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 54 participants with ASXL3 (Bainbridge-Ropers Syndrome).

October 2023

Ages in Years

Developmental and Behavioral Conditions

Note: 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
Sign up online

STEP 2
Provide your genetic lab report

STEP 3
Share your important medical history

STEP 4
Fill out surveys

STEP 5
Provide a blood sample if you are interested

STEP 6
Update us every year

Log in to see next steps

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.
The **Child Behavior Checklist (CBCL)** is a survey used for caregivers to share their concerns about their children's behaviors and emotions.

Caregivers completed the CBCL for Ages 1.5-5 (CBCL/1.5-5) for 11 children in the Simons Searchlight ASXL3 community.

### Behavioral and Emotional Concerns
Ages 1.5-5 Years (11 individuals)

- **Aggression**
- **Sadness**
- **Anxiety**
- **Attention/Hyperactivity**
- **Oppositional Behavior**

### Top Behavioral and Emotional Concerns
Ages 1.5-5 Years (11 individuals)

- Chews on non-food items
- Gets into everything
- Doesn't respond when spoken to
- Quickly moves from one activity to the next

**Tip:** Longer bars mean more concerns reported by more people.

**Tip:** Bubbles show top 4 concerns reported in the group.

Kindly note that these summaries are from self-reported online research surveys and errors are possible. The behaviors and emotions shown may not apply to everyone, and individual caregiver perspectives and levels of concern may vary. Please contact us with any questions.
The Child Behavior Checklist (CBCL) is a survey used for caregivers to share their concerns about their children's behaviors and emotions.

Caregivers completed the CBCL for Ages 6-18 (CBCL/6-18) for 20 children in the Simons Searchlight ASXL3 community.

Behavioral and Emotional Concerns
Ages 6-18 Years (20 individuals)

- Aggression
- Sadness
- Anxiety
- Attention/Hyperactivity
- Oppositional Behavior

Little to no concern | Mild | Significant concern

Tip: Longer bars mean more concerns reported by more people.

Top Behavioral and Emotional Concerns
Ages 6-18 Years (20 individuals)

- Obsessions
- Impulsive
- Frequently distracted
- Repeats certain behaviors

Tip: Bubbles show top 4 concerns reported in the group.

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