Simons Searchlight Registry Update OCNDS

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 50 participants with OCNDS.

April 2023

**Ages in Years**

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>14</td>
</tr>
<tr>
<td>5-9</td>
<td>18</td>
</tr>
<tr>
<td>10-14</td>
<td>12</td>
</tr>
<tr>
<td>15-19</td>
<td>4</td>
</tr>
<tr>
<td>20-24</td>
<td>1</td>
</tr>
<tr>
<td>25+</td>
<td>1</td>
</tr>
</tbody>
</table>

**Developmental and Behavioral Conditions**

- ADHD: 7
- Anxiety: 6
- Autism: 10
- Intellectual Disability/Developmental Delay: 44
- Language Delay/Impairment: 47

**Neurological Problems**

- Tic Disorder: 2
- Small Head Size: 12
- Seizures: 13
- Movement Disorder: 8
- Low Muscle Tone: 37
- Large Head Size: 1
- High Muscle Tone: 2
- Cerebral Palsy: 2
- Cort Blind: 1
- Clumsy: 6

**Gastrointestinal Problems**

- Constipation: 28
- Diarrhea: 4
- GERD: 12
- Other: 1

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 OCNDS community! Progress for individuals in your community with OCNDS 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

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**STEP 2**
Provide your genetic lab report

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**STEP 3**
Share your important medical history

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**STEP 4**
Fill out surveys

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**STEP 5**
Provide a blood sample if you are interested

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**STEP 6**
Update us every year

Log in to see next steps

- 102
- 83
- 61
- 76
- 22
Information Spotlight on Development

We use a standardized measure called the Vineland Adaptive Behavior Scales (Vineland-3) to measure each person’s development in communication, self-care, social skills, and in younger children, motor skills.

The Vineland is a useful tool for researchers and doctors to see a snapshot of a person’s skills and watch how they change over time.

31 OCNDS participants ages 4 to 20 contributed to this report

Here is a look at how many OCNDS participants ages 4 to 20 years can do the following skills:

- 84% feed themselves
- 87% use functional speech
- 48% show interest in friends

Of children 4-9 years old, 100% are walking

We will continue to collect Vineland data every year. Over time, we will have a better understanding of how individuals with OCNDS change as they get older.