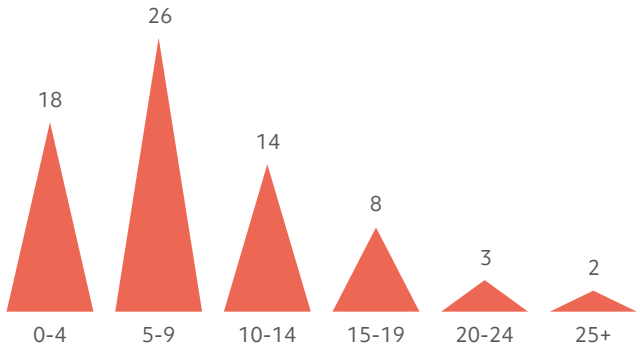
SIMONS SEARCHLIGHT

Simons Searchlight Registry Update **CSNK2A1/OCNDS**

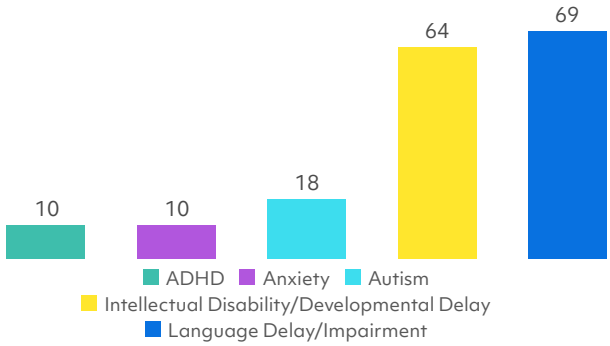
Data in these four graphs are from the medical history information collected in Simons Searchlight from 71 participants with CSNK2A1 (Okur-Chung Neurodevelopmental Syndrome, OCNDS).

April 2024

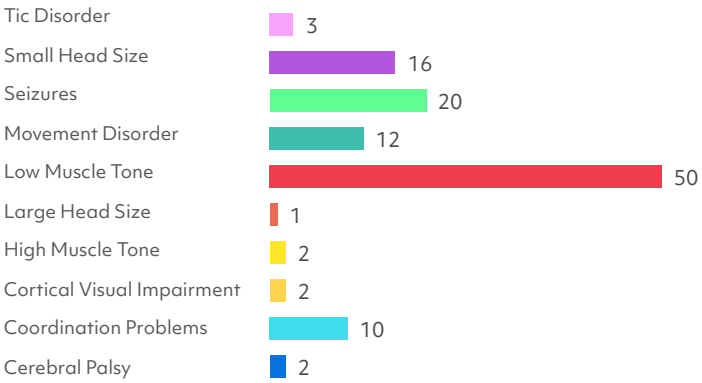
Ages in Years



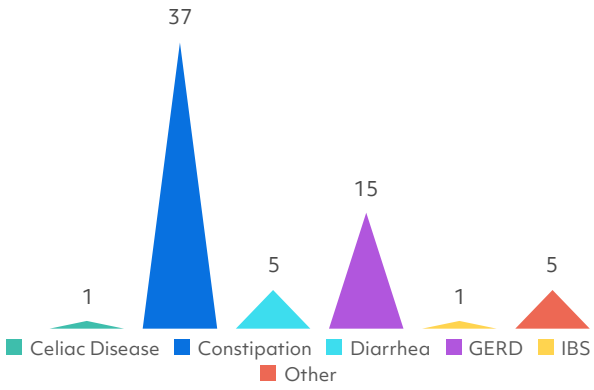
Developmental and Behavioral Conditions



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.

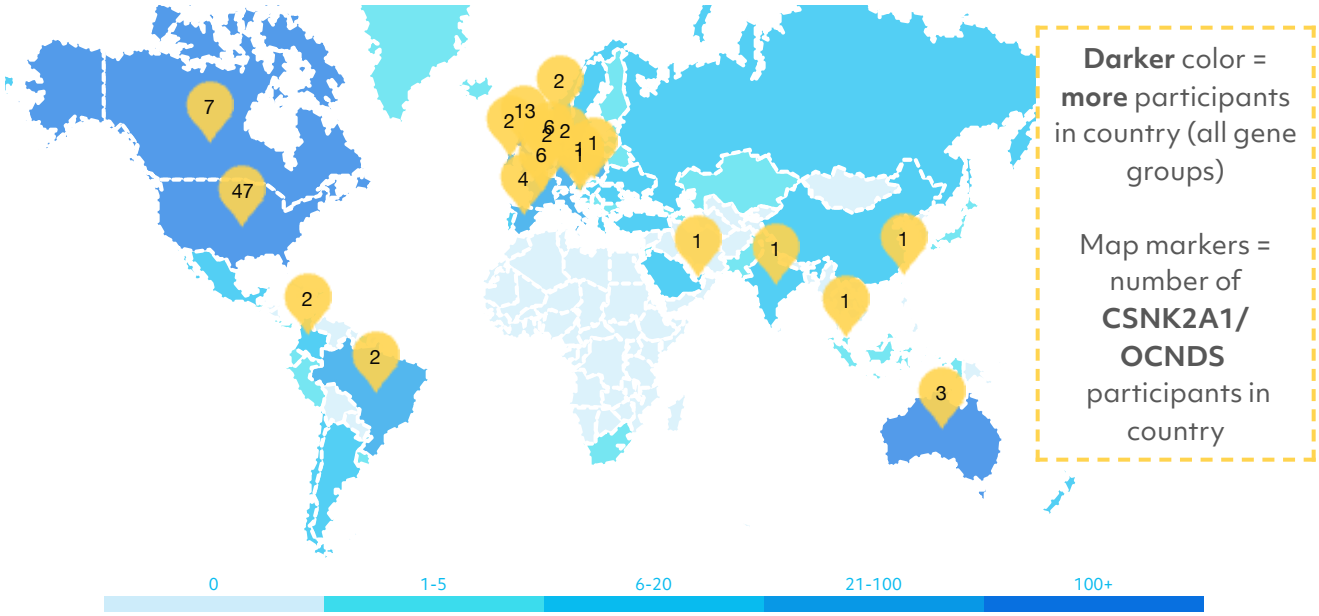
How to participate?

The information in this report is made possible by the active participation of the CSNK2A1/OCNDS community! Progress for individuals in your community with CSNK2A1/OCNDS 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.

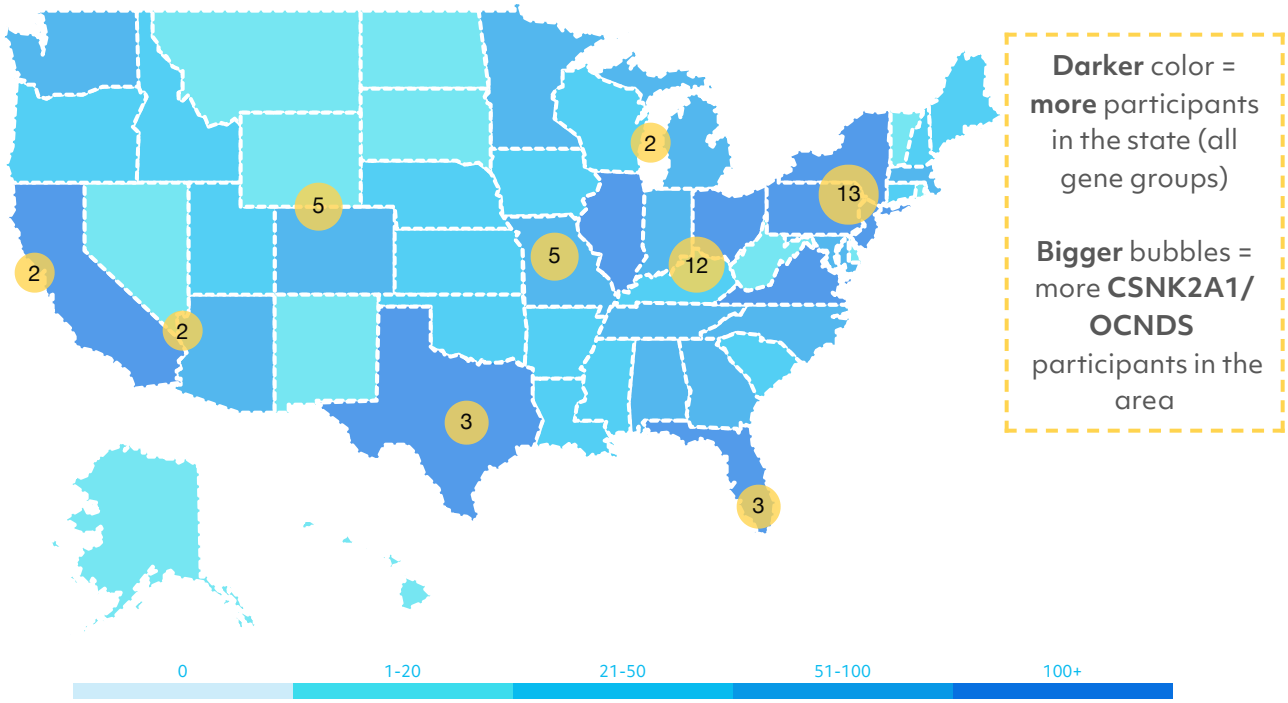
STEP 1	STEP 2	STEP 3	STEP 4	STEP 5	STEP 6
Sign up online	Provide your genetic lab report	Share your important medical history	Fill out surveys	Provide a blood sample if you are interested	Update us every year
129	105	79	92	24	Log in to see next steps

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

Simons Searchlight families live in **75** countries globally, including **105 CSNK2A1/OCNDS** participants in **20** countries.



Most Simons Searchlight families live in the United States. See where **47 CSNK2A1/OCNDS** participants live across the 50 states.



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

SIMONS SEARCHLIGHT