The report shows data collected in Simons Searchlight from 1q21.1 deletion participants. Data from other published research is not included.

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

Graphs show counts of individuals in each category. Personal 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.

About this Report

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March 2021

Simons Searchlight Registry Update
1q21.1 deletion

1q21.1 deletion Progress

- Registered Families
- Receive with Genetic Change Converter
- Self-Reports Agreement
- Medical History Phone Call

Ages in Years

- 0-4
- 5-9
- 10-14
- 15-19
- 20+

Developmental & Behavioral Diagnoses

- Intellectual Disability/Development Delay
- Autism
- Language Impairment
- OCD
- Anxiety
- ADHD

Gastrointestinal Problems

- IBD
- Crohn's Disease
- Inflammatory Bowel Disease
- GERD
- Diarrhea
- Constipation
- In ammatory Bowel Disease
- Celiac Disease
- Other

Neurological Problems

- Clumsy
- Low Muscle Tone
- High Muscle Tone
- Small Head Size
- Movement Disorder
- Tic Disorder
- Cerebral Palsy

Seizures

- Complex Partial
- Infantile Spasms
- Infantile
- Grand Mal

Participation & Registration

Learn more at SimonsSearchlight.org

Includes families registered with all variant types