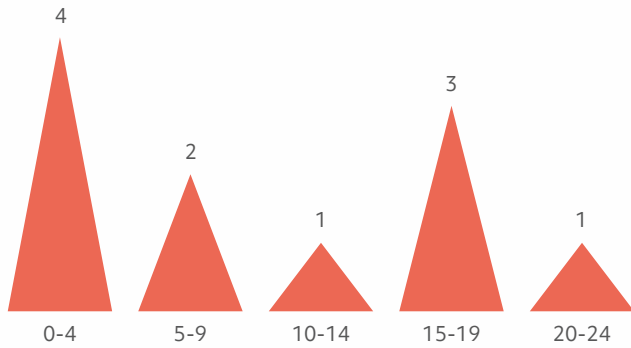


Simons Searchlight Registry Update TBR1

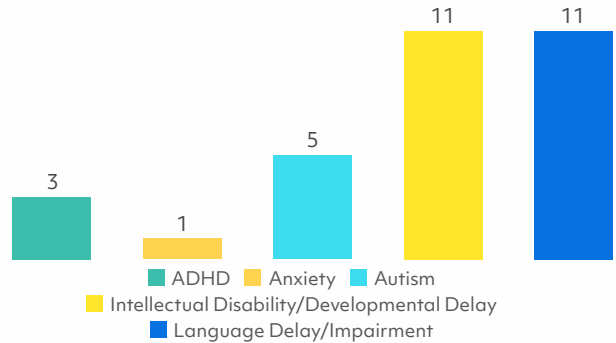
Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 11 participants with TBR1.

April 2023

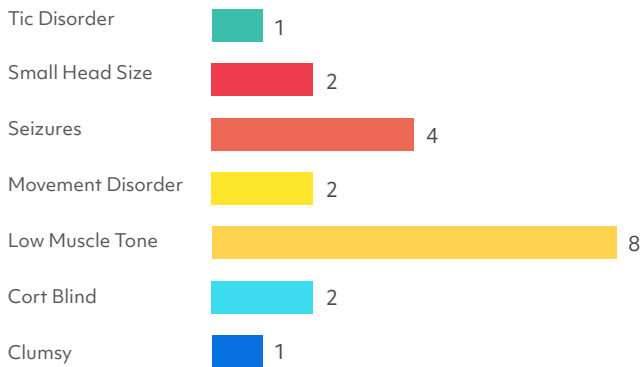
Ages in Years



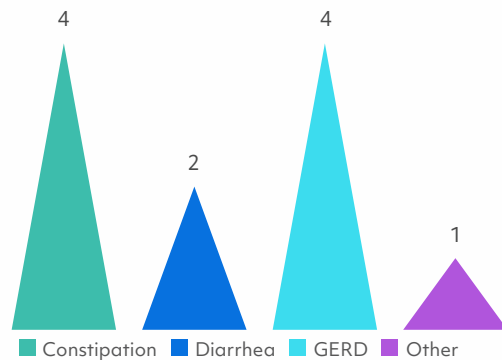
Developmental and Behavioral Conditions



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 TBR1 community! Progress for individuals in your community with TBR1 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

24



STEP 2

Provide your genetic lab report

18



STEP 3

Share your important medical history

12



STEP 4

Fill out surveys

18



STEP 5

Provide a blood sample if you are interested

4



STEP 6

Update us every year

Log in to see next steps

Information Spotlight on Development

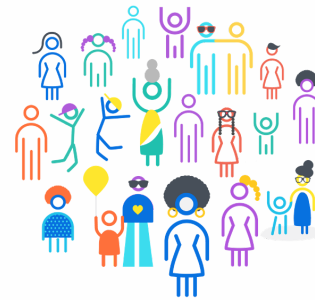


We use a standardized measure called the Vineland Adaptive Behavior Scales (Vineland-3) to measure each person's development in communication, self-care, social skills, and in younger children, motor skills.

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.



5 TBR1 participants ages 4 to 25 contributed to this report



Here is a look at how many TBR1 participants ages 4 to 25 years can do the following skills:



60% feed themselves



60% use functional speech



20% 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 TBR1 change as they get older.