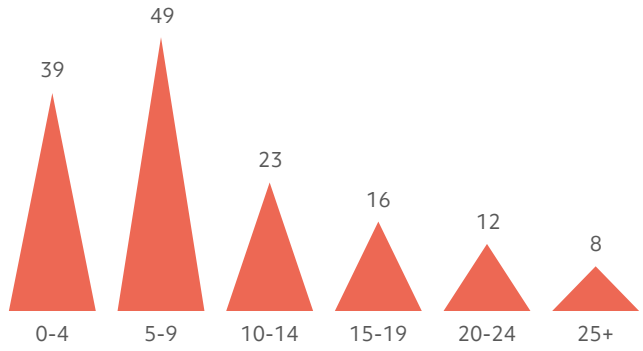
SIMONS SEARCHLIGHT

Simons Searchlight Registry Update **STXBP1**

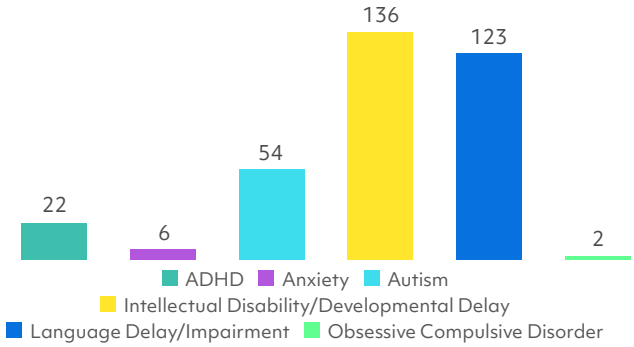
Data in these four graphs are from the medical history information collected in Simons Searchlight from 147 participants with STXBP1-related syndrome (STXBP1 Encephalopathy).

October 2026

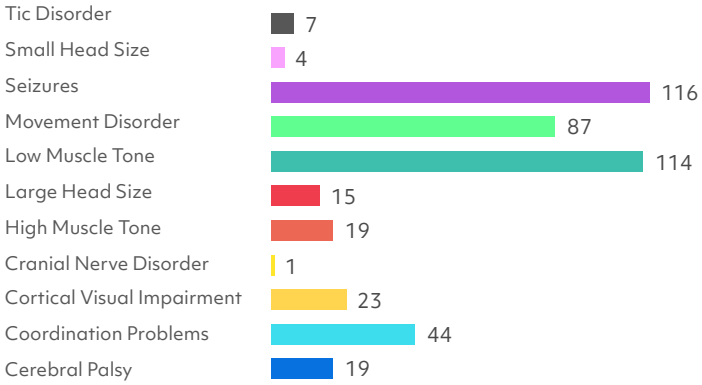
Ages in Years



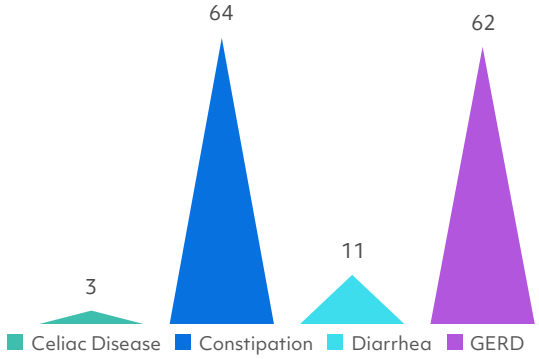
Developmental and Behavioral Conditions



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. Graphs include only individuals with pathogenic or likely pathogenic variants, and without additional variants.

How to participate?

The information in this report is made possible by the active participation of the STXBP1 community! Progress for individuals in your community with STXBP1 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
320	254	160	188	79	Log in to see next steps