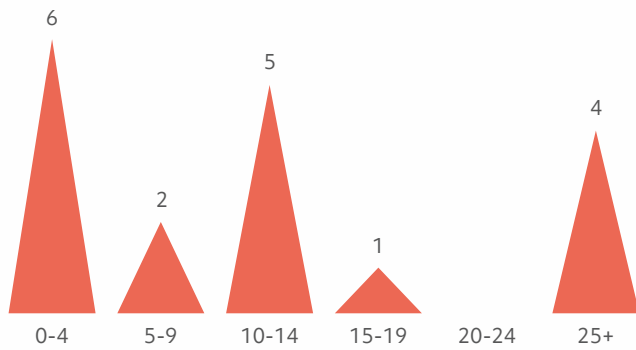


Simons Searchlight Registry Update **DISTAL 16p11.2 deletion**

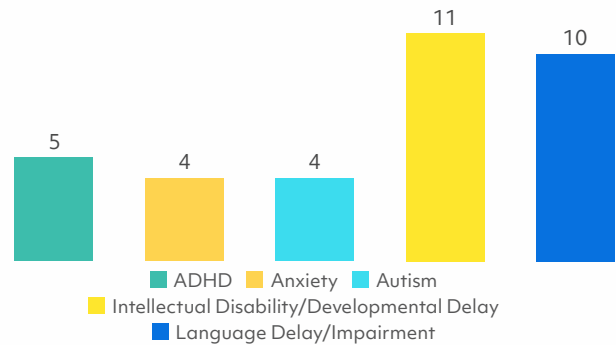
Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 18 participants with a DISTAL 16p11.2 deletion.

April 2023

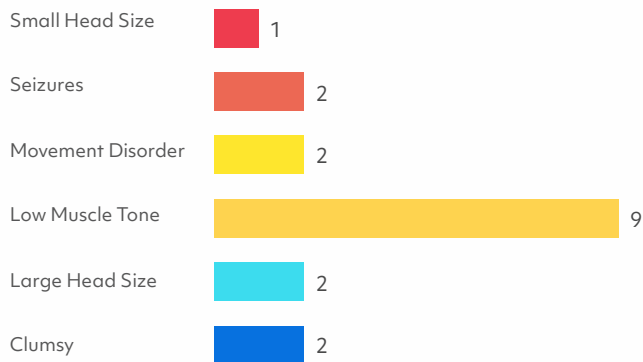
Ages in Years



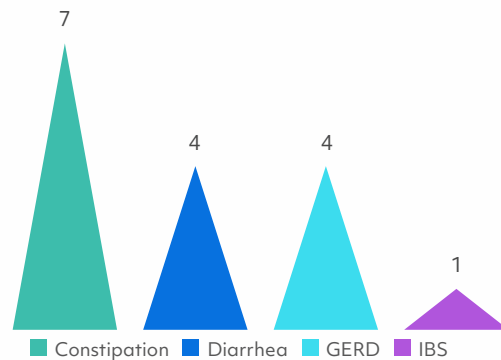
Developmental and Behavioral Conditions



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 DISTAL 16p11.2 deletion community! Progress for individuals in your community with DISTAL 16p11.2 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

74



STEP 2

Provide your genetic lab report

68



STEP 3

Share your important medical history

19



STEP 4

Fill out surveys

47



STEP 5

Provide a blood sample if you are interested

5



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.



**11 DISTAL 16p11.2
deletion participants ages
4 to 15 contributed to this
report**



Here is a look at how many DISTAL 16p11.2 deletion participants ages 4 to 15 years can do the following skills:



100% feed themselves



100% use functional
speech



73% 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 DISTAL 16p11.2 deletion change as they get older.