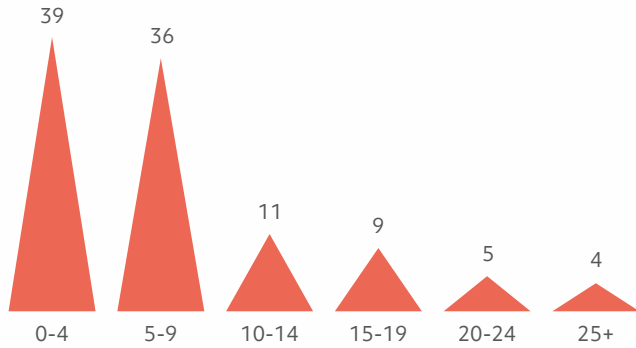


## Simons Searchlight Registry Update PPP2R5D

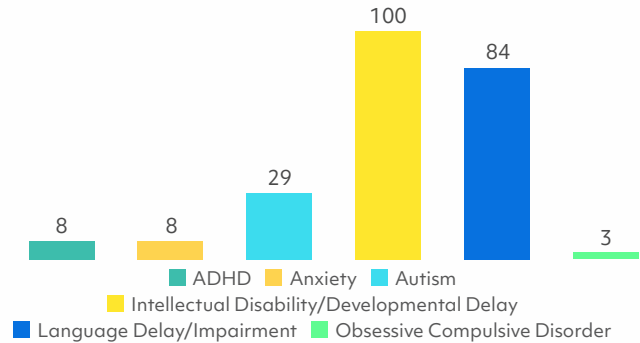
Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 104 participants with PPP2R5D.

April 2023

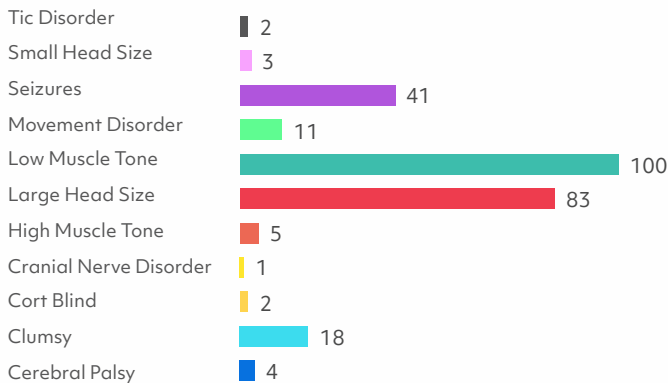
### Ages in Years



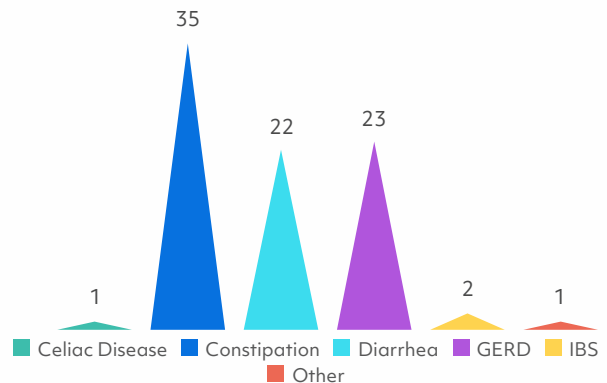
### Developmental and Behavioral Conditions



### 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 PPP2R5D community! Progress for individuals in your community with PPP2R5D 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

172



### STEP 2

Provide your genetic lab report

148



### STEP 3

Share your important medical history

119



### STEP 4

Fill out surveys

137



### STEP 5

Provide a blood sample if you are interested

45



### STEP 6

Update us every year

Log in to see next steps

# Information Spotlight on Development



We use a standardized measure called the Vineland Adaptive Behavior Scales (Vineland-3) to measure each person's development in communication, self-care, social skills, and in younger children, motor skills.

The Vineland is a useful tool for researchers and doctors to see a snapshot of a person's skills and watch how they change over time.



**49 PPP2R5D participants  
ages 4 to 29 contributed to  
this report**



Here is a look at how many PPP2R5D participants ages 4 to 29 years can do the following skills:



78% feed themselves



67% use functional  
speech



43% show interest in  
friends



Of children 4-9 years old,  
96% are walking

We will continue to collect Vineland data every year. Over time, we will have a better understanding of how individuals with PPP2R5D change as they get older.