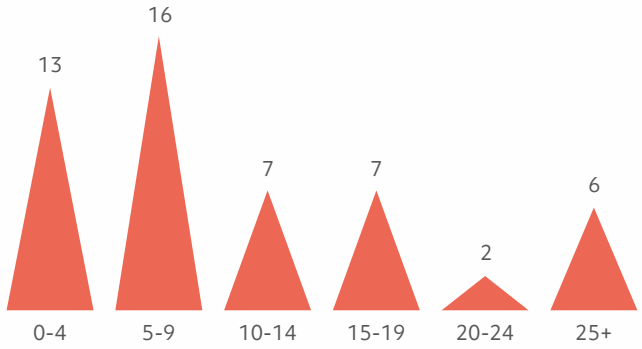
SIMONS SEARCHLIGHT

Simons Searchlight Registry Update **ASXL3 (Bainbridge-Ropers syndrome)**

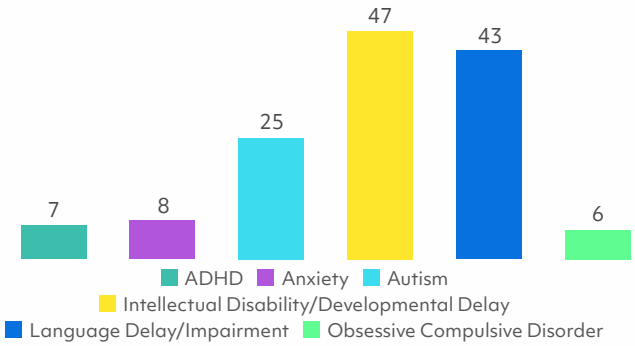
Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 51 participants with ASXL3 (Bainbridge-Ropers syndrome).

August 2023

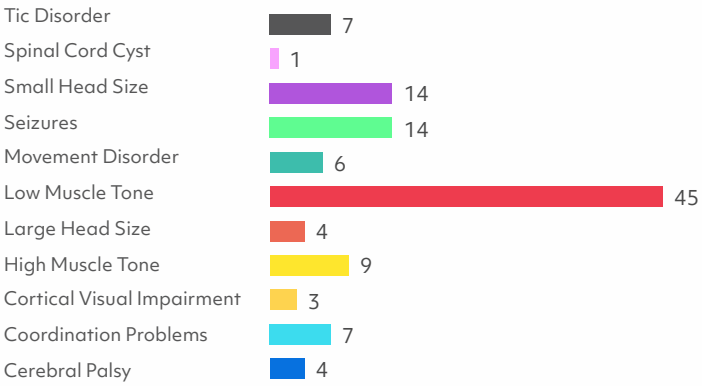
Ages in Years



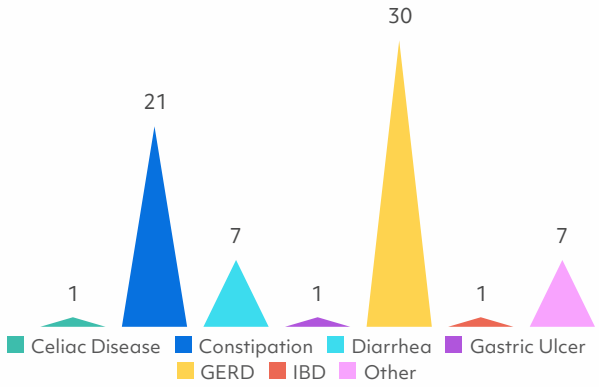
Developmental and Behavioral Conditions



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.

How to participate?

The information in this report is made possible by the active participation of the ASXL3 community! Progress for individuals in your community with ASXL3 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
115	85	60	64	27	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.

28 ASXL3 participants contributed Vineland-3 data to this report

Scan the QR code below or use the following link (bit.ly/Searchlight_Vineland_Graph) for a video from Dr. LeeAnne Green Snyder, 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 ASXL3 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.

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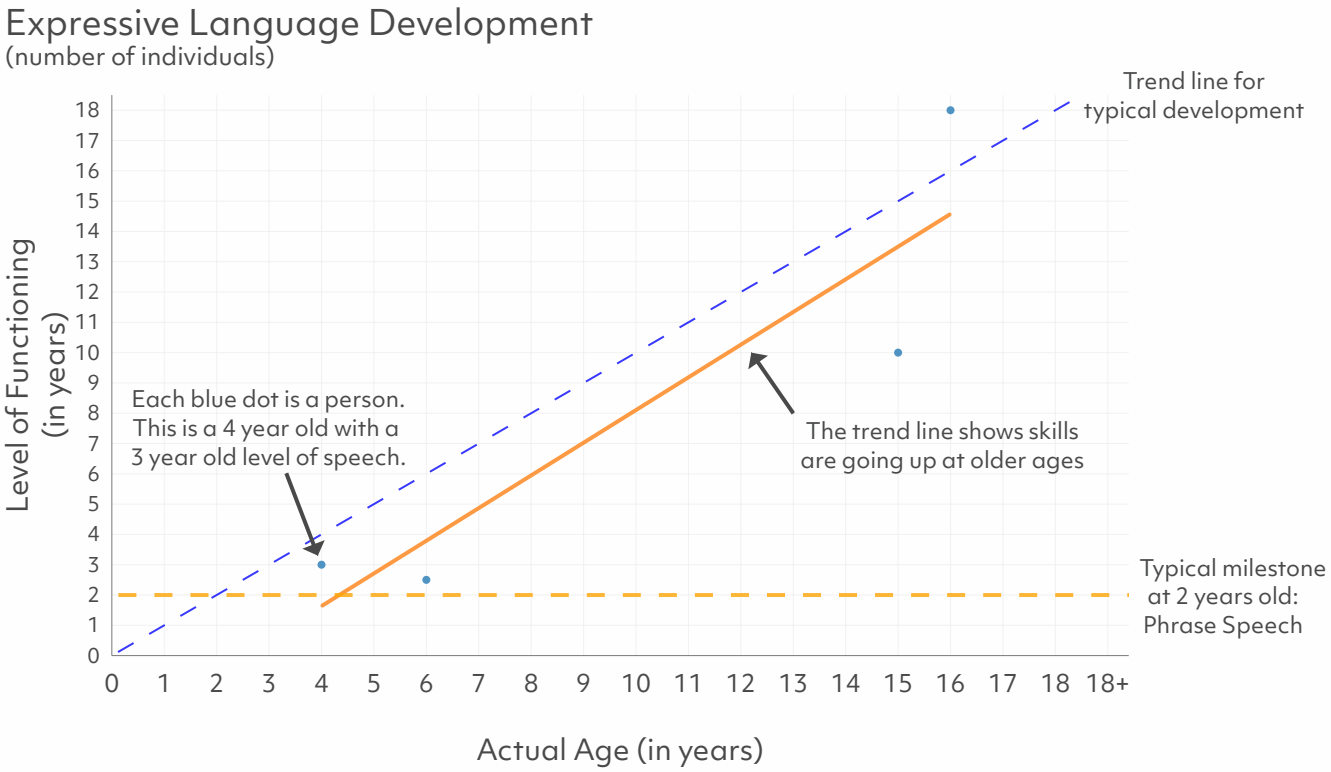
Sample graph:

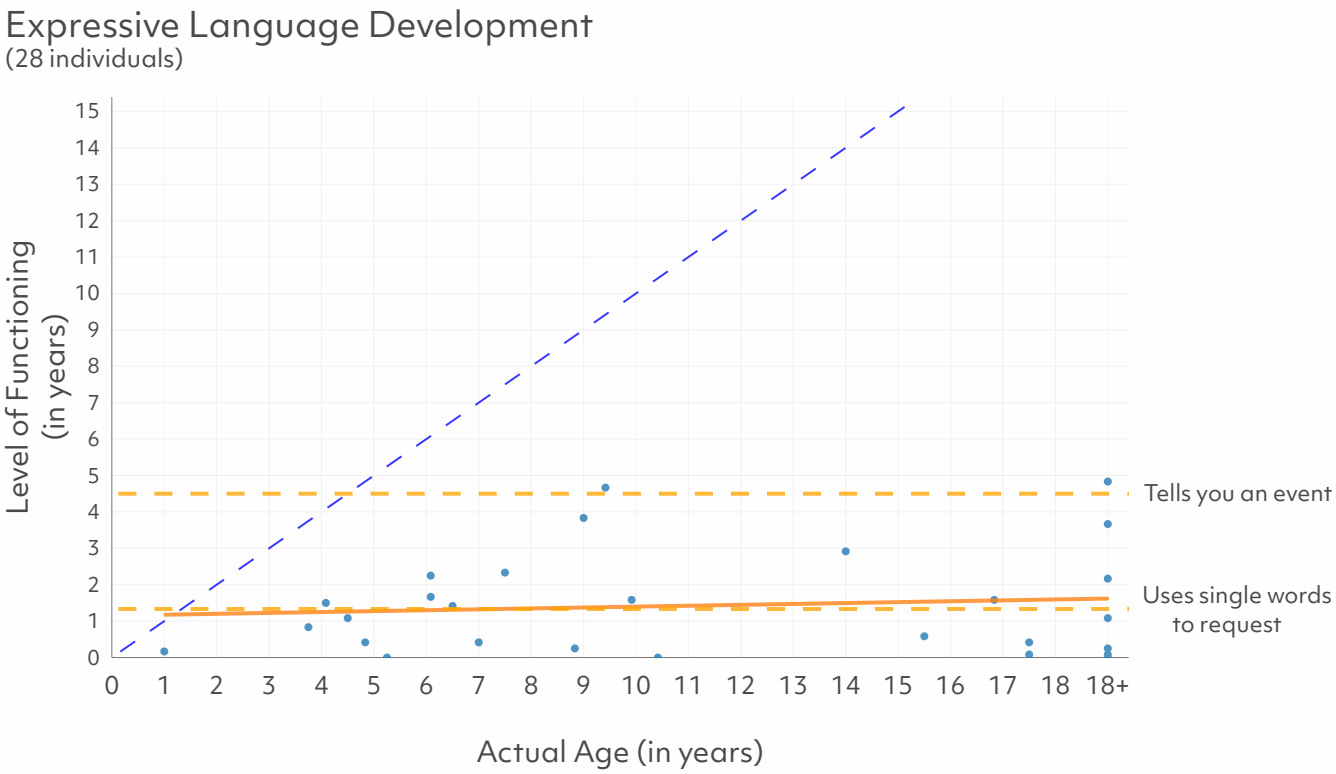
Developmental Levels in Speech at Younger and Older Ages



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 ASXL3



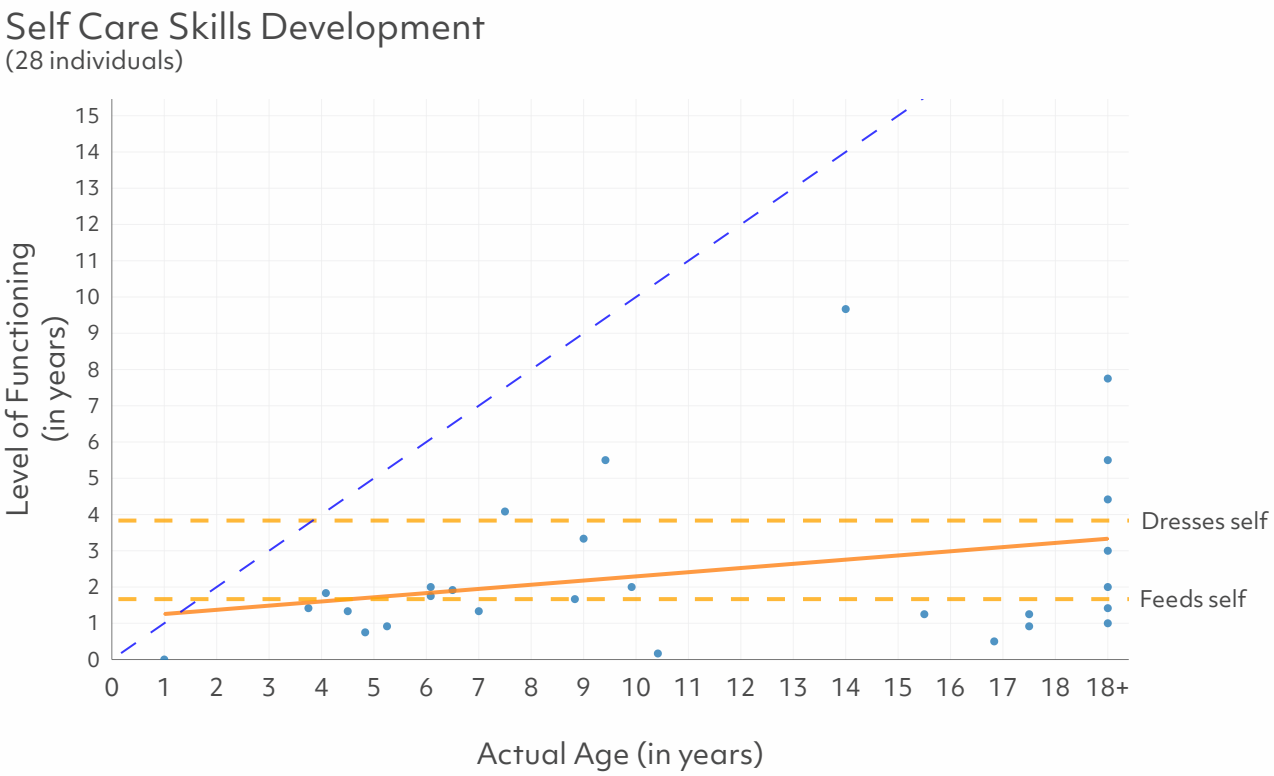
What does this mean as my child gets older?

Along the bottom is the actual age of the person.

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

50% of individuals are likely to be using language at age 4 and older.

Developmental Levels in Self Care at Younger and Older Ages in ASXL3



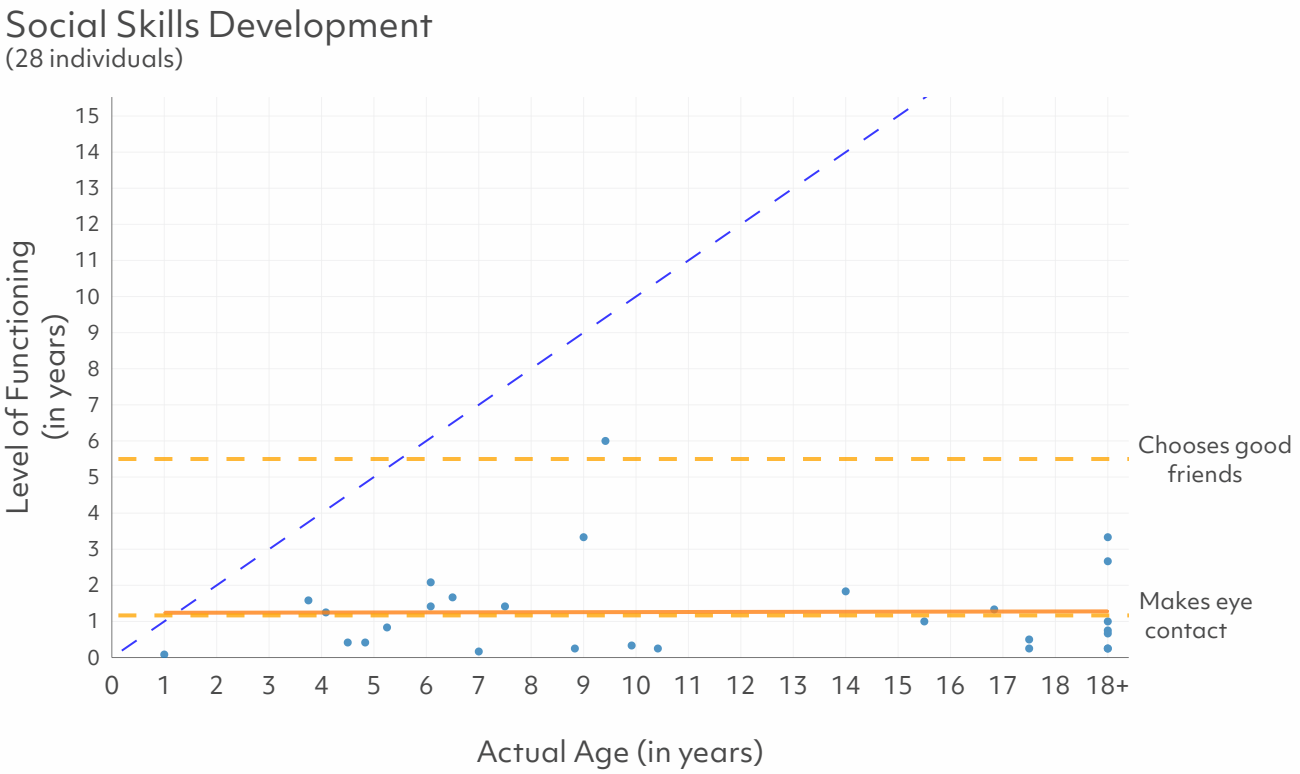
What does this mean as my child gets older?

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.

58% of individuals are likely to be feeding themselves at age 4 and older.

Developmental Levels in Social Skills at Younger and Older Ages in ASXL3



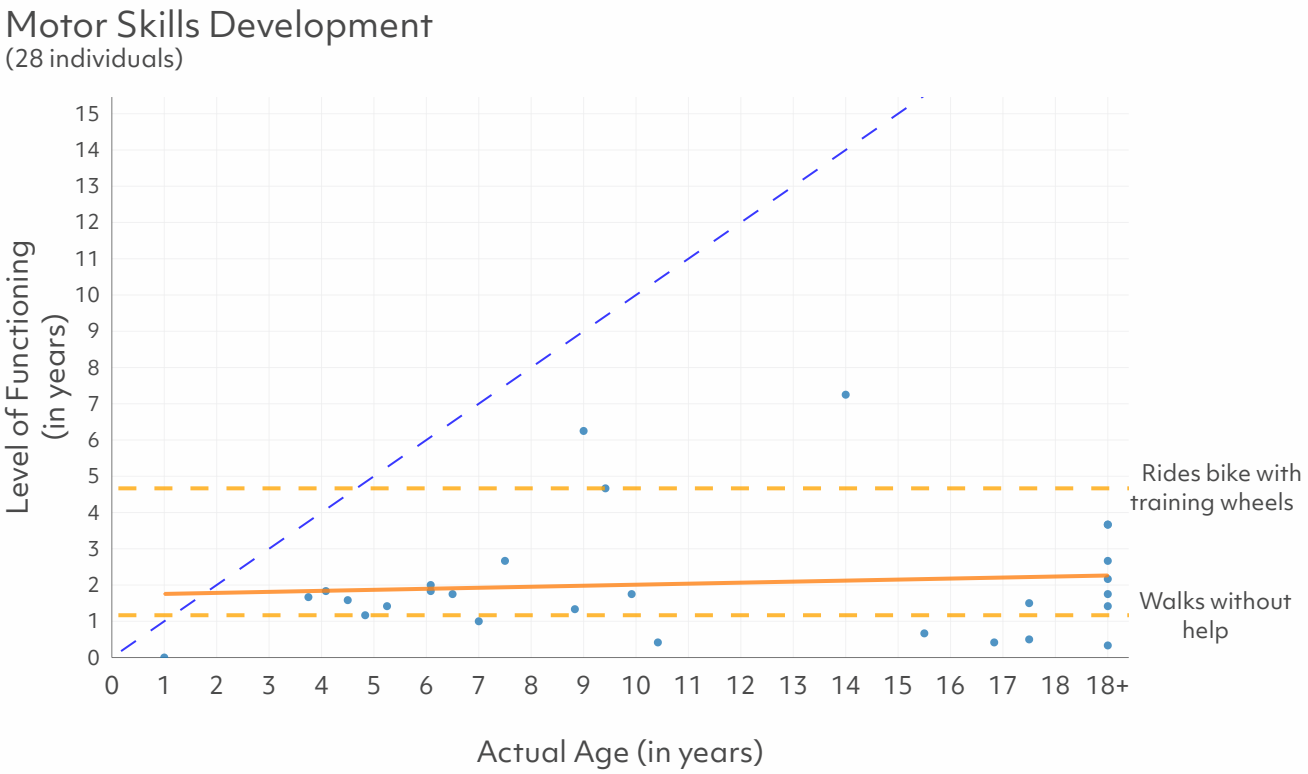
What does this mean as my child gets older?

Along the bottom is the actual age of the person.

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

42% 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 ASXL3



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.

77% of individuals are likely to be walking at age 4 and older.