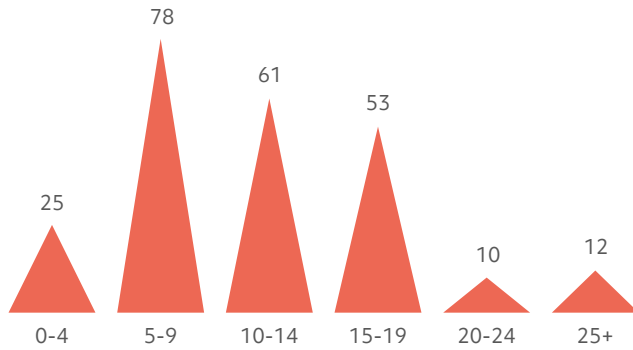


Simons Searchlight Registry Update 16p11.2 deletion

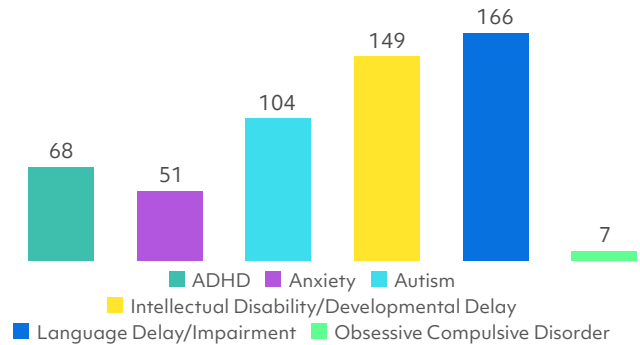
Data in these four graphs are from the medical history information collected in Simons Searchlight from 239 participants with 16p11.2 deletion syndrome.

April 2024

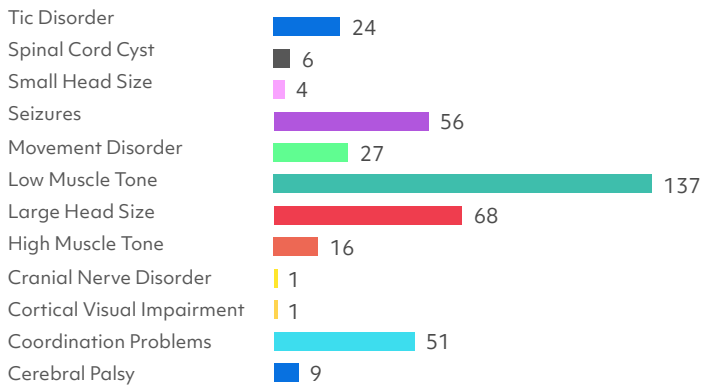
Ages in Years



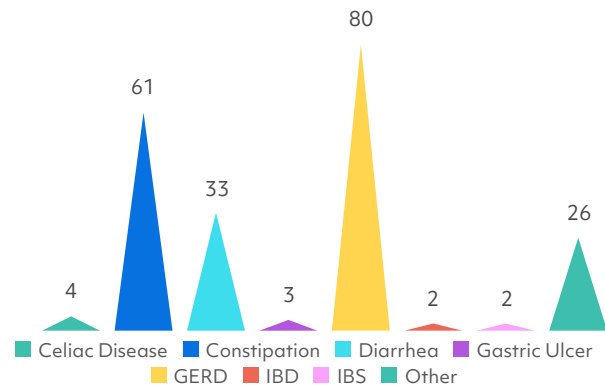
Developmental and Behavioral Conditions



Neurological Conditions



Gastrointestinal Conditions



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

522



STEP 2

Provide your genetic lab report

316



STEP 3

Share your important medical history

245



STEP 4

Fill out surveys

265



STEP 5

Provide a blood sample if you are interested

110



STEP 6

Update us every year

Log in to see next steps

Darker color = more participants in country (all gene groups)

Map markers = number of 16p11.2 deletion participants in country

Country	Number of Participants
USA	238
Canada	19
Brazil	2
UK	19
France	1
Germany	1
Italy	5
Spain	1
Sweden	1
Poland	1
Belgium	4
China	1
Australia	20
Argentina	3

Darker color = more participants in the state (all gene groups)

Bigger bubbles = more 16p11.2 deletion participants in the area

State	Number of Participants
Alaska	1
Arizona	14
Arkansas	13
California	13
Colorado	9
Connecticut	2
Delaware	20
District of Columbia	27
Florida	7
Georgia	26
Hawaii	1
Idaho	1
Illinois	20
Indiana	20
Iowa	20
Kansas	10
Kentucky	20
Louisiana	10
Maine	1
Massachusetts	63
Michigan	2
Minnesota	1
Mississippi	10
Missouri	20
Montana	1
Nebraska	1
Nevada	14
New Hampshire	1
New Jersey	20
New Mexico	1
New York	63
North Carolina	26
North Dakota	1
Ohio	20
Oklahoma	10
Oregon	14
Pennsylvania	20
Rhode Island	1
South Carolina	26
South Dakota	1
Tennessee	20
Texas	10
Utah	1
Vermont	1
Virginia	20
Washington	14
West Virginia	20
Wisconsin	20
Wyoming	1

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