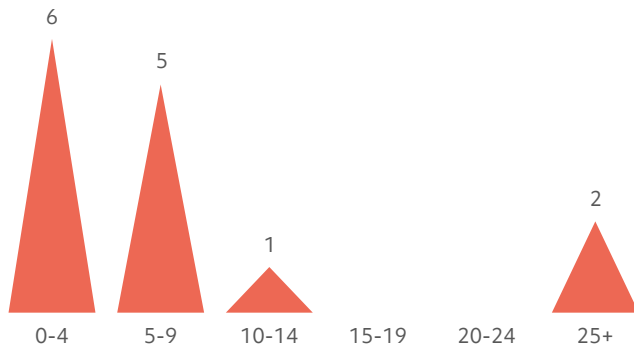


# Simons Searchlight Registry Update CLCN4

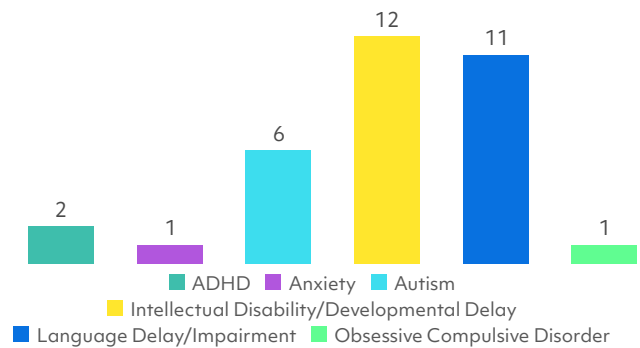
Data in these four graphs are from the medical history information collected in Simons Searchlight from 14 participants with CLCN4 (Raynaud-Claes syndrome).

April 2024

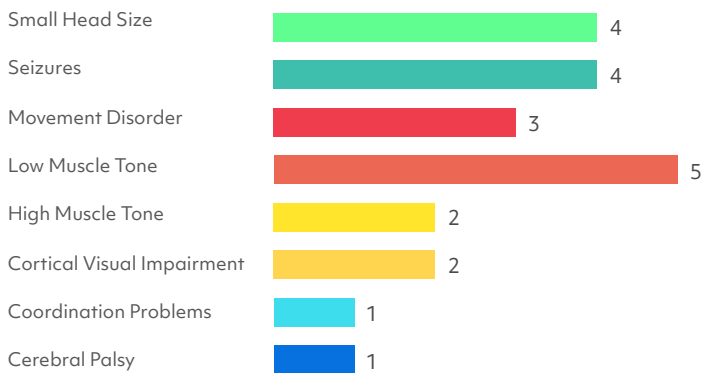
## Ages in Years



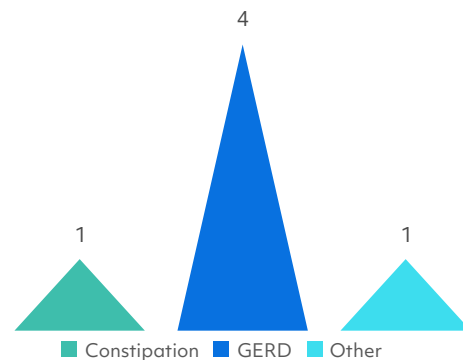
## Developmental and Behavioral Conditions



## 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 CLCN4 community! Progress for individuals in your community with CLCN4 is shown below - log in to your [simonssearchlight.org](https://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

48



### STEP 2

Provide your genetic lab report

30



### STEP 3

Share your important medical history

18



### STEP 4

Fill out surveys

19



### STEP 5

Provide a blood sample if you are interested

5



### STEP 6

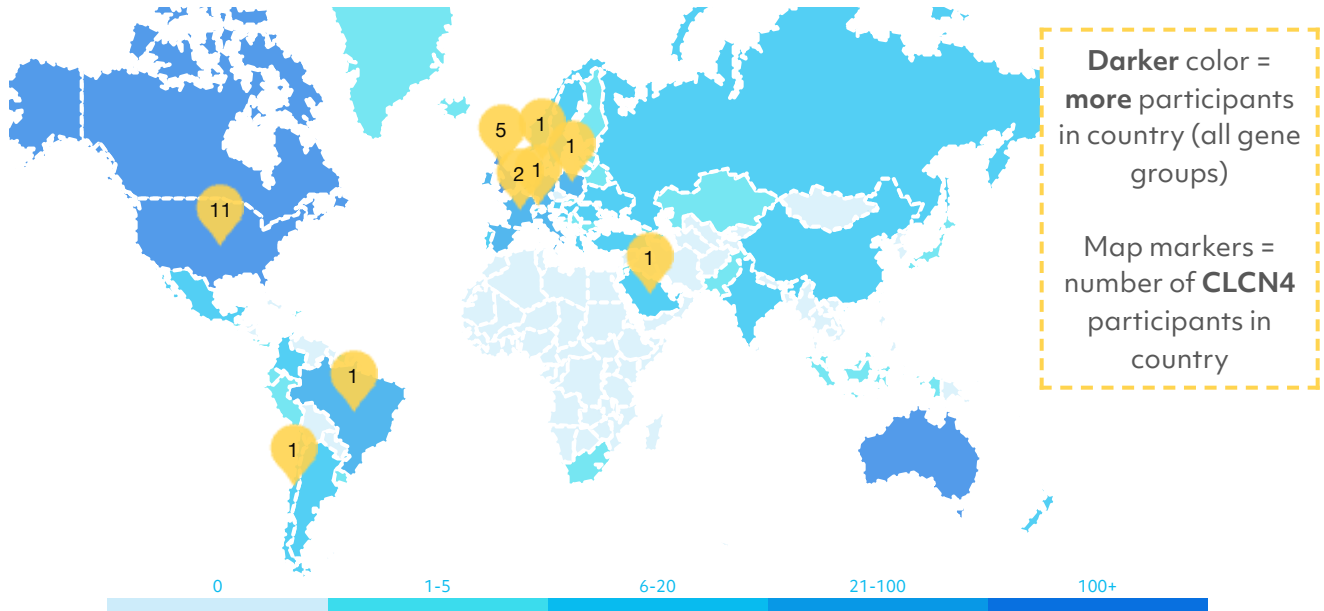
Update us every year

Log in to see next steps

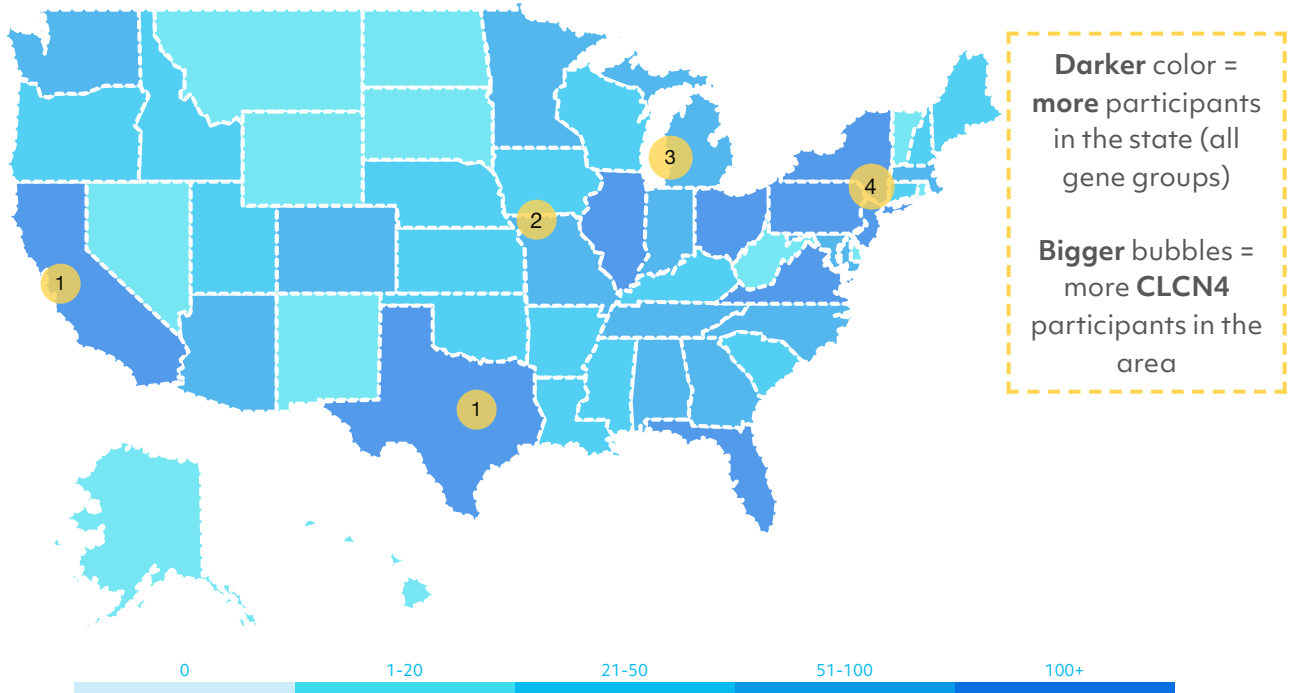
# Information Spotlight: Where in the world are Simons Searchlight families?



Simons Searchlight families live in **75** countries globally, including **24 CLCN4** participants in **9** countries.



Most Simons Searchlight families live in the United States. See where **11 CLCN4** participants live across the 50 states.



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