Simons Searchlight Registry Update SLC6A1

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 63 participants with SLC6A1.

April 2023

Ages in Years

Developmental and Behavioral Conditions

Neurological Problems

Gastrointestinal Problems

Tic Disorder
Small Head Size
Seizures
Movement Disorder
Low Muscle Tone
Large Head Size
High Muscle Tone
Clumsy

ADHD
Anxiety
Autism
Intellectual Disability/Developmental Delay
Language Delay/Impairment
Obsessive Compulsive Disorder

Constipation
Diarrhea
GERD

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 SLC6A1 community! Progress for individuals in your community with SLC6A1 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
165

STEP 2
Provide your genetic lab report
128

STEP 3
Share your important medical history
95

STEP 4
Fill out surveys
110

STEP 5
Provide a blood sample if you are interested
20

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.

28 SLC6A1 participants ages 4 to 25 contributed to this report

Here is a look at how many SLC6A1 participants ages 4 to 25 years can do the following skills:

- 82% feed themselves
- 79% use functional speech
- 46% 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 SLC6A1 change as they get older.