Simons Searchlight Registry
Update DISTAL 16p11.2 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 DISTAL 16p11.2 deletion community! Progress for individuals in your community with DISTAL 16p11.2 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.

How to Participate

1. Sign up online
2. Provide your genetic lab report
3. Share your important medical history
4. Fill out surveys
5. Provide a blood sample if you are interested
6. Update us every year

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 16 participants with DISTAL 16p11.2 deletion.

- ADHD
- Anxiety
- Autism
- Intellectual disability/developmental delay
- Language delay

- Constipation
- Diarrhea
- GERD
- IBS