Simons Searchlight Registry Update SLC6A1

November, 2022

Ages in Years

Developmental and Behavioral Conditions

Neurological Problems

Gastrointestinal Problems

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 SLC6A1 community! Progress for individuals in your community with SLC6A1 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
These graphs are created using data from the medical history phone interviews and seizure history surveys collected in Simons Searchlight.

**Types of Seizures reported in the Medical History Interview**

<table>
<thead>
<tr>
<th>Seizure Type</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tonic</td>
<td>1</td>
<td>0.2%</td>
</tr>
<tr>
<td>Simple partial</td>
<td>6</td>
<td>1.2%</td>
</tr>
<tr>
<td>Petit mal</td>
<td>34</td>
<td>6.7%</td>
</tr>
<tr>
<td>Myoclonic</td>
<td>24</td>
<td>4.8%</td>
</tr>
<tr>
<td>Infantile spasm</td>
<td>1</td>
<td>0.2%</td>
</tr>
<tr>
<td>Grand mal</td>
<td>5</td>
<td>1.0%</td>
</tr>
<tr>
<td>Complex partial</td>
<td>2</td>
<td>0.4%</td>
</tr>
<tr>
<td>Atonic drop attack</td>
<td>23</td>
<td>4.6%</td>
</tr>
</tbody>
</table>

- **51%** of individuals with SLC6A1 are taking seizure medication.

**Age that Seizure First Started**

- 39 individuals reported experiencing seizures before age 4.
- 5 individuals reported experiencing seizures between ages 5-9.
- 1 individual reported experiencing seizures between ages 10-14.
- 1 individual reported experiencing seizures between ages 15-19.
- 1 individual reported experiencing seizures after age 20.

*Some individuals may not have provided an age of onset.*

**Seizure Medications Reported to be Most Effective**

- Clobazam: 3 participants
- Clonazepam: 2 participants
- Lamotrigine: 2 participants
- Levetiracetam: 2 participants
- Valproic Acid: 12 participants

- **51 participants** reported experiencing seizures.

*Thank you for contributing knowledge to Simons Searchlight!*