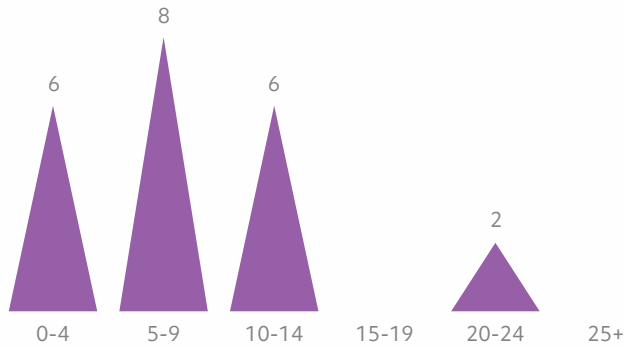


# Simons Searchlight Registry Update SETBP1

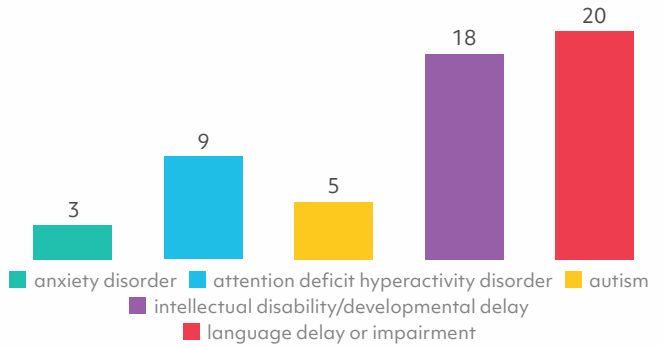
November, 2022

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 22 participants with SETBP1.

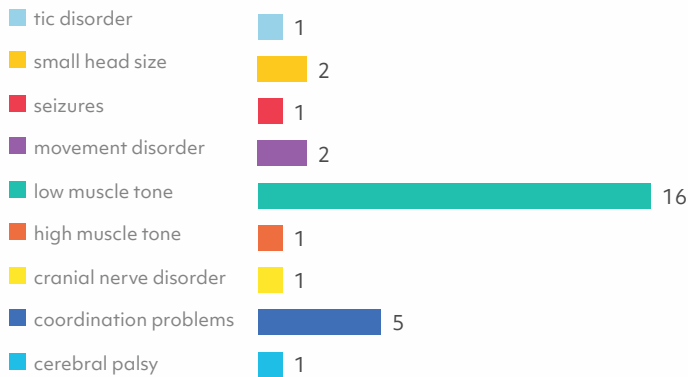
## Ages in Years



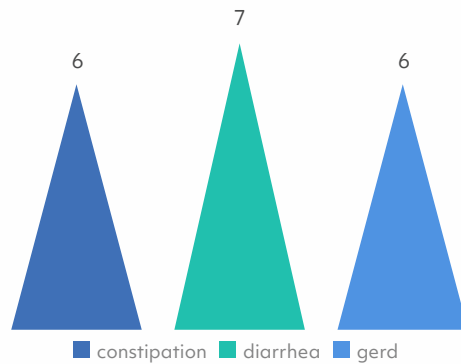
## Developmental and Behavioral Conditions



## 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 SETBP1 community! Progress for individuals in your community with SETBP1 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



73

### STEP 2

Provide your genetic lab report



61

### STEP 3

Share your important medical history



34

### STEP 4

Fill out surveys



47

### STEP 5

Provide a blood sample if you are interested



18

### STEP 6

Update us every year



Log in to see next steps