About this Report

The report shows data collected in Simons Searchlight from 16p11.2 Deletion participants. Data from other published research are not included.

Data presented in this report come primarily from the medical history phone call. The data are current and may reflect information not yet available in an official researcher data release.

Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.

This report may look different from previous reports because we have streamlined our process and updated the variants.

Participants

Graphs include data and information strictly from the online phase of our study.

Ages in Years

Individual participants: 158

Participation & Registration

Learn more at SimonsSearchlight.org

STEP 1
Sign up online.

STEP 2
Provide your clinical lab report.

STEP 3
Schedule medical history phone call with a genetic counselor.

STEP 4
Fill out surveys.

STEP 5
Provide a blood sample if you are interested.

STEP 6
We follow up with you over time.

16p11.2 Deletion Progress

Includes families registered with all variant types

- Registered Families: 439
- Person with Genetic Change Consented: 294
- Lab Reports Approved: 206
- Medical History Phone Call: 159
### Developmental & Behavioral Diagnoses

Individual participants: 158

- Intellectual Disability/Developmental Delay: 78
- Autism: 57
- Language Impairment: 37
- ADHD: 26
- OCD: 1
- Anxiety: 1

### Gastrointestinal Problems

Individual participants: 158

- GERD: 65
- Diarrhea: 38
- Celiac Disease: 2
- Constipation: 17

### Neurological Problems

Individual participants: 158

- Clumsy: 44
- Low Muscle Tone: 13
- High Muscle Tone: 45
- Large Head Size: 4
- Small Head Size: 5
- Cyst in the Spinal Cord: 11
- Movement Disorder: 19
- Tic Disorder: 8
- Cerebral Palsy: 1
- Cortical Blindness: 1

### Seizures

Individual participants: 158

- Myoclonic: 1
- Simple Partial: 7
- Complex Partial: 9
- Atonic Drop Attack: 3
- Infantile Spasm: 2
- Petit Mal: 17
- Grand Mal: 24

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Simon's Searchlight 2021

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