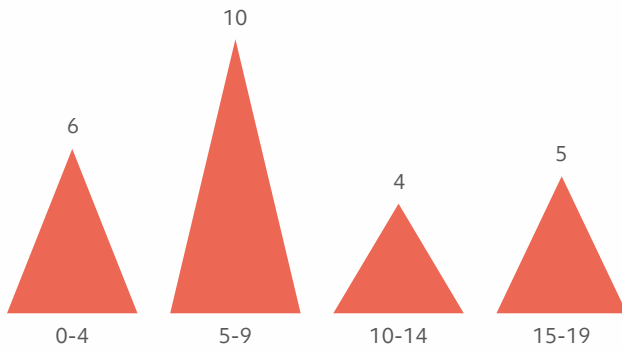# SIMONS SEARCHLIGHT
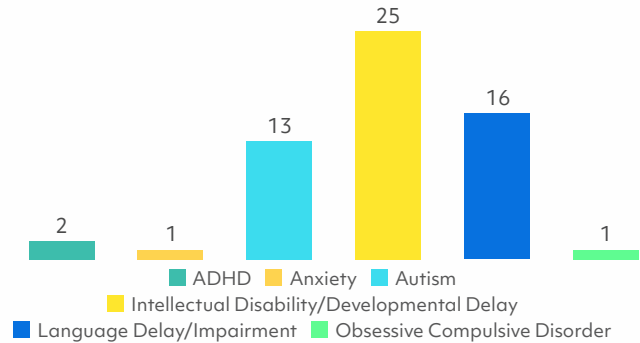
Simons Searchlight Registry Update **PACS1**

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 25 participants with PACS1.
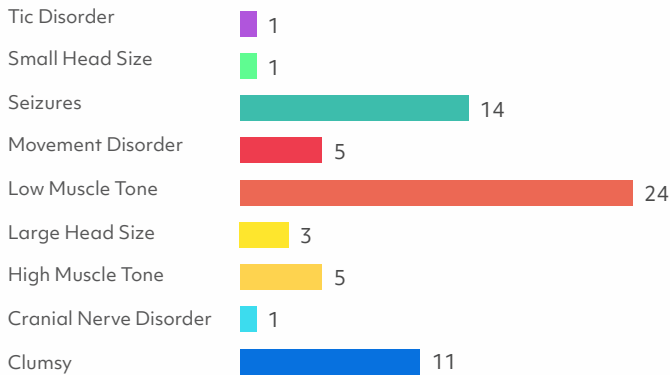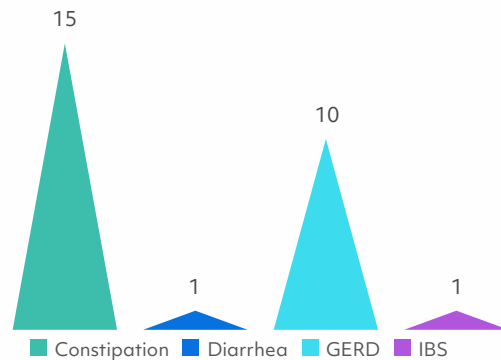
April 2023

Ages in Years

- 0-4: 6
- 5-9: 10
- 10-14: 4
- 15-19: 5

Developmental and Behavioral Conditions

- ADHD: 2
- Anxiety: 1
- Autism: 13
- Intellectual Disability/Developmental Delay: 25
- Language Delay/Impairment: 16
- Obsessive Compulsive Disorder: 1

Neurological Problems

- Tic Disorder: 1
- Small Head Size: 1
- Seizures: 14
- Movement Disorder: 5
- Low Muscle Tone: 24
- Large Head Size: 3
- High Muscle Tone: 5
- Cranial Nerve Disorder: 1
- Clumsy: 11

Gastrointestinal Problems

- Constipation: 15
- Diarrhea: 1
- GERD: 10
- IBS: 1

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 PACS1 community! Progress for individuals in your community with PACS1 is shown below - log in to your 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
49

STEP 2
Provide your genetic lab report
36

STEP 3
Share your important medical history
25

STEP 4
Fill out surveys
32

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.

9 PACS1 participants ages 6 to 18 contributed to this report

Here is a look at how many PACS1 participants ages 6 to 18 years can do the following skills:

78% feed themselves

44% use functional speech

33% 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 PACS1 change as they get older.