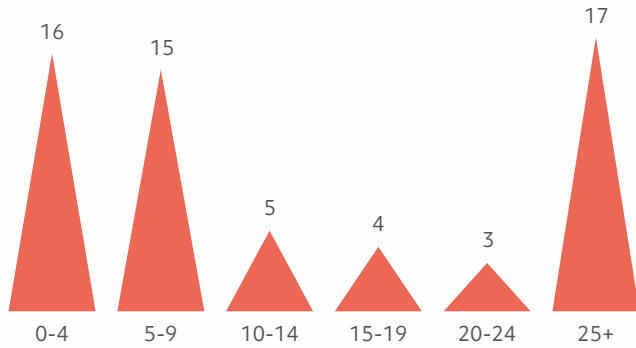


Simons Searchlight Registry Update 1q21.1 deletion

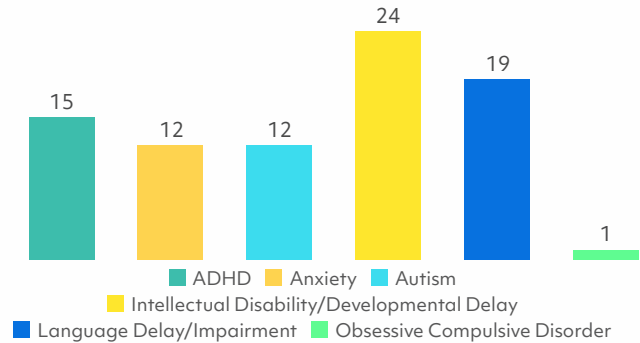
Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 60 participants with a 1q21.1 deletion.

April 2023

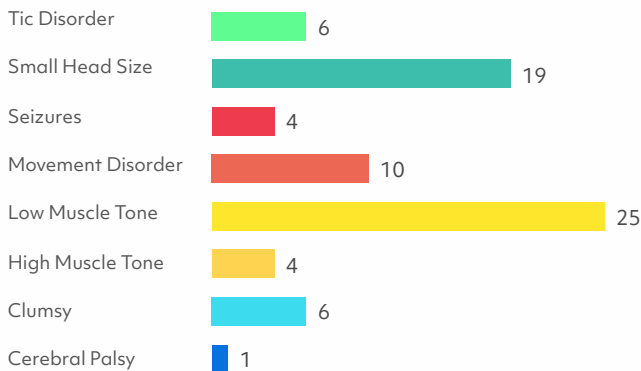
Ages in Years



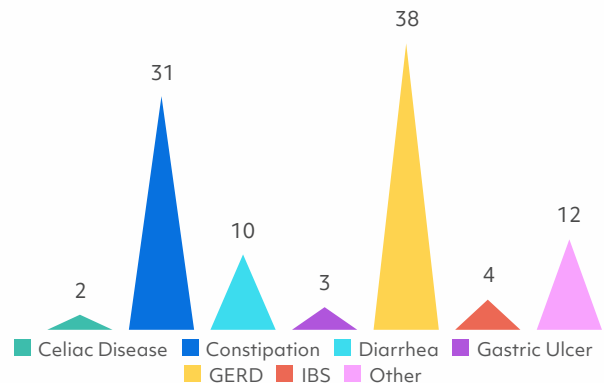
Developmental and Behavioral Conditions



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 1q21.1 deletion community! Progress for individuals in your community with 1q21.1 deletion 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

141



STEP 2

Provide your
genetic
lab report

84



STEP 3

Share your
important
medical history

62



STEP 4

Fill out
surveys

68



STEP 5

Provide a blood
sample if you are
interested

21



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.



**21 1q21.1 deletion
participants ages 4 to 23
contributed to this report**



Here is a look at how many 1q21.1 deletion participants ages 4 to 23 years can do the following skills:



100% feed themselves



100% use functional
speech



76% 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 1q21.1 deletion change as they get older.