Simons Searchlight Registry Update 15q11.2 BP1-BP2 deletion

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 27 participants with a 15q11.2 BP1-BP2 deletion.

October 2023

**Ages in Years**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>9</td>
</tr>
<tr>
<td>5-9</td>
<td>3</td>
</tr>
<tr>
<td>10-14</td>
<td>1</td>
</tr>
<tr>
<td>15-19</td>
<td>4</td>
</tr>
<tr>
<td>20-24</td>
<td>10</td>
</tr>
<tr>
<td>25+</td>
<td>0</td>
</tr>
</tbody>
</table>

**Developmental and Behavioral Conditions**

- ADHD: 7
- Anxiety: 12
- Autism: 7
- Intellectual Disability/Developmental Delay: 9
- Language Delay/Impairment: 13
- Obsessive Compulsive Disorder: 3

**Neurological Conditions**

- Small Head Size: 1
- Seizures: 5
- Movement Disorder: 2
- Low Muscle Tone: 10
- Large Head Size: 3
- High Muscle Tone: 2
- Cortical Visual Impairment: 1
- Coordination Problems: 1

**Gastrointestinal Conditions**

- Constipation: 7
- Diarrhea: 5
- GERD: 9
- IBD: 1
- IBS: 3
- Other: 3

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 15q11.2 BP1-BP2 deletion community! Progress for individuals in your community with 15q11.2 BP1-BP2 deletion 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
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 5 children in the Simons Searchlight 15q11.2 BP1-BP2 deletion community.

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

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

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

- **Difficulty waiting**
- **Quickly frustrated**
- **Impatient**
- **Trouble sleeping alone**

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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 **9** children in the Simons Searchlight 15q11.2 BP1-BP2 deletion community.

### Behavioral and Emotional Concerns
Ages 6-18 Years (9 individuals)

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

![Graph showing behavioral concerns]

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

### Top Behavioral and Emotional Concerns
Ages 6-18 Years (9 individuals)

- **Obsessions**
- **Impulsive**
- **Hyperactive**
- **Specific fears (e.g. animals, places, situations)**

![Graph showing top concerns]

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

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