Data in this report are from **11 participants** with MED13L. 5 females and 6 males are represented.

Participants were between **4 and 29** years old. The average age was **11** years.

Simons Searchlight created this Voice of the Community survey to hear about the challenges that family members experience related to their genetic condition.

Researchers use Voice of the Community surveys to help inform assessment and treatment decisions from a patient-centered approach.

Symptoms Reported for People with MED13L

Caregivers were asked to report all the current symptoms experienced by their family members with MED13L. A list of 32 symptoms was provided. Bars in the graph show the number of people who currently experience the symptom.

- **Intellectual disability/delay**: 10
- **Difficulty with fine motor control**: 10
- **Limited or absent speech**: 8
- **Low muscle tone**: 8
- **Limited means of communication**: 7
- **Difficulty with social interaction**: 6
- **Repetitive or rigid behavior**: 6
- **Mood swings**: 5
- **Gastrointestinal problems**: 5
- **Not using toilet for bowel movements**: 5
- **Anxiety**: 5
- **Attention issues**: 4
- **Not using toilet for urinating**: 4
- **Picky eating, food aversions or refusal**: 4
- **Self-injurious behavior**: 3
- **Aggression toward others**: 3
- **Tantrums**: 3
- **Sensory issues**: 3
- **Feeding problems**: 3
- **Overeating or sneaking food**: 3
- **Sleep problems**: 3
- **Visual impairment**: 2
- **Difficulty walking**: 2
- **Irritability**: 2
- **Hearing impairment**: 1
- **High muscle tone**: 1
- **Hyperactivity**: 1
- **Respiratory/breathing problems**: 1

Note: People may be shown in more than one bar if they reported multiple symptoms.
Symptoms with the Greatest Impact

Caregivers were asked to rank 3 symptoms that have the most impact on them or their family members with MED13L. Below, we show the 3 symptoms that were reported to have the most impact.

1. Limited or absent speech
2. Intellectual disability / delay
3. Anxiety

Symptoms with a High or Very High Impact

Caregivers were asked to rate the impact for every symptom experienced by their family members with MED13L. They rated the impact for each symptom from 'no impact' to 'very high impact.'

This table shows the number of people with MED13L who are either highly impacted or very highly impacted by a given symptom.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability/delays</td>
<td>8</td>
</tr>
<tr>
<td>Limited or absent speech</td>
<td>7</td>
</tr>
</tbody>
</table>

Most Challenging Daily Activities

Caregivers selected all the daily activities that are most challenging for their family members with MED13L. Bars in the graph show the number of people with MED13L that have trouble with each daily activity.

- Using speech/language to communicate: 9
- Engaging in learning: 7
- Independence in everyday care: 7
- Using the toilet: 6
- Social interaction and participation: 5
- Nonverbal communication: 4
- Feeding/eating: 4
- Using their hands: 2
- Attending school or having a job: 2
- Participating in community outings: 2
- Walking: 1
- Regular sleep: 1

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.
Caregivers were asked to rank 3 treatment targets that are most important to their family members with MED13L. This graph shows the 3 treatment targets ranked as most important.

1. Improve speech / language
2. Improve learning and cognition
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!