Simons Searchlight Registry Update
Distal 16p11.2 Deletion
March 2021

About this Report

The report shows data collected in Simons Searchlight from Distal 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.

Participation & Registration
Learn more at SimonsSearchlight.org

Distal 16p11.2 deletion Progress
Includes families registered with all variant types

- Registered Families: 36
- Person with Genetic Change Consented: 43
- Lab Reports Approved: 43
- Medical History Phone Call: 13
### Developmental & Behavioral Diagnoses

- **Individual participants:** 11
- **Intellectual Disability/Development Delay:** 5
- **Autism:** 4
- **Language Impairment:** 3
- **ADHD:** 2
- **Anxiety:** 1

### Gastrointestinal Problems

- **Individual participants:** 11
- **GERD:** 4
- **Diarrhea:** 3
- **Constipation:** 6
- **Irritable Bowel Syndrome:** 1

### Neurological Problems

- **Individual participants:** 11
- **Clumsy:** 2
- **Low Muscle Tone:** 8
- **Large Head Size:** 2
- **Small Head Size:** 1
- **Movement Disorder:** 1

### Seizures

- **Individual participants:** 11
- **Atonic Drop Attack:** 1
- **Petit Mal:** 1
- **Grand Mal:** 1

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*Distal 16p11.2 Deletion Registry Snapshot ©Simons Searchlight 2021*