Data in this report are from 32 participants with GRIN2B. 16 females and 16 males are represented.

Participants were between 3 and 24 years old. The average age was 11 years.

Caregivers were asked to report all the current symptoms experienced by their family members with GRIN2B. A list of 32 symptoms was provided. Bars in the graph show the number of people who currently experience the symptom.

Symptoms Reported for People with GRIN2B

Intellectual disability/delay: 31
Difficulty with fine motor control: 27
Limited or absent speech: 25
Low muscle tone: 23
Limited means of communication: 20
Repetitive or rigid behavior: 20
Attention issues: 19
Sensory issues: 19
Gastrointestinal problems: 18
Difficulty with social interaction: 17
Not using toilet for urinating: 15
Not using toilet for bowel movements: 14
Feeding problems: 14
Hyperactivity: 13
Sleep problems: 13
Difficulty walking: 12
Mood swings: 12
Anxiety: 12
Self-injurious behavior: 12
Visual impairment: 11
Irritability: 10
High muscle tone: 8
Picky eating, food aversions or refusal: 8
Uncontrolled movements: 7
Epilepsy: 6
Tantrums: 5
Pain or discomfort: 4
Aggression toward others: 3
Overeating or sneaking food: 1
Apnea: 1

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**

- Eyes, ears, nose, throat: 1
- Chest: 1
- Muscular: 1
- Skin: 1
- Head: 3
- Stomach/GI/Digestive: 4

Symptoms with the Greatest Impact

Caregivers were asked to rank 3 symptoms that have the most impact on them or their family members with GRIN2B. Below, we show the 3 symptoms that were reported to have the most impact.

1. Intellectual disability / delay
2. Limited or absent speech
3. Limited means of communication

Note: People may be shown in more than one category if they reported more than one type of pain.
Symptoms with a High or Very High Impact

Caregivers were asked to rate the impact for every symptom experienced by their family members with GRIN2B. They rated the impact for each symptom from 'no impact' to 'very high impact.'

This table shows the number of people with GRIN2B who are either highly impacted or very highly impacted by a given symptom.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Impact Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability / delay</td>
<td>27</td>
</tr>
<tr>
<td>Limited or absent speech</td>
<td>23</td>
</tr>
<tr>
<td>Limited means of communication</td>
<td>17</td>
</tr>
<tr>
<td>Difficulty with fine motor control</td>
<td>15</td>
</tr>
<tr>
<td>Attention issues</td>
<td>10</td>
</tr>
<tr>
<td>Sensory issues</td>
<td>9</td>
</tr>
<tr>
<td>Difficulty with social interaction</td>
<td>9</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>9</td>
</tr>
<tr>
<td>Difficulty walking</td>
<td>9</td>
</tr>
<tr>
<td>Gastrointestinal problems</td>
<td>8</td>
</tr>
<tr>
<td>Repetitive or rigid behaviors</td>
<td>8</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>8</td>
</tr>
<tr>
<td>Feeding problems</td>
<td>8</td>
</tr>
<tr>
<td>Not using the toilet for bowel movements</td>
<td>7</td>
</tr>
<tr>
<td>Self-injurious behavior</td>
<td>7</td>
</tr>
<tr>
<td>Anxiety</td>
<td>6</td>
</tr>
<tr>
<td>Not using the toilet for urinating</td>
<td>6</td>
</tr>
<tr>
<td>Mood swings</td>
<td>6</td>
</tr>
<tr>
<td>Irritability</td>
<td>6</td>
</tr>
<tr>
<td>Low muscle tone</td>
<td>5</td>
</tr>
</tbody>
</table>

Notes:
- People may be shown in more than one row if they reported multiple symptoms.
- Symptoms that affected at least 5 or more people were included.
Caregivers selected all the daily activities that are most challenging for their family members with GRIN2B. Bars in the graph show the number of people with GRIN2B that have trouble with each daily activity.

- Independence in everyday care: 23
- Engaging in learning: 19
- Using speech/language to communicate: 19
- Social interaction and participation: 16
- Using the toilet: 14
- Using their hands: 13
- Feeding/eating: 13
- Nonverbal communication: 12
- Participating in community outings: 11
- Regular sleep: 9
- Walking: 8
- Sitting up: 8
- Attending school or having a job: 6

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.

- Mobility: 1
- Sensory sensitivity: 1
- Specialized medical supports needed: 1
- Using language for communication: 2
- Behavior: 5

Note: People may appear in more than one bar if they reported multiple challenges.
Caregivers were asked to rank 3 treatment targets that are most important to their family members with GRIN2B. This graph shows the 3 treatment targets ranked as most important.

1. Improve learning and cognitive ability
2. Improve speech / language
3. Improve behavior

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!