SPARK
SNAPSHOT

Report 1: UPDATED
Data from Dec 2015 - Jan 2019

Simons Powering Autism Research
Did you know that

59,179 people with autism are participating in SPARK?

Welcome to the SPARK Snapshot

— a window into the autism journey of SPARK participants. We’ve compiled these interesting findings from information that families have provided.
Many more children with autism have enrolled in SPARK than adults with autism. We need more adults to participate to better understand autism throughout the lifespan.

Who Is Participating in SPARK?

**Number of Children with Autism**

**Children**

**Number of Adults with Autism**

**Adults**

**50,466**

**8,713**

The proportion of adult women with autism in SPARK is a little higher than expected, but it is lower than what’s reported in other studies of autism in adults.

**Ratio of Males to Females in Adults Over 18**

2 to 1

Boys with autism outnumber girls 4 to 1 in SPARK — a ratio similar to the one usually reported in other autism studies. This is one clue that SPARK is a good representation of families with autism in the U.S.
Who Is Participating in SPARK?

SPARK represents the whole lifespan, from toddlers who received their diagnosis before 2 to some of the first diagnosed cases, now in their 80s. We also have babies with autism enrolled whom we can watch as they grow and change over time.

Number of participants with autism <18 by age group

- Age 1-4: 12,051
- Age 5-11: 25,734
- Age 12-17: 12,681

Number of participants with autism >18 by age group

- Age 18-24: 4,688
- Age 25-34: 2,327
- Age 35-44: 945
- Age 45-54: 476
- Age >55: 277
Diagnosis

**Children Under 18**

Boys and girls were diagnosed on average between ages 4 and 4.5. On average, children enrolled in SPARK seem to have been diagnosed a little later than those in other autism studies. This may be because they are from a larger sample of the U.S.

**Adults Over 18**

Independent adults with autism were diagnosed later than dependent adults with autism. Some adults were not diagnosed until their 60s or 70s, likely reflecting increased recognition of autism in recent years.

<table>
<thead>
<tr>
<th>Age at Diagnosis</th>
<th>Boys</th>
<th>Girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age</td>
<td>4.2</td>
<td>4.5</td>
</tr>
<tr>
<td>Average age</td>
<td>21.8</td>
<td>19.8</td>
</tr>
<tr>
<td>Average age</td>
<td>5.9</td>
<td>7.4</td>
</tr>
</tbody>
</table>

*SPARKforAutism.org*
Professionals Who Made the Diagnosis

Families are receiving diagnostic evaluations from multiple care providers, most commonly clinical psychologists, medical specialists and entire teams of experts. The school also plays this role for many families.

Language

Most children enrolled in SPARK are able to use full sentences to communicate.
Pregnancy, Birth History and Associated Conditions

SPARK families reported many concerns about pregnancy and birth for their children, but serious complications causing brain injury are no more likely than they are in the general population.

Adults with autism also struggle with depression and anxiety. Independent adults with autism report depression and anxiety at over three times the rate of the general population.

Premature birth occurs slightly more often in babies who are later found to have autism than it does in other babies. Birth complications such as prematurity are known to increase the risk for developmental disability, and some research says it increases the risk for autism.

Percent with Birth Complications
7%

Percent Born Prematurely
12%

Associated conditions reported by Dependent Adults with ASD
20% have a diagnosis of depression
33% anxiety disorder
40% ADHD

Associated conditions reported by Independent Adults with ASD
49% have a diagnosis of depression
39% anxiety disorder
40% ADHD
Pregnancy, Birth History and Associated Conditions

Associated Conditions in Children with Autism
- 5% have a diagnosis of depression
- 18% have anxiety
- 36% have ADHD
- 14% have cognitive impairment
- 59% have sleep problems
- 58% have eating problems

The rate of attention deficit (ADHD) in SPARK is over 3 times higher than it is in the general population. Diagnoses of conditions like ADHD and anxiety may rise now that the new diagnostic system used by doctors encourages all other conditions to be documented. Over half of parents report that their child has problems with sleep and eating.

Seizures
The rate of seizure disorders in SPARK is higher than it is in the general population. But SPARK’s reported rate is much lower than the rates reported by other autism studies. We need everyone in SPARK to finish their basic medical screening survey to give us a complete picture.
Past Genetic Testing for Autism

9,927 people or 27%

People Who Have Had Genetic Testing Related to Autism in the Past

Even though it is known that autism is strongly influenced by genetics, most families have not received genetic testing before.

Most Common Genetic Findings Reported by Families in SPARK

A small number of families report they received a genetic diagnosis in the past that could explain their autism. The most common known genetic cause of autism, and the most common reported in SPARK, is Fragile X syndrome.

We still have much to learn about genetic causes, and SPARK offers the chance to increase our understanding.

<table>
<thead>
<tr>
<th>Number of People</th>
<th>Genetic Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>207</td>
<td>Fragile X</td>
</tr>
<tr>
<td>77</td>
<td>15q11-q13 duplication</td>
</tr>
<tr>
<td>46</td>
<td>22q11 deletion</td>
</tr>
<tr>
<td>41</td>
<td>PTEN</td>
</tr>
<tr>
<td>36</td>
<td>7q11.23 deletion</td>
</tr>
<tr>
<td>30</td>
<td>Rett syndrome (MECP2)</td>
</tr>
<tr>
<td>30</td>
<td>22q13 deletion</td>
</tr>
<tr>
<td>28</td>
<td>15q deletion</td>
</tr>
<tr>
<td>17</td>
<td>NF1</td>
</tr>
<tr>
<td>27</td>
<td>Angelman syndrome</td>
</tr>
<tr>
<td>17</td>
<td>16p11.2 deletion</td>
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<tr>
<td>17</td>
<td>ADNP</td>
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<tr>
<td>15</td>
<td>Noonan syndrome</td>
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<tr>
<td>10</td>
<td>SCN2A</td>
</tr>
<tr>
<td>10</td>
<td>1p16.3 deletion</td>
</tr>
<tr>
<td>10</td>
<td>1q21.1 duplication</td>
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</tbody>
</table>
Thank you
to all of the participating families!
Together, we can learn so much more.