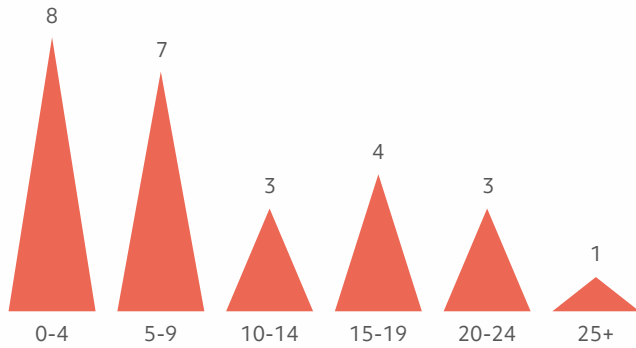


# Simons Searchlight Registry Update **DYRK1A**

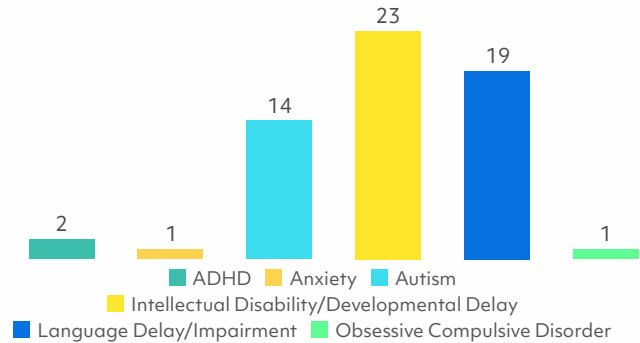
Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight in 26 participants with DYRK1A.

April 2023

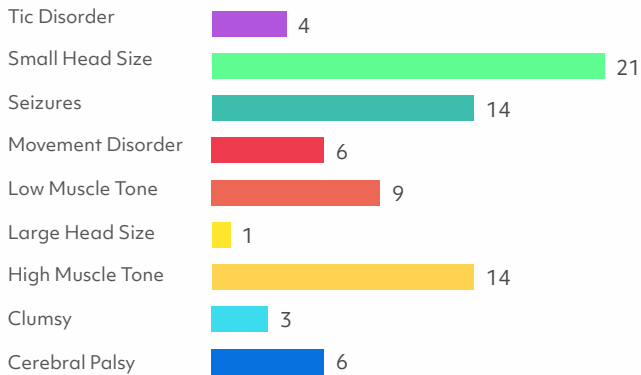
## Ages in Years



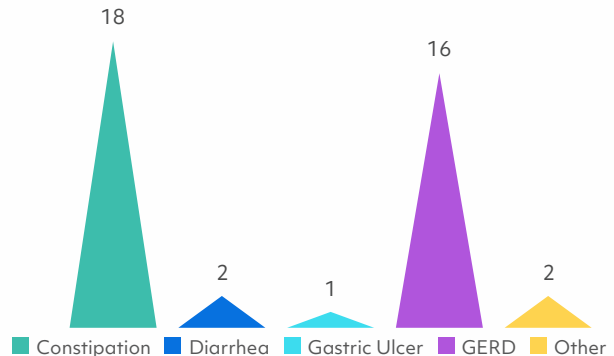
## Developmental and Behavioral Conditions



## 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 DYRK1A community! Progress for individuals in your community with DYRK1A 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

49



### STEP 3

Share your important medical history

29



### STEP 4

Fill out surveys

42



### STEP 5

Provide a blood sample if you are interested

12



### 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.



**10 DYRK1A participants  
ages 4 to 25 contributed to  
this report**



Here is a look at how many DYRK1A participants ages 4 to 25 years can do the following skills:



70% feed themselves



80% use functional  
speech



10% show interest in  
friends

We will continue to collect Vineland data every year. Over time, we will have a better understanding of how individuals with DYRK1A change as they get older.