

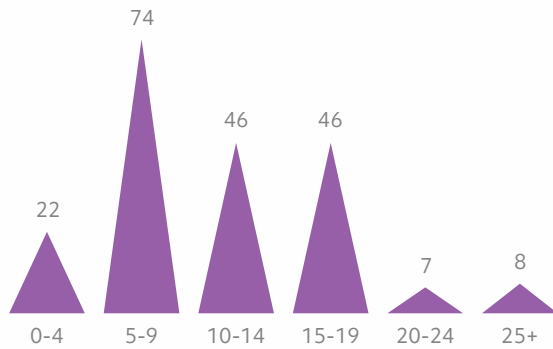
Simons Searchlight Registry Update 16p11.2 deletion

SIMONS
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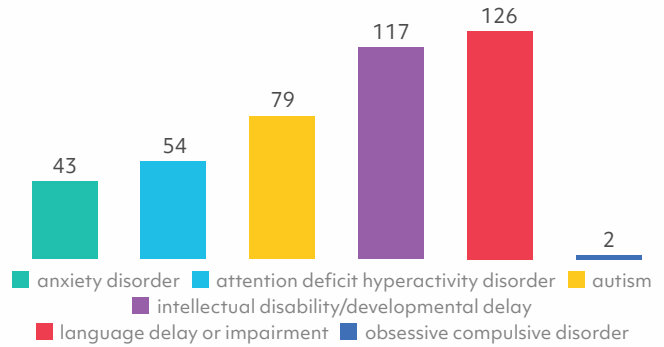
November, 2022

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 203 participants with 16p11.2 deletion.

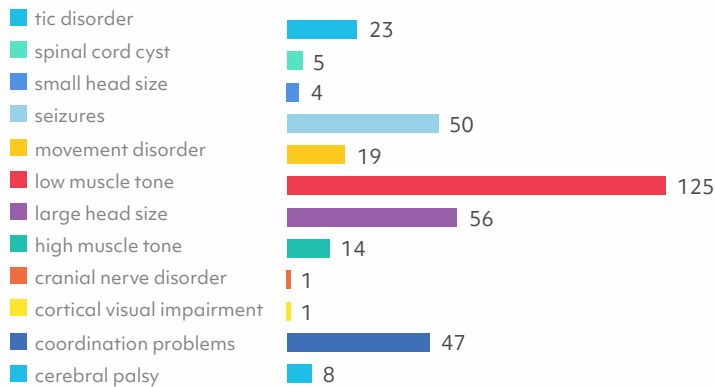
Ages in Years



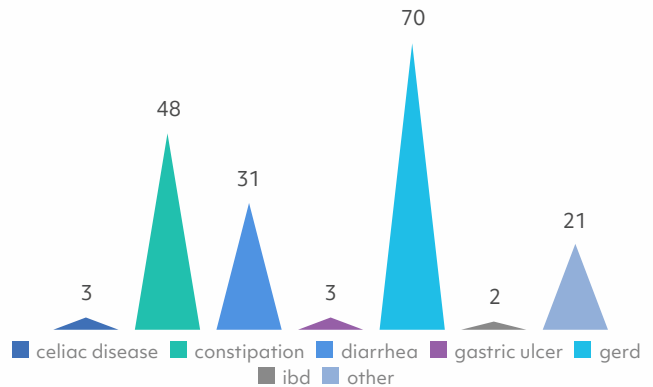
Developmental and Behavioral Conditions



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 16p11.2 deletion community! Progress for individuals in your community with 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.

STEP 1

Sign up online



475

STEP 2

Provide your genetic lab report



283

STEP 3

Share your important medical history



205

STEP 4

Fill out surveys



247

STEP 5

Provide a blood sample if you are interested



106

STEP 6

Update us every year

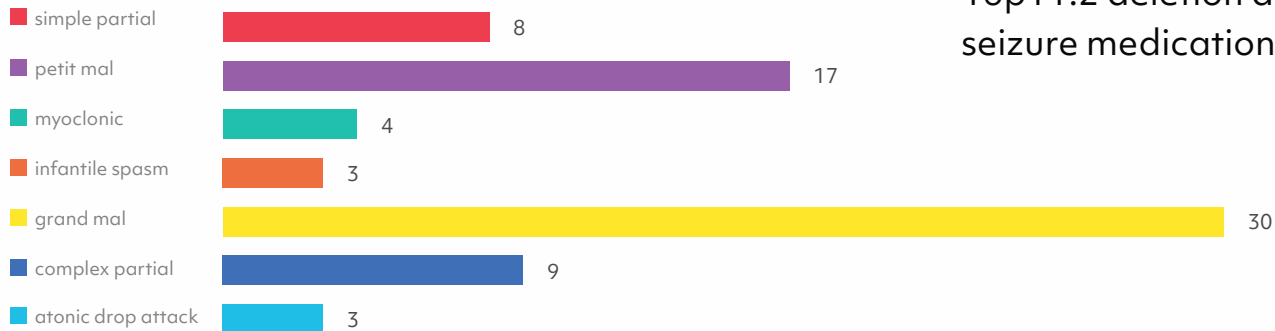


Log in to see next steps

Information Spotlight for 16p11.2 deletion: Seizures

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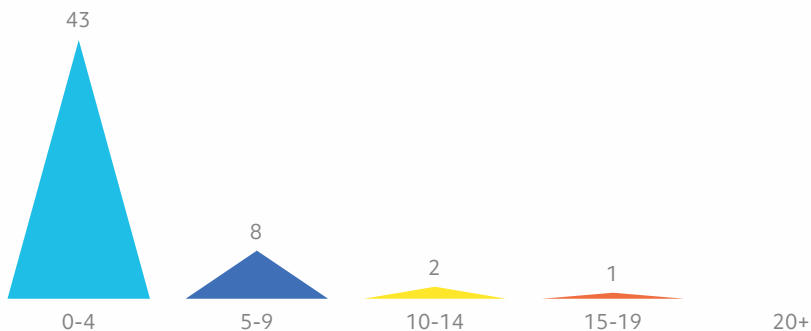
Types of Seizures reported in the Medical History Interview



11% of individuals with 16p11.2 deletion are taking seizure medication.

A look at the Seizure History Survey

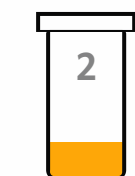
Age that Seizure First Started



68 report experiencing seizures.

- Some individuals may not have provided an age of onset.

Seizure Medications Reported to be Most Effective (68 participants)



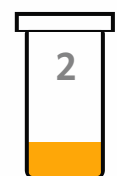
Lamotrigine



Levetiracetam



Oxcarbazepine



Phenobarbital



Valproic Acid

Thank you

for contributing knowledge
to Simons Searchlight!