

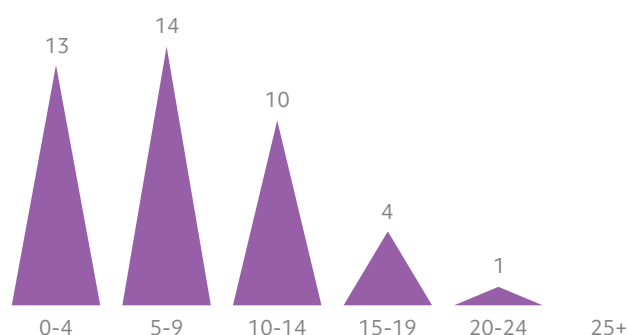
# Simons Searchlight Registry Update CSNK2A1

April, 2022

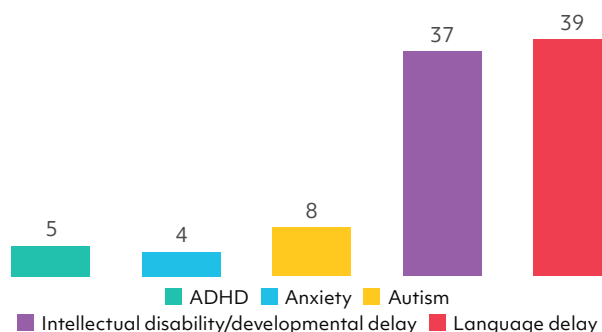
SIMONS  
SEARCHLIGHT

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 42 participants with CSNK2A1.

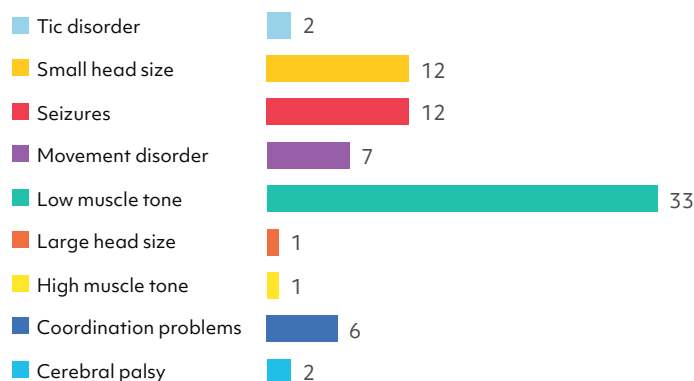
## Ages in Years



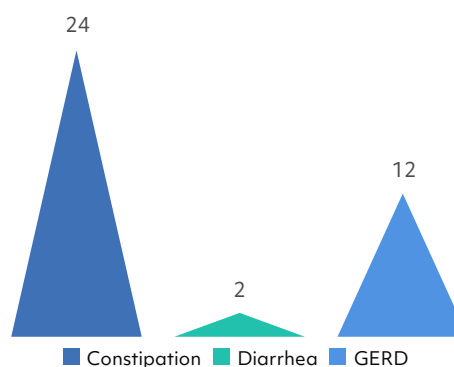
## Developmental and Behavioral Conditions



## 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.

## How to Participate

The information in this report is made possible by the active participation of the CSNK2A1 community! Progress for individuals in your community with CSNK2A1 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



80

### STEP 2

Provide your genetic lab report



65

### STEP 3

Share your important medical history



46

### STEP 4

Fill out surveys



55

### STEP 5

Provide a blood sample if you are interested



17

### STEP 6

Update us every year



Log in to see next steps

The **Quality of Life Inventory** is a scientific survey where we asked caregivers to describe how their family member with CSNK2A1 responds to life experiences.

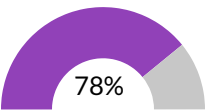
It measures quality of life by looking at the following areas: physical health, psychological well-being, social relationships, leisure, and independence.

These graphs reflect the percentage of people who reported "Often" or "Very Often" for each question.

The questionnaire was given to family members of people 2 years and older.

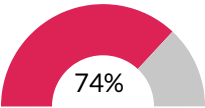
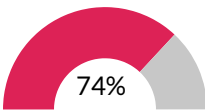
23 people with CSNK2A1 are shown.

**Health & Well-being**



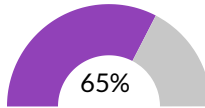
Has energy for daily activities

Is in good health



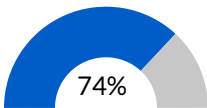
Is alert and aware

Sleeps well

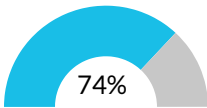


**Feelings & Emotions**

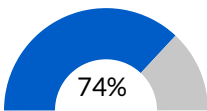
In a good mood



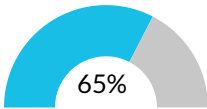
Smiles



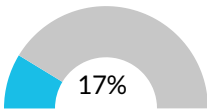
Expresses happiness using body language



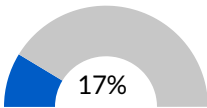
Laughs or giggles



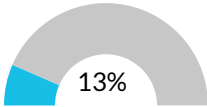
Unsettled for no reason



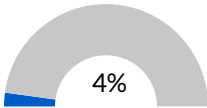
Displays aggression



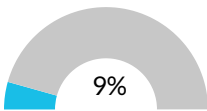
Feels upset or angry



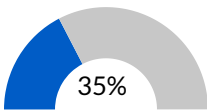
Withdrawn, low mood



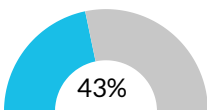
Intentionally self harms



Dislikes changes in routine



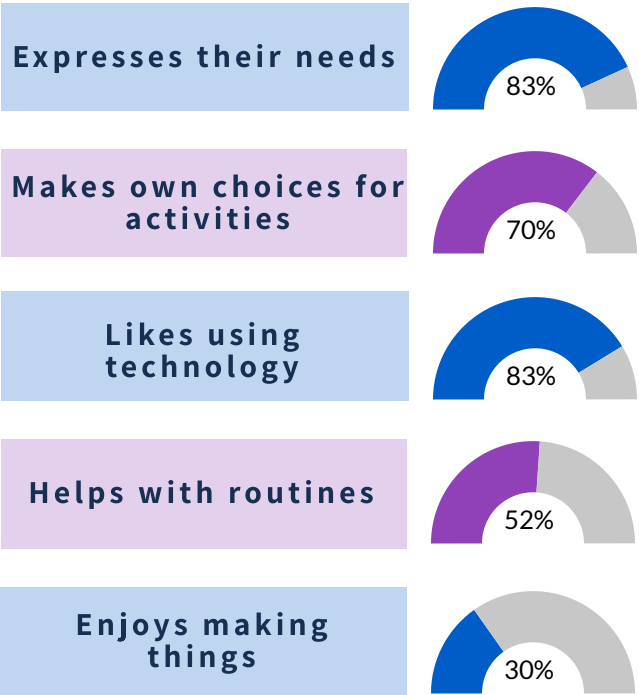
Displays anxiety or agitation



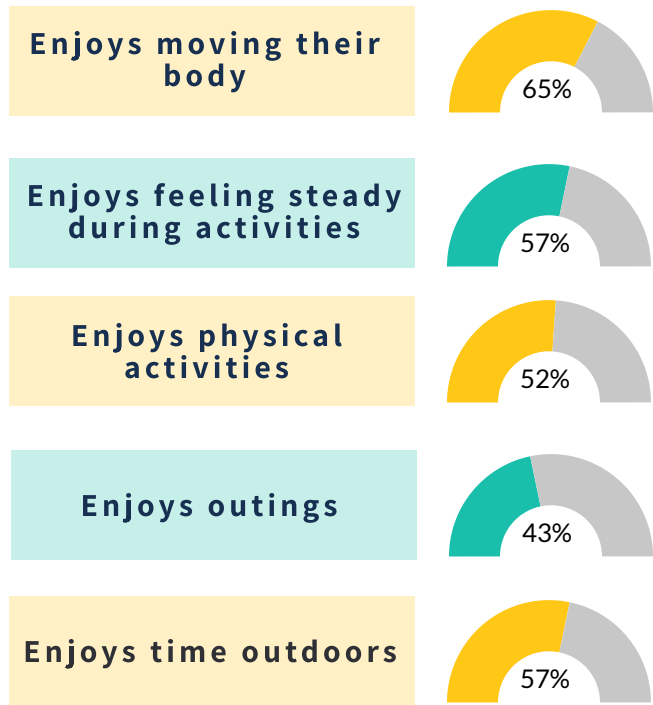
"Quality of life is a common survey of patient-centered outcomes in clinical trials and natural history studies."

- Alison Holbrook, PhD

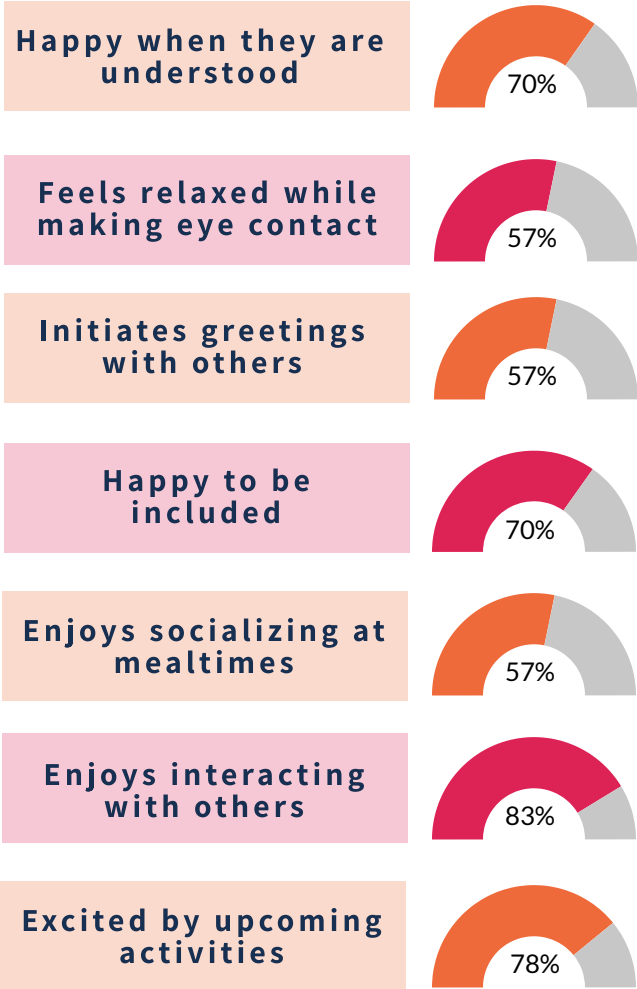
Daily Life



Activities & the Outdoors



Family & Friends



Thank you

for contributing knowledge to Simons Searchlight!