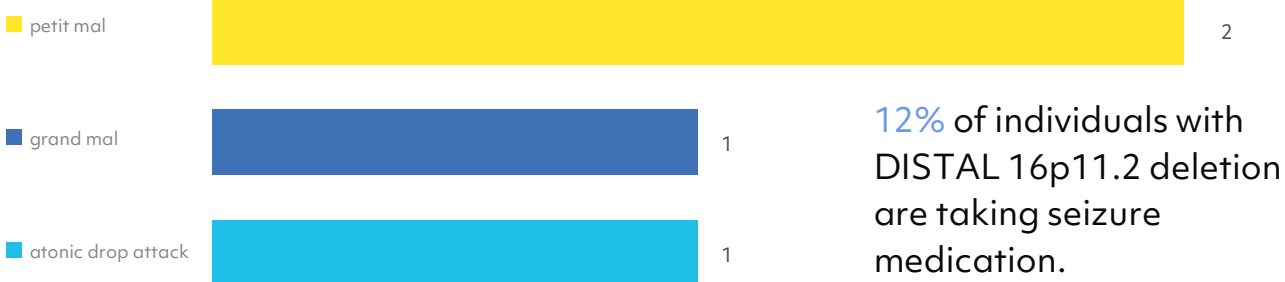


Log in to see next steps

# Information Spotlight for DISTAL 16p11.2 deletion: Seizures

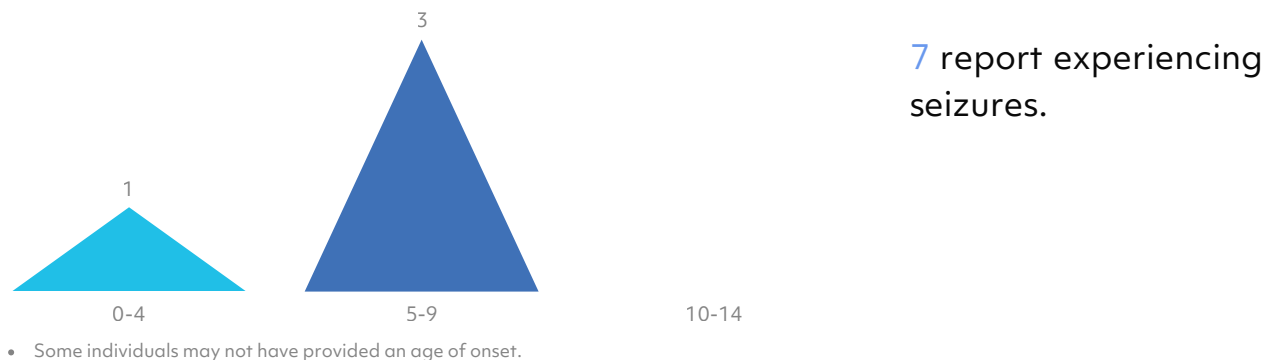
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## Types of Seizures reported in the Medical History Interview



## A look at the Seizure History Survey

### Age that Seizure First Started



**Thank you**

for contributing knowledge  
to Simons Searchlight!