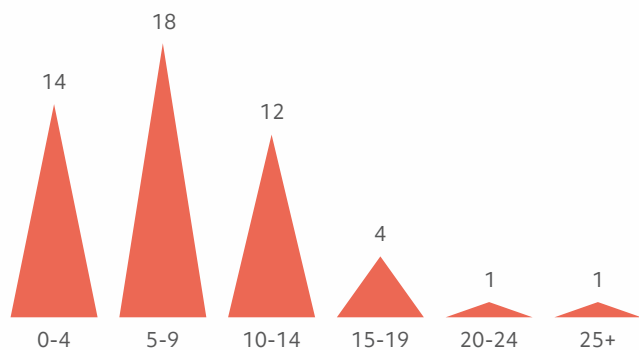


Simons Searchlight Registry Update **OCNDS**

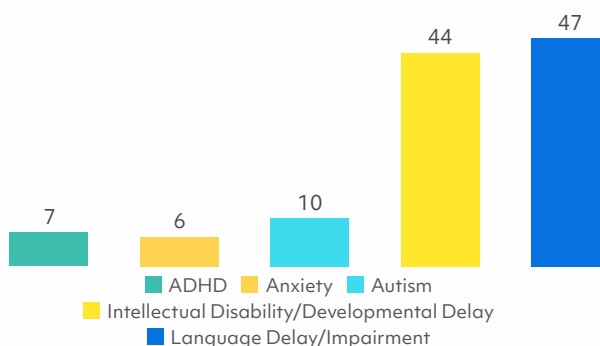
Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 50 participants with OCNDS.

April 2023

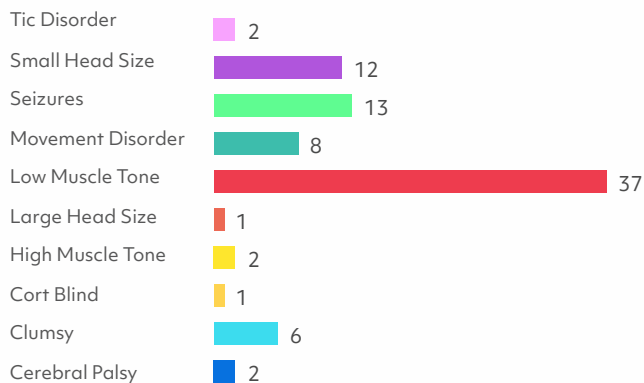
Ages in Years



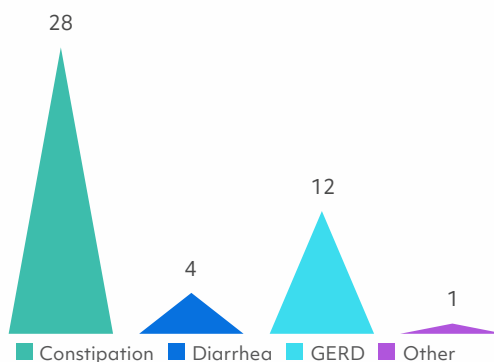
Developmental and Behavioral Conditions



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 OCNDS community! Progress for individuals in your community with OCNDS 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

102



STEP 2

Provide your
genetic
lab report

83



STEP 3

Share your
important
medical history

61



STEP 4

Fill out
surveys

76



STEP 5

Provide a blood
sample if you are
interested

22



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.



**31 OCNDS participants
ages 4 to 20 contributed to
this report**



Here is a look at how many OCNDS participants ages 4 to 20 years can do the following skills:



84% feed themselves



87% use functional
speech



48% show interest in
friends



Of children 4-9 years old,
100% are walking

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