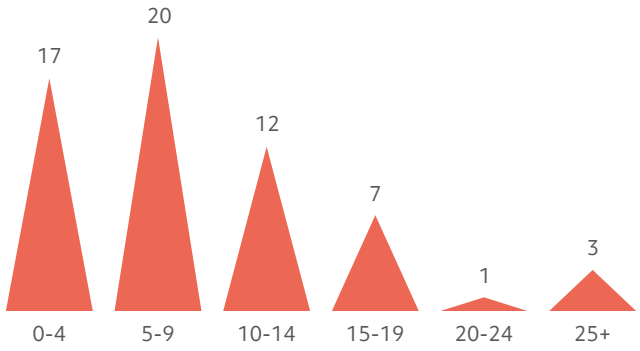
SIMONS SEARCHLIGHT

# Simons Searchlight Registry Update **DYNC1H1**

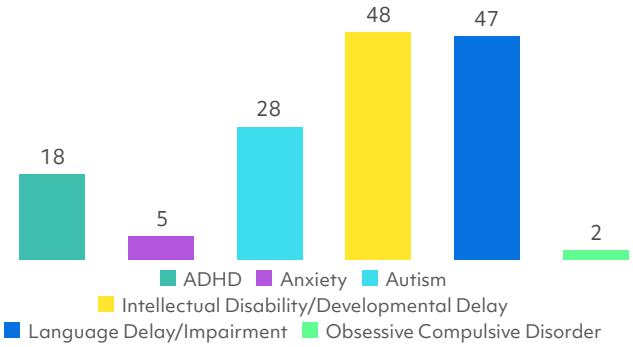
Data in these four graphs are from the medical history information collected in Simons Searchlight from 60 participants with DYNC1H1-related syndrome.

**October 2026**

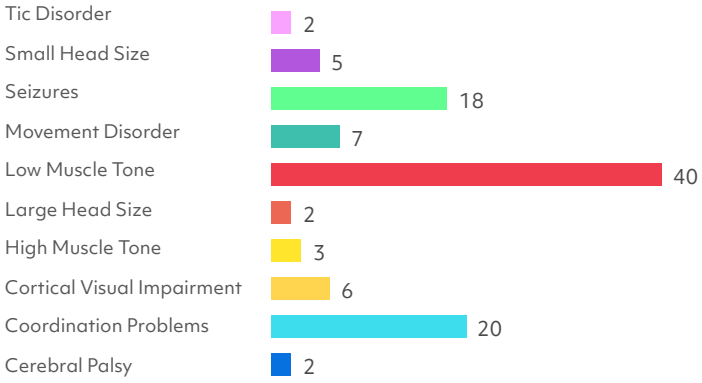
## Ages in Years



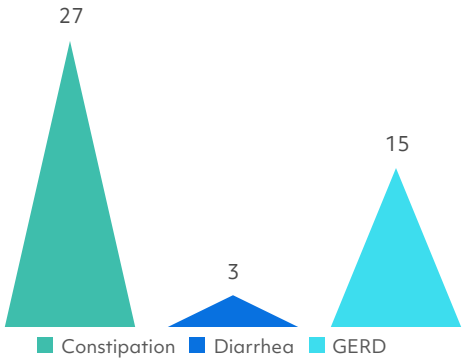

## Developmental and Behavioral Conditions




## 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 DYNC1H1 community! Progress for individuals in your community with DYNC1H1 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 |
| 157 | 132 | 84 | 108 | 13 | Log in to see next steps |