Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 23 participants with PACS1.

**How to Participate**

The information in this report is made possible by the active participation of the PACS1 community! Progress for individuals in your community with a PACS1 variant is shown below — log in to your [simonssearchlight.org](http://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.

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**Participant Age at Most Recent Interview**

**Developmental & Behavioral Diagnoses**

**Neurological Problems**

**Gastrointestinal Problems**

- Data in the four graphs are from the medical history phone interviews collected in Simons Searchlight on 23 participants with PACS1.

Notes:
- Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.
- Graphs show data as of the last medical history interview completed on participants who have a pathogenic or likely pathogenic variant.

#### Participant Age at Most Recent Interview

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>6</td>
</tr>
<tr>
<td>5-9</td>
<td>10</td>
</tr>
<tr>
<td>10-14</td>
<td>3</td>
</tr>
<tr>
<td>15-19</td>
<td>4</td>
</tr>
</tbody>
</table>

#### Developmental & Behavioral Diagnoses

- Intellectual Disability/Development Delay: 23
- Autism: 12
- Language Impairment: 14
- ADHD: 1
- Anxiety: 1
- OCD: 1

#### Neurological Problems

- Movement Disorder: 5
- Small Head Size: 1
- Large Head Size: 2
- Low Muscle Tone: 22
- High Muscle Tone: 4
- Clumsy: 11
- Cortical blindness: 11
- Seizures: 79

#### Gastrointestinal Problems

- GERD: 10
- Diarrhea: 1
- Constipation: 14
- IBS: 1

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Participant Age at Most Recent Interview:

- 0-4 years: 6
- 5-9 years: 10
- 10-14 years: 3
- 15-19 years: 4

**Notes:**
- Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.
- Graphs show data as of the last medical history interview completed on participants who have a pathogenic or likely pathogenic variant.
Information Spotlight: **Deeper Dive into Sleep**

**The Simons Searchlight Sleep Supplement** is a custom survey. We worked with members of the Simons Searchlight community and sleep researchers to design these questions. It asks caregivers about children's sleep habits and the impact of health issues on sleep behaviors. The survey looks at children between ages 2 and 18 years of age. 6 children with PACS1 are represented.

**Getting Enough Sleep**

- Always (16.67%)
- Usually (66.67%)
- Sometimes (16.67%)

**Children with PACS1 fall asleep in 58 minutes on average.**

**Medical issues related to sleep problems in children with PACS1***

- GI symptoms
- Mood disorder
- Medication side effects
- Sleep apnea/snoring
- Restless legs
- Pain

**Best Ways to Help Sleep: Community Recommendations***

- Medication
- Withholding naps
- Bed time routine or ritual
- Parent lying in their bed until they fall asleep

*Caregivers were able to select more than one answer

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**Thank you** for contributing knowledge to Simons Searchlight!