Data in this report are from 12 participants with DYRK1A. 6 females and 6 males are represented.

Participants were between 1 and 21 years old. The average age was 8 years.

Symptoms Reported for People with DYRK1A

Caregivers were asked to report all the current symptoms experienced by their family members with DYRK1A. A list of 32 symptoms was provided. Bars in the graph show the number of people who currently experience the symptom.

Note: People may be shown in more than one bar if they reported multiple symptoms.
If people reported having pain or discomfort as a symptom, they were asked to describe where they experienced it.

This graph shows the number of people who experienced each type of pain.

### Type of Pain or Discomfort

- Dental
- Stomach/GI/Digestive
- Skin

Caregivers were asked to rank 3 symptoms that have the most impact on them or their family members with DYRK1A. Below, we show the 3 symptoms that were reported to have the most impact.

#### 1. Intellectual disability / delay

#### 2. Limited or absent speech

#### 3. Picky eating

#### Symptoms with a High or Very High Impact

Caregivers were asked to rate the impact for every symptom experienced by their family members with DYRK1A. They rated the impact for each symptom from 'no impact' to 'very high impact.'

This table shows the number of people with DYRK1A who are either highly impacted or very highly impacted by a given symptom.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability/delays</td>
<td>10</td>
</tr>
<tr>
<td>Limited or absent speech</td>
<td>10</td>
</tr>
<tr>
<td>Gastrointestinal problems</td>
<td>7</td>
</tr>
<tr>
<td>Limited means of communication</td>
<td>5</td>
</tr>
<tr>
<td>Sensory issues</td>
<td>5</td>
</tr>
</tbody>
</table>

**Notes:**
- People may be shown in more than one row or category if they reported multiple symptoms.
- Symptoms that affected at least 5 or more people were included.
Most Challenging Daily Activities

Caregivers selected all the daily activities that are most challenging for their family members with DYRK1A. Bars in the graph show the number of people with DYRK1A that have trouble with each daily activity.

Using speech/language to communicate: 12
Independence in everyday care: 10
Using the toilet: 6
Using their hands: 5
Regular sleep: 5
Engaging in learning: 4
Nonverbal communication: 4
Feeding/eating: 3
Social interaction and participation: 2
Attending school or having a job: 2
Participating in community outings: 2
Walking: 1

Barriers to Participating in Community Outings

Mobility: 1
Sensory sensitivity: 1

If people reported difficulty participating in community outings, they were asked to describe the biggest barrier to participation.

This graph shows the most common barriers to participating in community outings.

Note: People may appear in more than one bar if they reported multiple challenges.
Important Targets for Drug Treatments

Caregivers were asked to rank 3 treatment targets that are most important to their family members with DYRK1A. This graph shows the 3 treatment targets ranked as most important.

1. Improve learning and cognitive ability
2. Improve speech / language
3. Improve eating or feeding

Simons Searchlight is grateful to all the caregivers representing their family members. This survey is an initial step to better understand the symptoms and challenges faced by your community. Your participation can help guide future research efforts to fully describe the needs and priorities of your community and plan for effective treatments.

Thank you for contributing knowledge to Simons Searchlight!