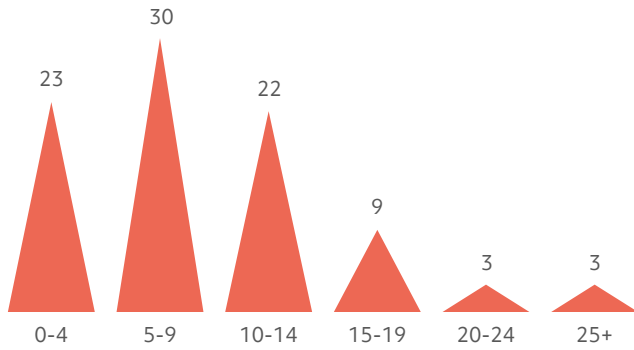


# Simons Searchlight Registry Update CSNK2A1/OCNDS

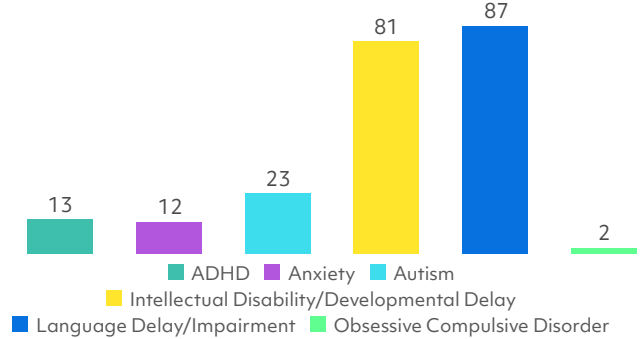
Data in these four graphs are from the medical history information collected in Simons Searchlight from 90 participants with CSNK2A1 (Okur-Chung Neurodevelopmental Syndrome, OCNDS).

April 2025

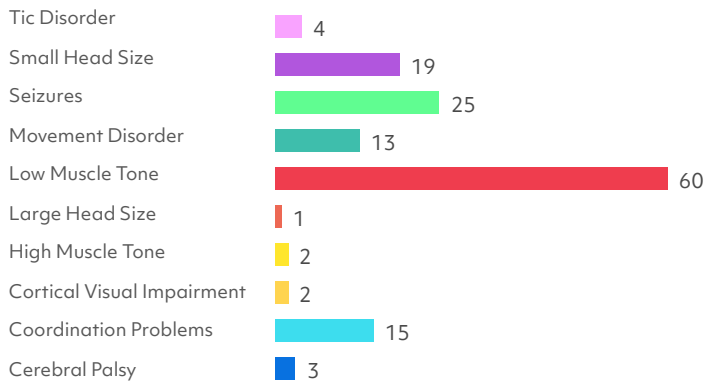
## Ages in Years



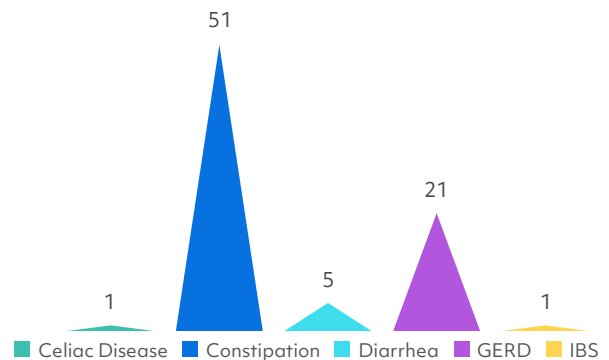
## Developmental and Behavioral Conditions



## 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 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 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

169



### STEP 2

Provide your  
genetic  
lab report

143



### STEP 3

Share your  
important  
medical history

107



### STEP 4

Fill out  
surveys

125



### STEP 5

Provide a blood  
sample if you are  
interested

30



### STEP 6

Update us  
every year

Log in to see  
next steps

# Information Spotlight: Deeper Dive into Development

We use a standardized measure called the Vineland Adaptive Behavior Scales (Vineland-3) to measure each person's development in communication, self-care, social skills, and in younger children, motor skills.

We can learn how skills develop over time by looking at growth charts. The sample graph on the next page is an example growth chart, and the graphs afterwards show real Vineland-3 data from your community.

When we plot everyone together, we can see what people can do at younger and older ages. This is one snapshot in time. The more people fill out their Vineland over time, the more we can estimate what true longitudinal growth looks like for everyone in your community.



**61 CSNK2A1 participants  
contributed Vineland-3  
data to this report**



**Scan the QR code below or click the following link**  
**([www.bit.ly/Searchlight\\_Vineland\\_Graph](http://www.bit.ly/Searchlight_Vineland_Graph))** for a video from Dr. LeeAnne Green Snyder, former Clinical Research Scientist for Simons Searchlight, on how to read the Vineland Adaptive Behavior Scales growth charts.



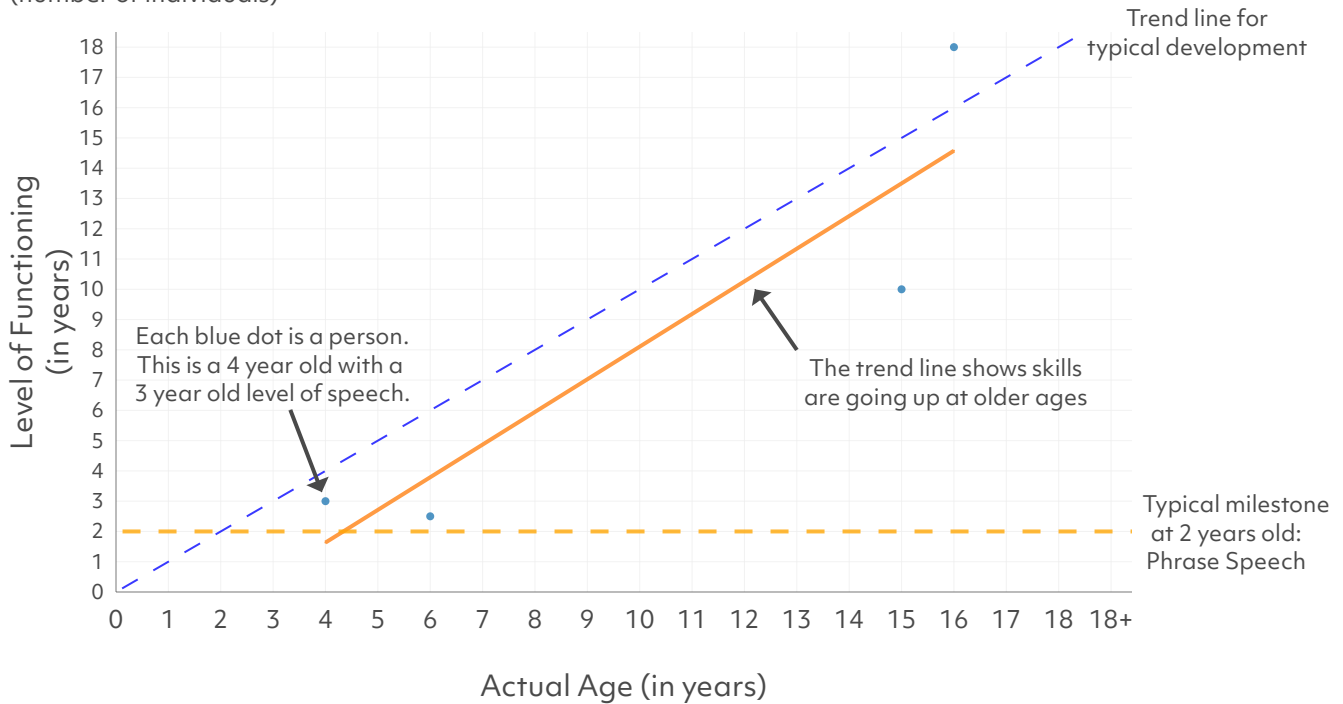
We will continue to collect Vineland data every year. Over time, we will have a better understanding of how individuals with CSNK2A1 change as they get older

Kindly note that these charts are from self-reported online research surveys and errors are possible. The skills shown are only estimates and may not apply to everyone. Remember that everyone develops at their own pace, and individual perspectives and responses may vary. Please let us know if you have any questions.

# Sample graph:

## Developmental Levels in Speech at Younger and Older Ages

### Expressive Language Development (number of individuals)



**What does  
this mean as  
my child gets  
older?**

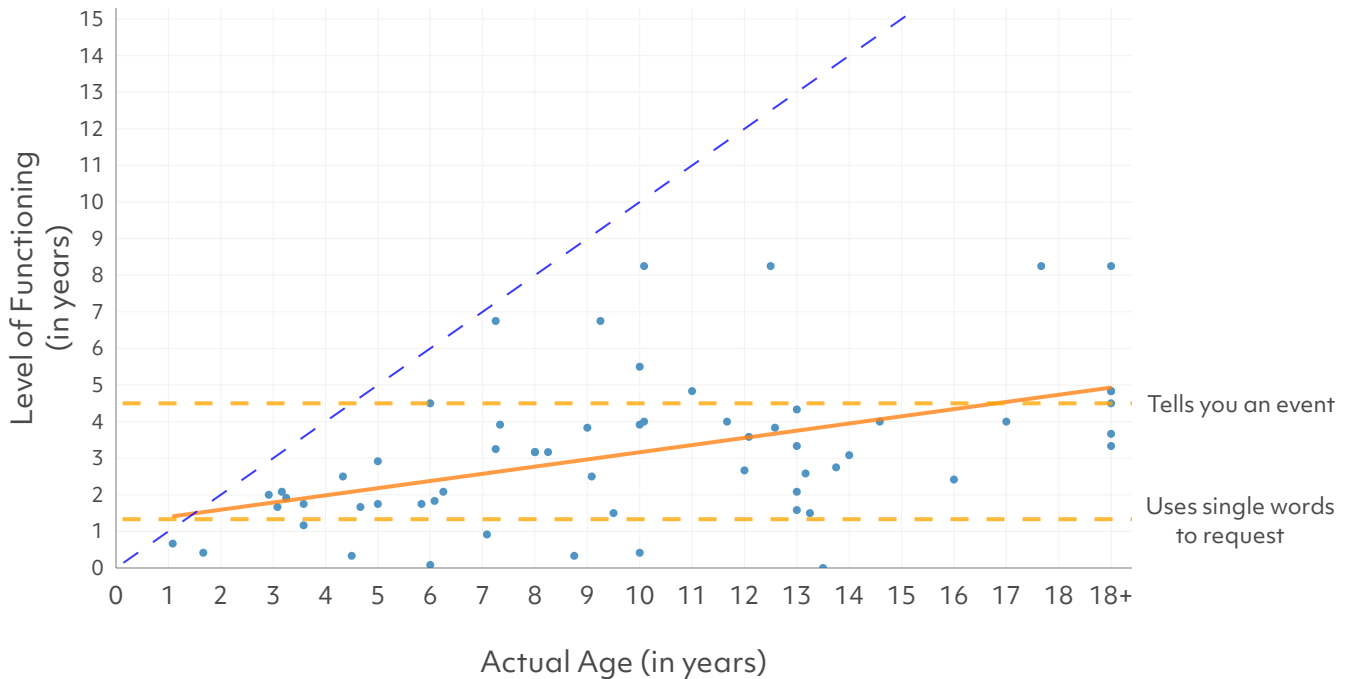
Along the  
bottom is the  
actual age of  
the person.

The dots are  
placed at the level  
at which they are  
expressing  
themselves.

A percentage of  
individuals are  
likely to be using  
language at age 4  
and older.

# Developmental Levels in Speech at Younger and Older Ages in CSNK2A1

## Expressive Language Development (60 individuals)



1 participant excluded as a potential outlier, defined here by level of functioning in years exceeding actual age in years.

**What does  
this mean as  
my child gets  
older?**

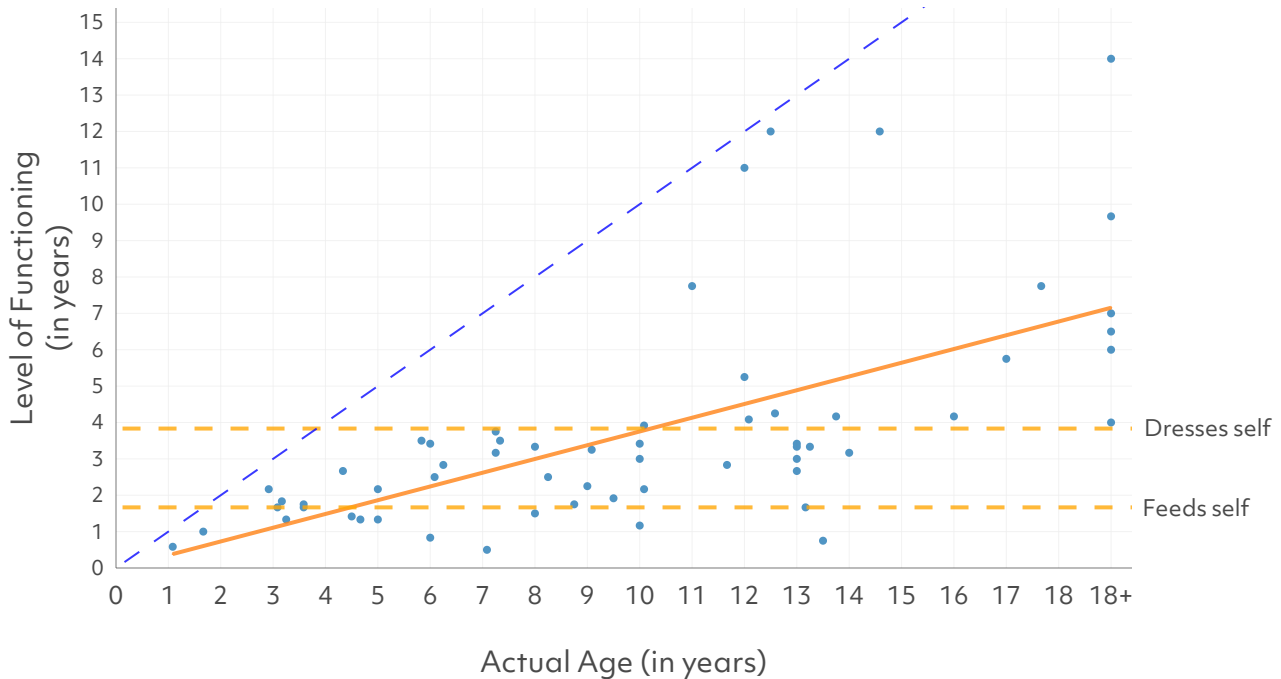
Along the  
bottom is the  
actual age of  
the person.

The dots are  
placed at the level  
at which they  
express  
themselves.

88% of individuals  
are likely to be  
using language at  
age 4 and older.

# Developmental Levels in Self Care at Younger and Older Ages in CSNK2A1

## Self Care Skills Development (60 individuals)



1 participant excluded as a potential outlier, defined here by level of functioning in years exceeding actual age in years.

**What does  
this mean as  
my child gets  
older?**

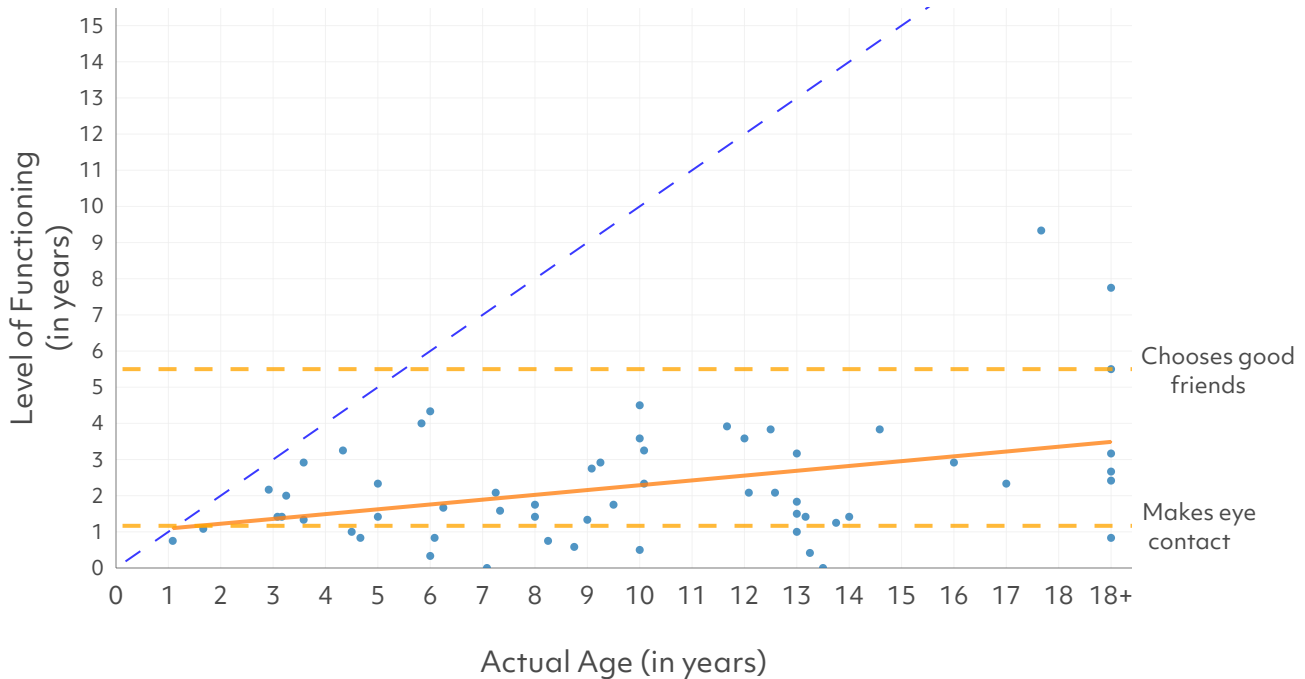
Along the  
bottom is the  
actual age of  
the person.

The dots are  
placed at the level  
at which they can  
do things for  
themselves.

85% of individuals  
are likely to be  
feeding  
themselves at age  
4 and older.

# Developmental Levels in Social Skills at Younger and Older Ages in CSNK2A1

## Social Skills Development (58 individuals)



3 participants excluded as potential outliers, defined here by level of functioning in years exceeding actual age in years.

**What does  
this mean as  
my child gets  
older?**

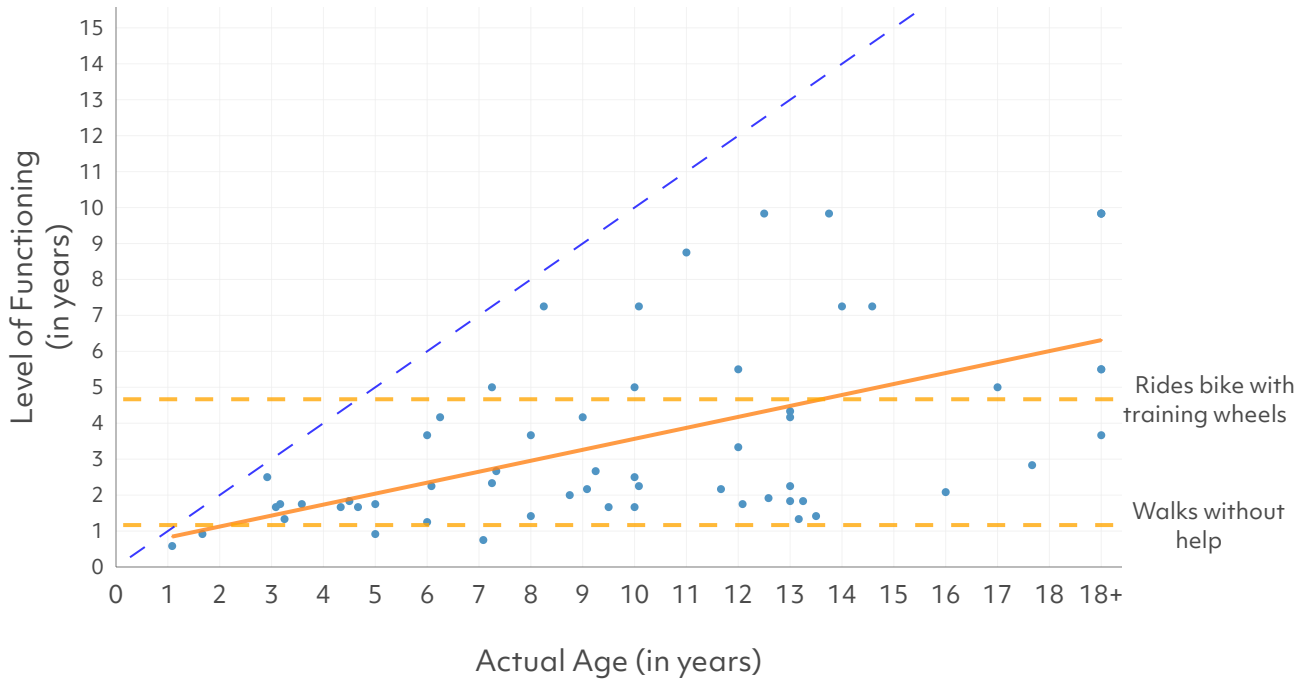
Along the  
bottom is the  
actual age of  
the person.

The dots are  
placed at the level  
of their social  
behavior.

76% of individuals  
are likely to be  
making eye  
contact at age 4  
and older.

# Developmental Levels in Motor Skills at Younger and Older Ages in CSNK2A1

## Motor Skills Development (59 individuals)



1 participant excluded as a potential outlier, defined here by level of functioning in years exceeding actual age in years.

**What does  
this mean as  
my child gets  
older?**

Along the  
bottom is the  
actual age of  
the person.

The dots are  
placed at the level  
of their motor  
skills.

96% of individuals  
are likely to be  
walking at age 4  
and older.