Simons Searchlight Registry
Update 1q21.1 deletion
July, 2022

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

STEP 2
Provide your genetic lab report

STEP 3
Share your important medical history

STEP 4
Fill out surveys

STEP 5
Provide a blood sample if you are interested

STEP 6
Update us every year

Log in to see next steps

140
76
57
62
20

Celiac disease
Constipation
Diarrhea
Gastric ulcer
GERD

ADHD
Anxiety
Autism

Intellectual disability/developmental delay
Language delay
OCD

Tic disorder
Small head size
Seizures
Movement disorder
Low muscle tone
High muscle tone
Coordination problems
Cerebral palsy

31
12
12
23
17
1

2
10
3
4