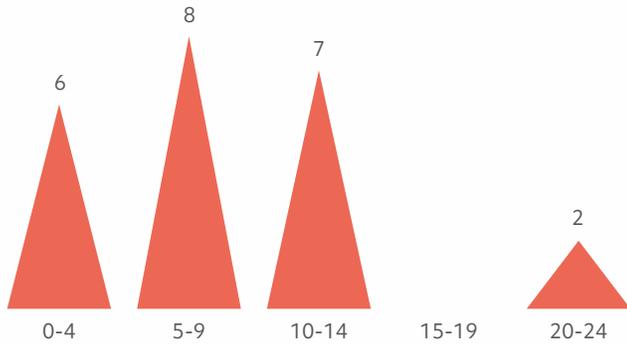


Simons Searchlight Registry Update SETBP1

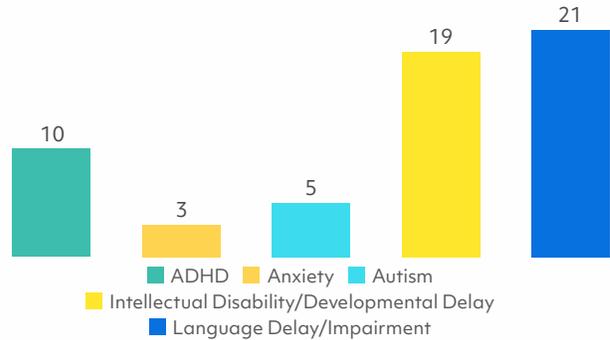
Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 23 participants with SETBP1.

April 2023

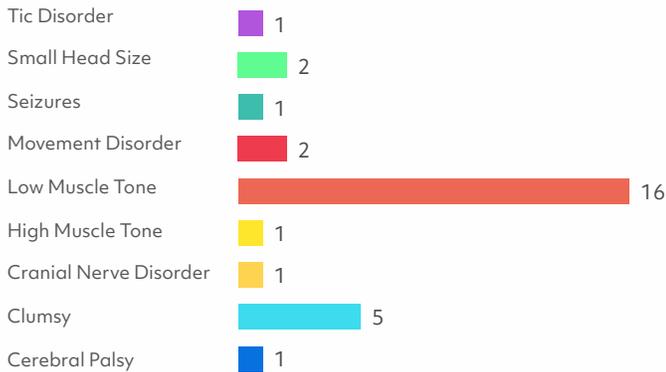
Ages in Years



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 SETBP1 community! Progress for individuals in your community with SETBP1 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

76



STEP 2

Provide your genetic lab report

62



STEP 3

Share your important medical history

34



STEP 4

Fill out surveys

48



STEP 5

Provide a blood sample if you are interested

18



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.



13 SETBP1 participants
ages 4 to 24 contributed to
this report



Here is a look at how many SETBP1 participants ages 4 to 24 years can do the following skills:



100% feed themselves



92% use functional
speech



69% 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 SETBP1 change as they get older.