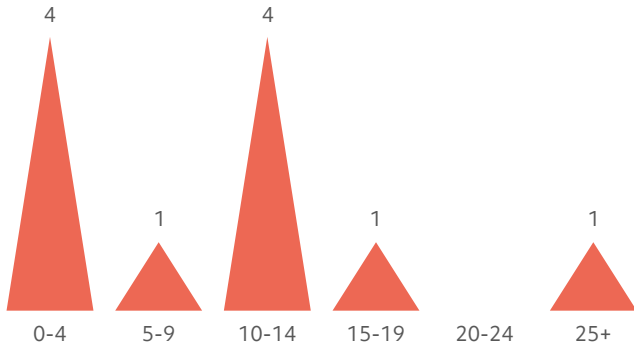


Simons Searchlight Registry Update 16p13.11 deletion

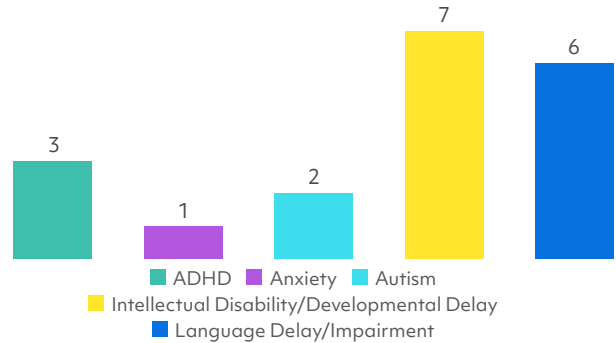
Data in these four graphs are from the medical history information collected in Simons Searchlight from 11 participants with 16p13.11 deletion syndrome.

April 2024

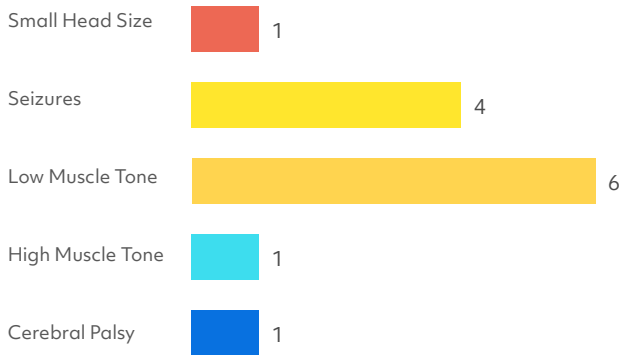
Ages in Years



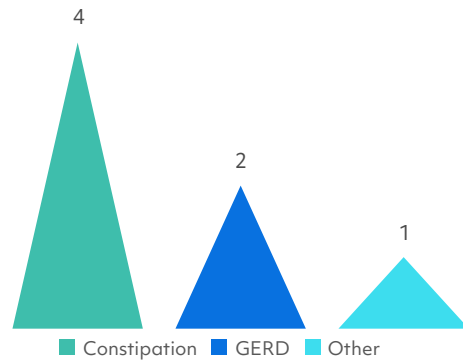
Developmental and Behavioral Conditions



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 16p13.11 deletion community! Progress for individuals in your community with 16p13.11 deletion is shown below - log in to your simonsearchlight.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

35



STEP 2

Provide your genetic lab report

24



STEP 3

Share your important medical history

14



STEP 4

Fill out surveys

14



STEP 5

Provide a blood sample if you are interested

3



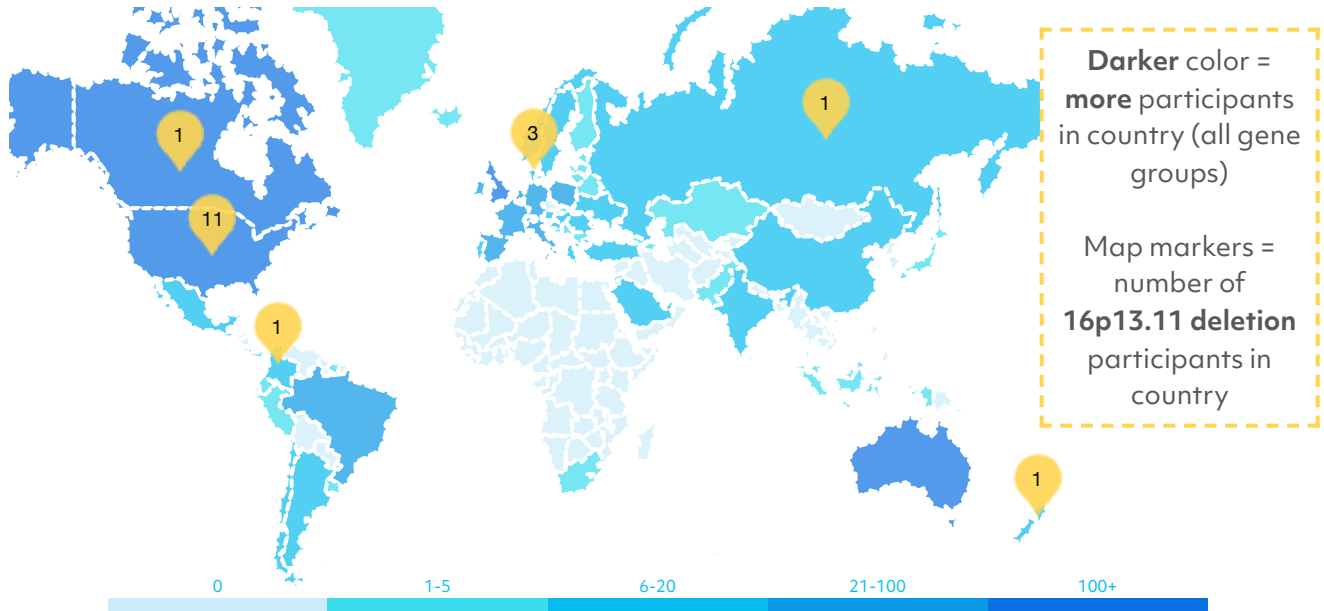
STEP 6

Update us every year

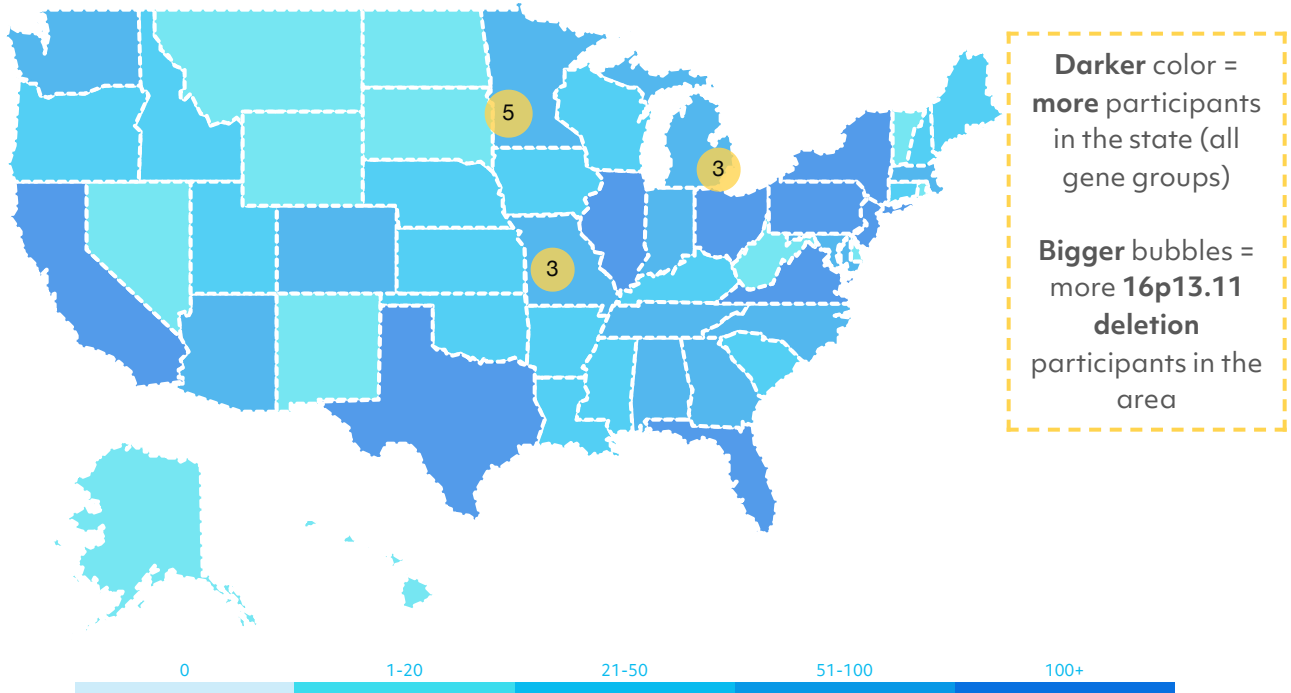
Log in to see next steps

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

Simons Searchlight families live in **75** countries globally, including **18 16p13.11 deletion** participants in **6** countries.



Most Simons Searchlight families live in the United States. See where **11 16p13.11 deletion** participants live across the 50 states.



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