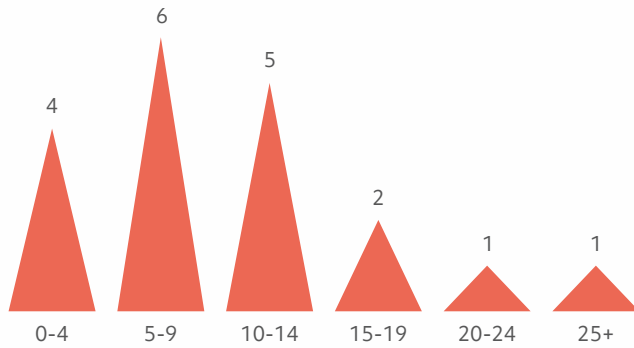


# Simons Searchlight Registry Update ADNP

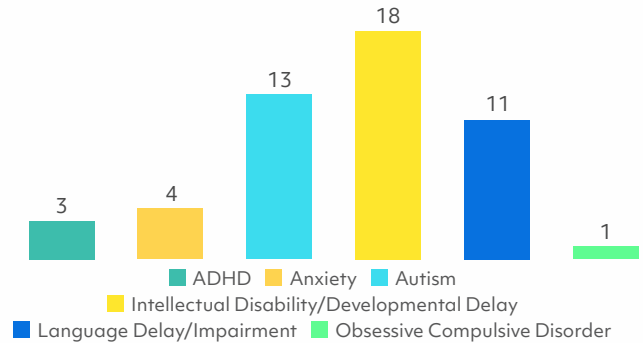
Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 19 participants with ADNP.

April 2023

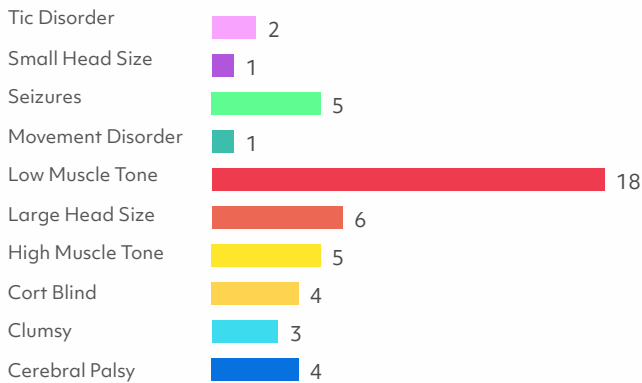
## Ages in Years



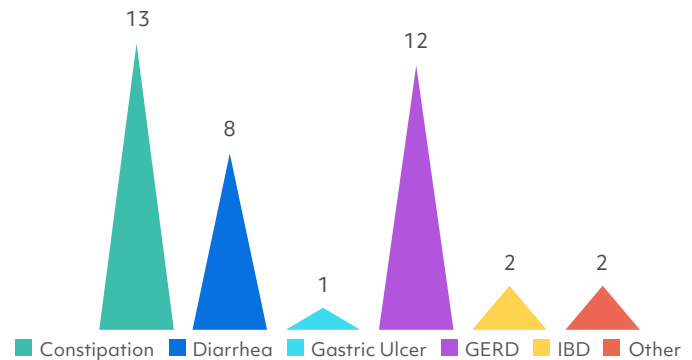
## Developmental and Behavioral Conditions



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

40



### STEP 2

Provide your genetic lab report

34



### STEP 3

Share your important medical history

26



### STEP 4

Fill out surveys

31



### STEP 5

Provide a blood sample if you are interested

9



### 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.



**8 ADNP participants ages  
4 to 29 contributed to this  
report**



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



50% feed themselves



50% use functional  
speech



38% 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 ADNP change as they get older.