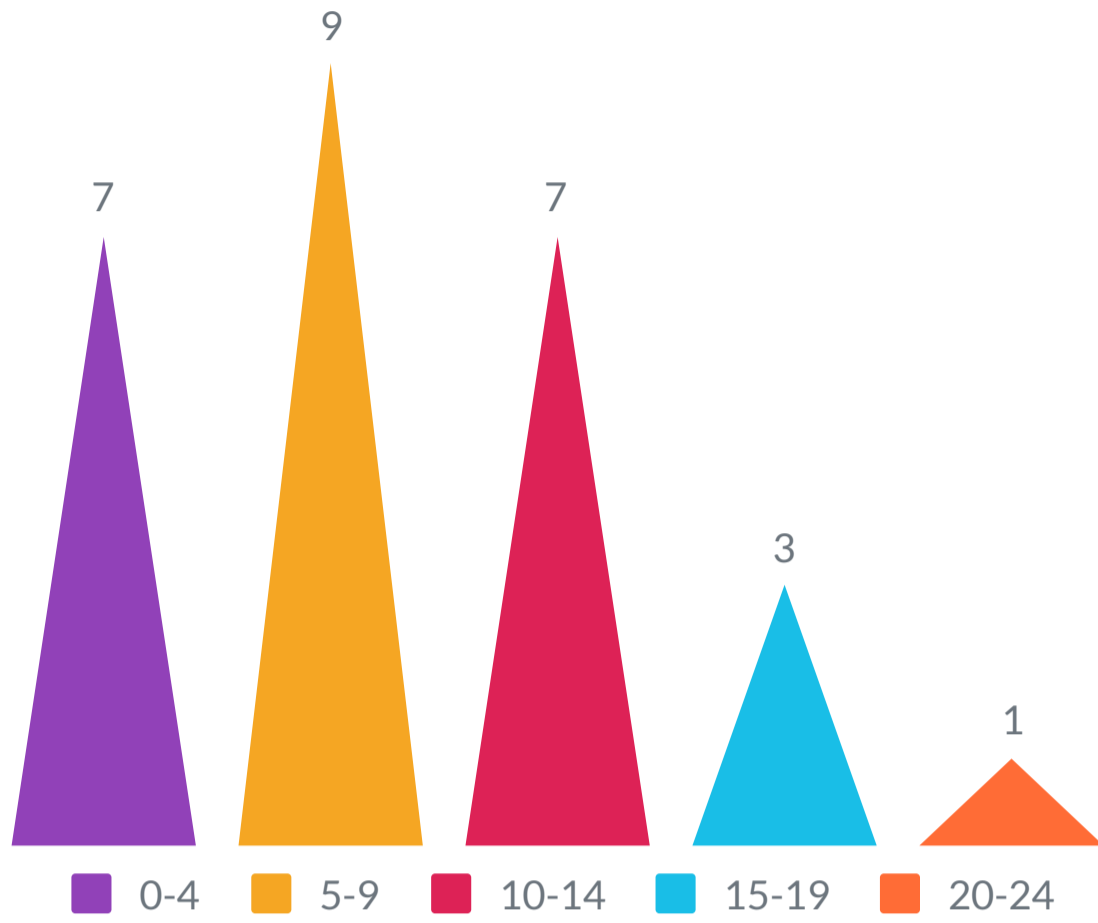


# Simons Searchlight Registry Update CSNK2A1 (Okur-Chung Syndrome)

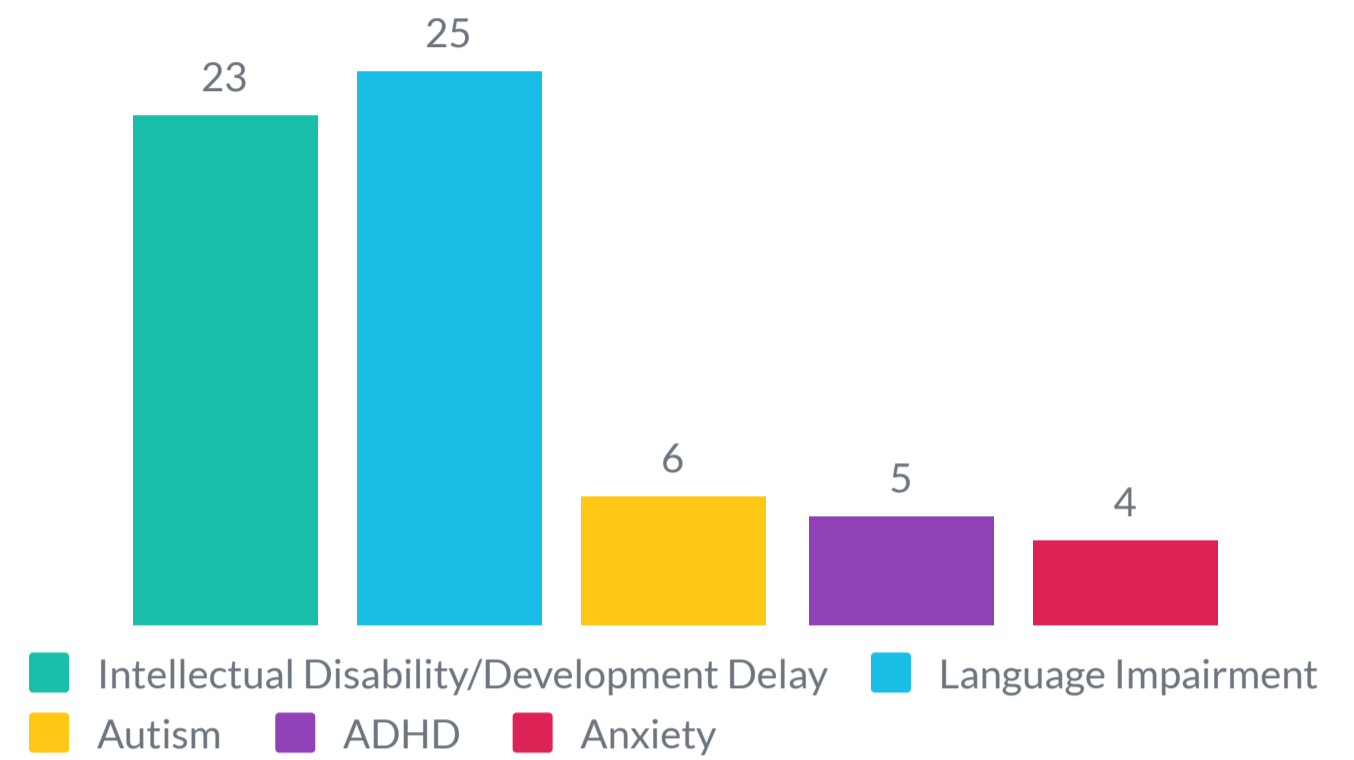
June 2021

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 27 participants with Okur-Chung Syndrome (OCNDS).

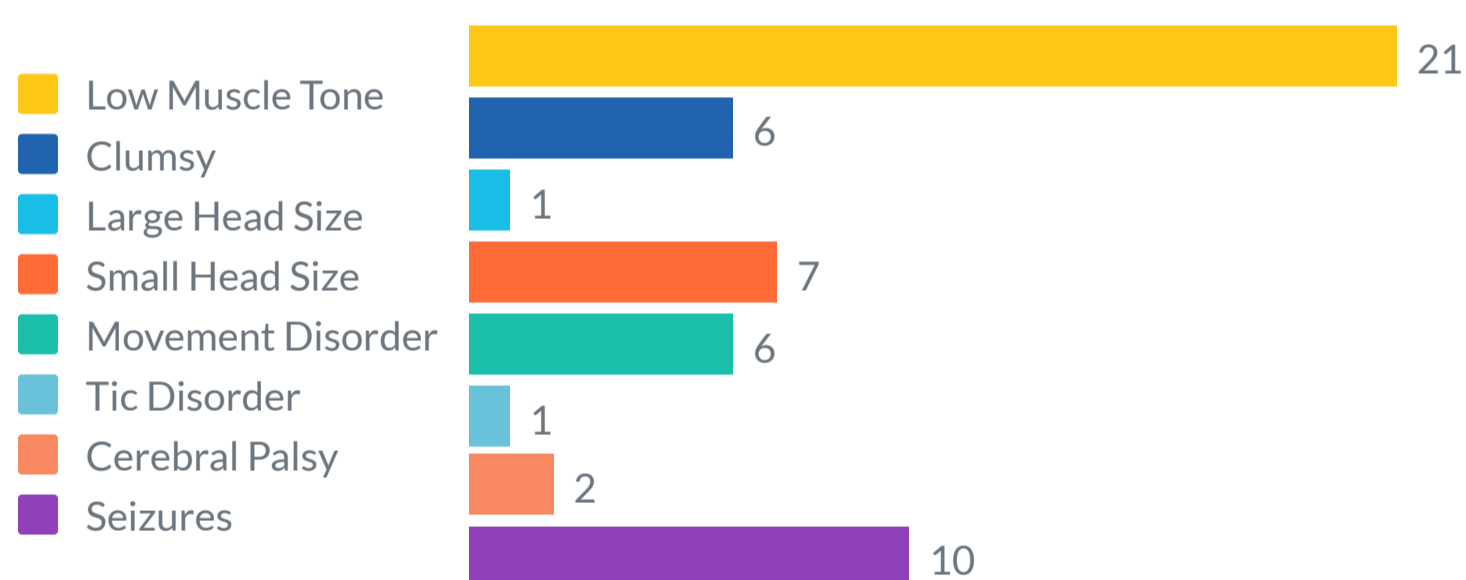
## Ages in Years



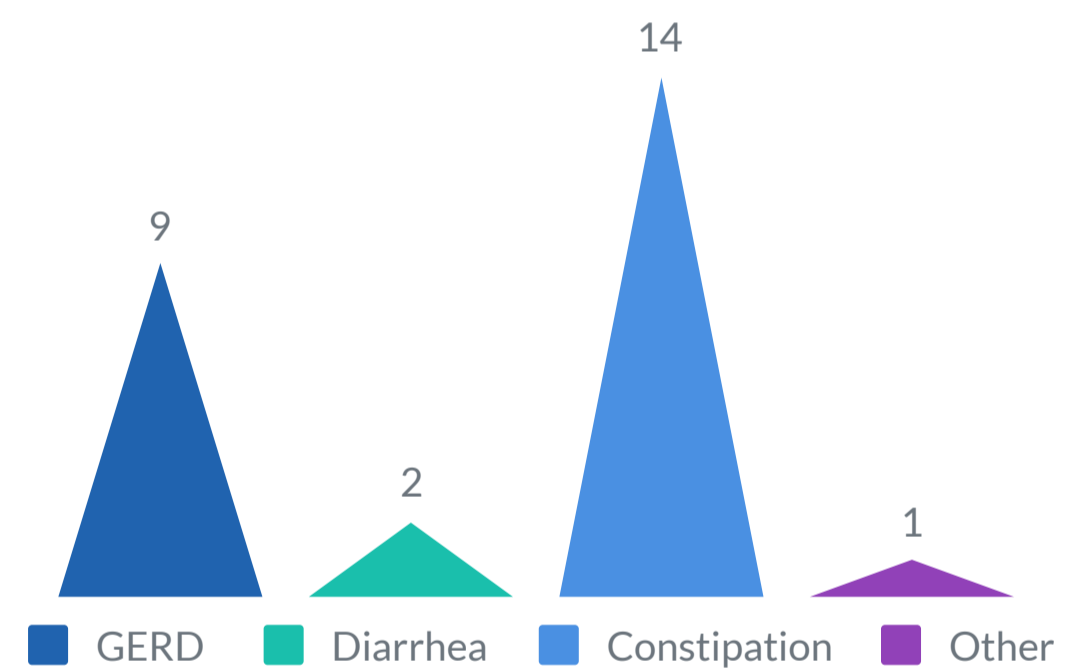
## Developmental & Behavioral Diagnoses



## Neurological Problems



## Gastrointestinal Problems



Notes:

- Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.
- Information on reported seizure types is included on the 2021 quarter 1 registry report available on [simonssearchlight.org/CSNK2A1](https://simonssearchlight.org/CSNK2A1)

## Participation & Registration

This ever-growing database is made possible by the active participation of the OCNDS community! Progress for individuals in your community with a CSNK2A1 variant is shown below -- log in to your [simonssearchlight.org](https://simonssearchlight.org) dashboard today to check for new surveys and other priority tasks. Your unique data could hold the clues scientists need to make progress and find answers.



# Information Spotlight: Child Behavior Checklist

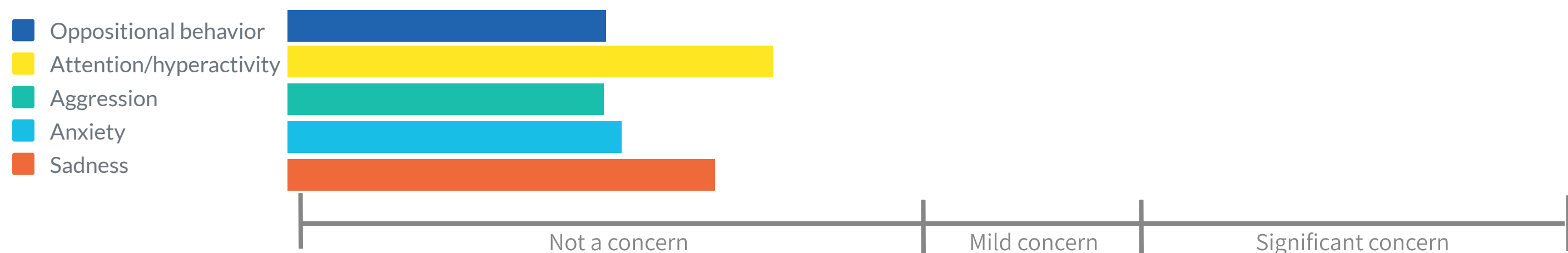
“ The Child Behavior Checklist (CBCL) is a survey used to understand behavioral and emotional concerns in children. ”

The bars in the graphs show the overall level of concern reported by Simons Searchlight caregivers who completed the CBCL survey about their children with OCNDS. Individual caregivers may have indicated a lower or higher level of concern than indicated by the overall group.

## Behavioral Concerns for ages 1.5-5yrs



## Behavioral Concerns for ages 6-18 yrs



### Top Behavioral Concerns

Ages 1.5-5 yrs



### Top Behavioral Concerns

Ages 6-18 yrs

