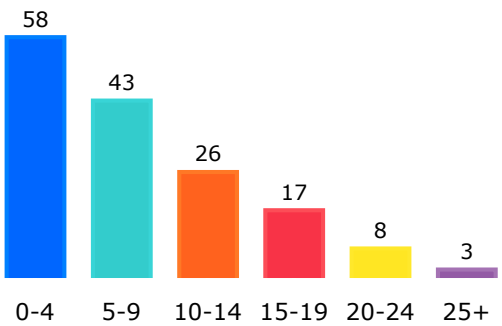
SIMONS SEARCHLIGHT

Simons Searchlight Registry Update **CTNNB1**

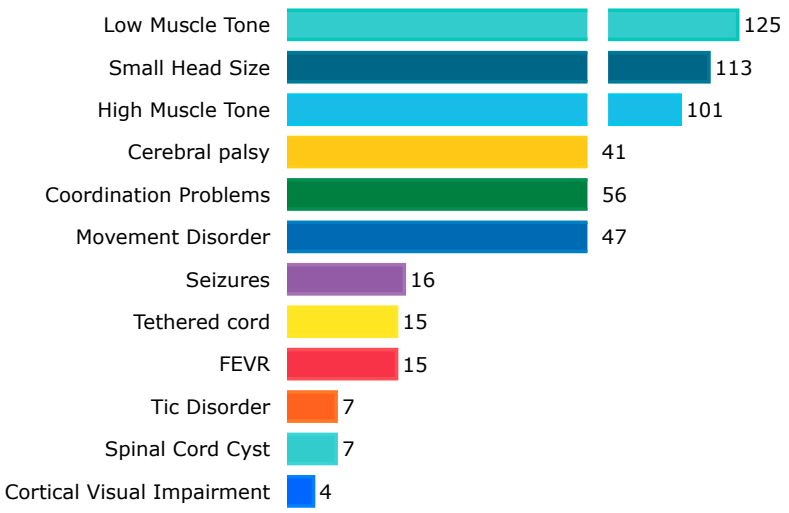
Data in these four graphs are from the medical history information collected in Simons Searchlight from **155** participants CTNNB1-related syndrome (CTNNB1-Neurodevelopmental Disorder)

July 2026

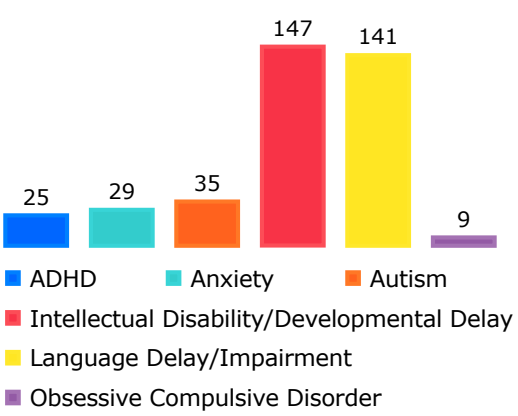
Ages in years



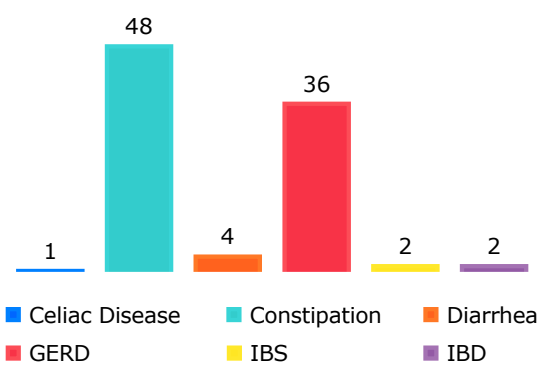
Neurological Conditions



Developmental and Behavioral Conditions



Gastrointestinal Conditions



NOTES: Graphs include only individuals with pathogenic or likely pathogenic variants (no VUS) and without additional genetic variants. Shown are counts of individuals in each category and one individual 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 CTNNB1community! Progress for individuals in your community with CTNNB1 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	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
314	252	168	205	56	Log in to see next steps