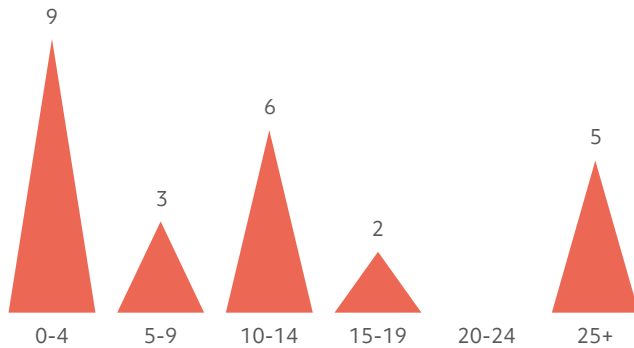


Simons Searchlight Registry Update **Distal 16p11.2 deletion**

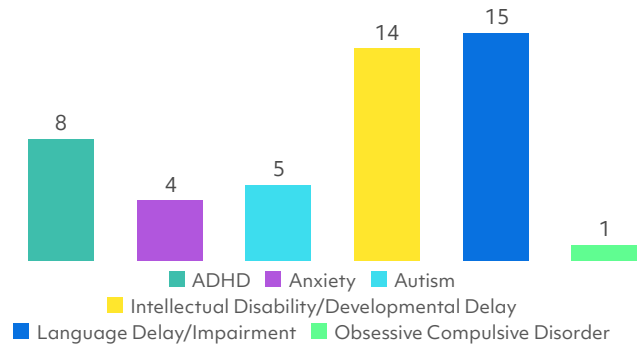
Data in these four graphs are from the medical history information collected in Simons Searchlight from 25 participants with Distal 16p11.2 deletion syndrome.

April 2024

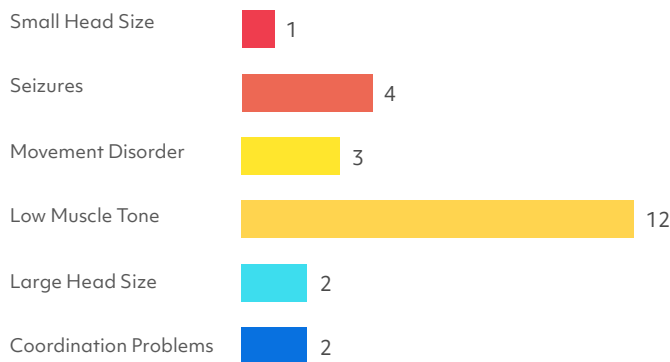
Ages in Years



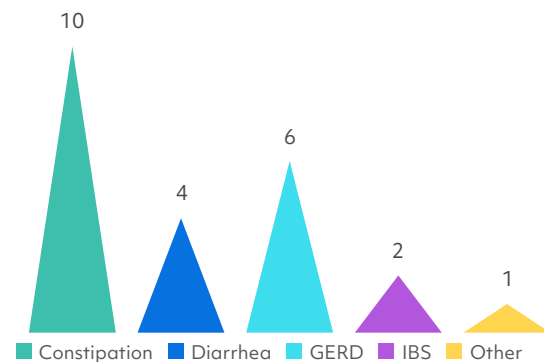
Developmental and Behavioral Conditions



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 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.



STEP 1

Sign up online

81



STEP 2

Provide your genetic lab report

77



STEP 3

Share your important medical history

34



STEP 4

Fill out surveys

53



STEP 5

Provide a blood sample if you are interested

5



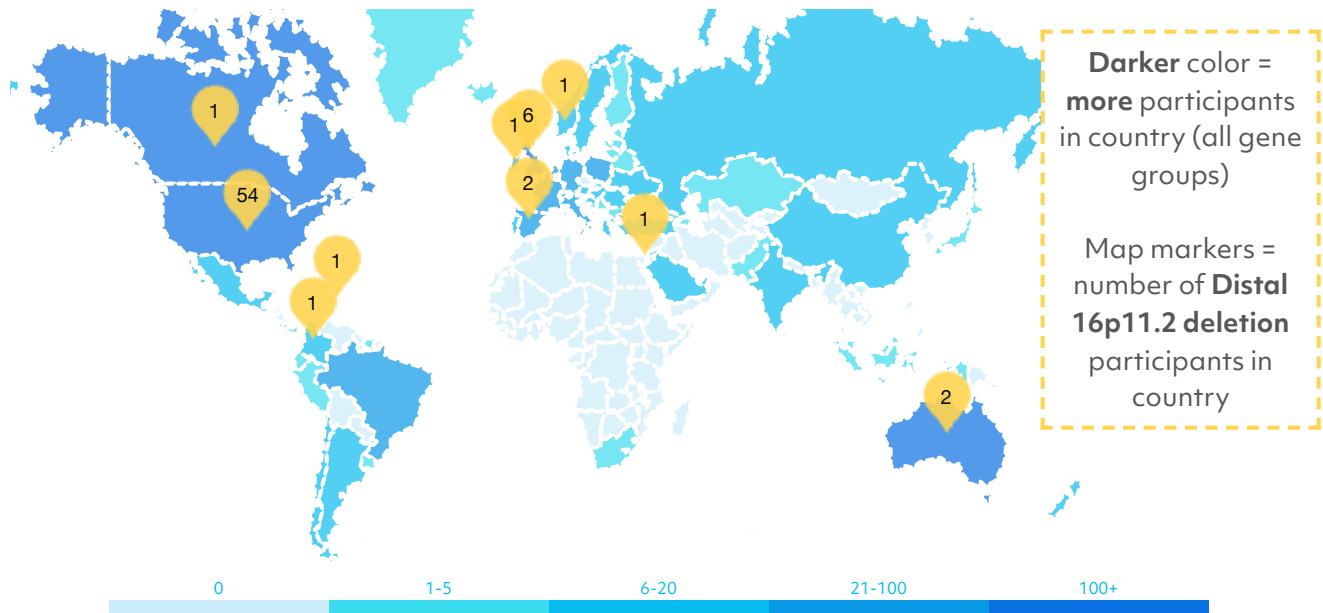
STEP 6

Update us every year

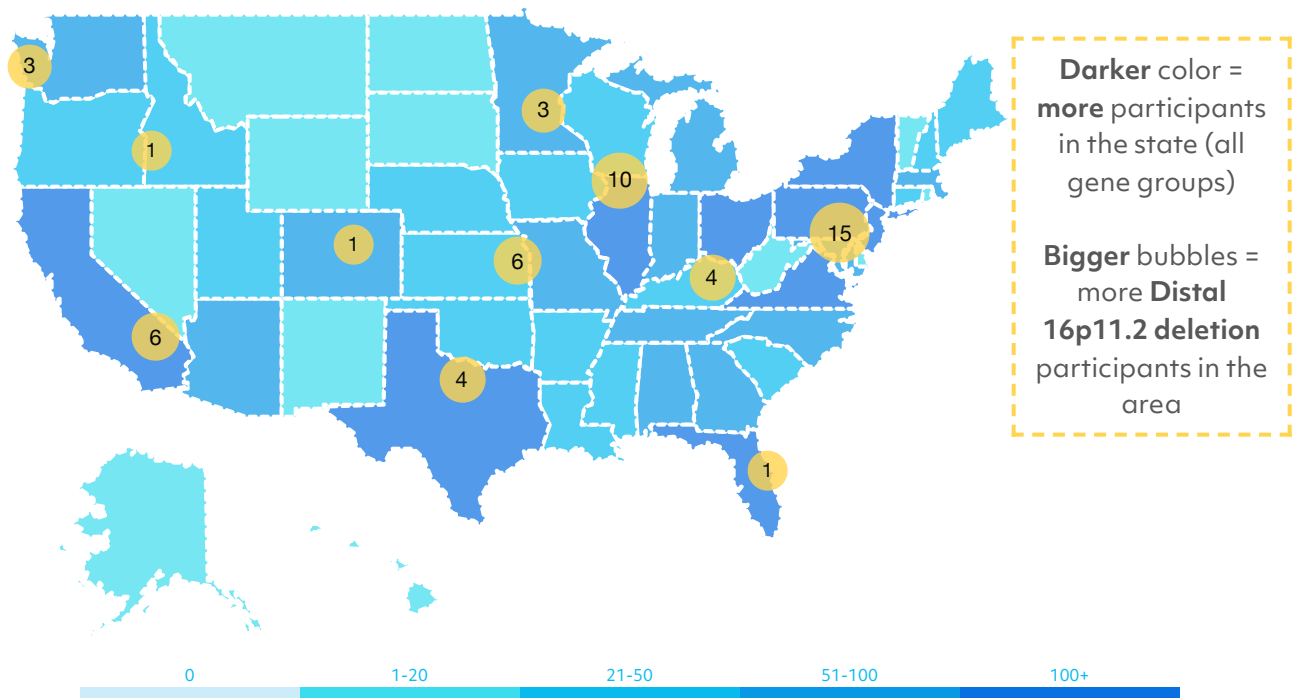
Log in to see next steps

Information Spotlight: Where in the world are Simons Searchlight families?

Simons Searchlight families live in **75** countries globally, including **70 Distal 16p11.2 deletion** participants in **10** countries.



Most Simons Searchlight families live in the United States. See where **54 Distal 16p11.2 deletion** participants live across the 50 states.



Thank you for participating in Simons Searchlight and helping us reach families worldwide!