Simons Searchlight Registry Update ADNP
April, 2022

**Ages in Years**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>3</td>
</tr>
<tr>
<td>5-9</td>
<td>7</td>
</tr>
<tr>
<td>10-14</td>
<td>4</td>
</tr>
<tr>
<td>15-19</td>
<td>2</td>
</tr>
<tr>
<td>20-24</td>
<td>1</td>
</tr>
<tr>
<td>25+</td>
<td></td>
</tr>
</tbody>
</table>

**Developmental and Behavioral Conditions**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHD</td>
<td>3</td>
</tr>
<tr>
<td>Anxiety</td>
<td>3</td>
</tr>
<tr>
<td>Autism</td>
<td>11</td>
</tr>
<tr>
<td>Intellectual disability/developmental delay</td>
<td>16</td>
</tr>
<tr>
<td>Language delay</td>
<td>9</td>
</tr>
<tr>
<td>OCD</td>
<td>1</td>
</tr>
</tbody>
</table>

**Neurological Problems**

- Tic disorder: 2
- Seizures: 4
- Movement disorder: 1
- Low muscle tone: 16
- Large head size: 6
- High muscle tone: 5
- Coordination problems: 3
- Cerebral palsy: 4

**Gastrointestinal Problems**

- Constipation: 12
- Diarrhea: 7
- Gastric ulcer: 10
- GERD: 2
- IBD: 2

**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 ADNP community! Progress for individuals in your community with ADNP 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
The **Quality of Life Inventory** is a scientific survey where we asked caregivers to describe how their family member with ADNP responds to life experiences.

It measures quality of life by looking at the following areas: physical health, psychological well-being, social relationships, leisure, and independence.

These graphs reflect the number of people who reported "Often" or "Very Often" for each question.

### Health & Well-being

- **Has energy for daily activities**: 5
- **Is in good health**: 5
- **Is alert and aware**: 5
- **Sleeps well**: 4

### Feelings & Emotions

- **In a good mood**: 3
- **Smiles**: 4
- **Expresses happiness using body language**: 4
- **Laughs or giggles**: 5
- **Unsettled for no reason**: 1
- **Displays aggression**: 2
- **Feels upset or angry**: 3
- **Withdrawn, low mood**: 1
- **Intentionally self harms**: 3
- **Dislikes changes in routine**: 0
- **Displays anxiety or agitation**: 2

We gratefully acknowledge Dr. Jenny Downs of the Telethon Kids Institute.

QI-Disability Parent Version © Telethon Kids Institute, 2017, 2021
Information Spotlight: Quality of Life

“Quality of life is a common survey of patient-centered outcomes in clinical trials and natural history studies.”
- Alison Holbrook, PhD

Daily Life

- Expresses their needs: 3
- Makes own choices for activities: 2
- Likes using technology: 5
- Helps with routines: 4
- Enjoys making things: 3

Activities & the Outdoors

- Enjoys moving their body: 1
- Enjoys feeling steady during activities: 2
- Enjoys physical activities: 1
- Enjoys outings: 1
- Enjoys time outdoors: 2

Family & Friends

- Happy when they are understood: 5
- Feels relaxed while making eye contact: 4
- Initiates greetings with others: 2
- Happy to be included: 3
- Enjoys socializing at mealtimes: 3
- Enjoys interacting with others: 3
- Excited by upcoming activities: 4

Thank you
for contributing knowledge to Simons Searchlight!