The Simons Simplex Community at IAN (SSC@IAN) is a sub-community within the Interactive Autism Network (IAN) research registry and database established in 2011 to represent more than 1400 families who participated in the original Simons Simplex Collection (SSC) study. In 2015, the SSC Family Update study was launched in an effort to update information for all SSC@IAN families. In addition, childhood participants who transition into adulthood provide a unique opportunity to enroll the next generation in ASD longitudinal data collection. In addition, child registrants who transition into adulthood from this cohort who had reached 18 years of age were given the option to participate and provide their consent as an independent adult. Updating research registries is important for new research initiatives and research as children.

Methods

Objectives

To update health, contact, and family information for SSC@IAN families.

To engage and re-consent young adults (18 years and older) with and without ASD and their young adult unaffected siblings without ASD who had been enrolled for research as children.

Methods

SSC@IAN parents were invited via email to complete a series of online forms that asked them to update a range of information about their family, including for offspring with ASD (“Probands”) and without ASD (“Designated Siblings”).

For a young adult proband and/or designated sibling (see Figure 1 for workflow): Parents were asked to declare legal status (legally independent or dependent). Parents of legally independent adults — both with and without ASD — were given the option to invite their adult children to re-consent and continue to participate in the SSC@IAN cohort. Those interested provided their child’s email address. Young adults were notified by email about SSC@IAN and given the option to participate and provide their consent as an independent adult. Consent was obtained electronically.

Results: Young Adults (18 years and older)

See Figure 1 for results summary. 100 young adults (Probands: 23 Independent + 49 Dependent = 72 Total; Unaffected Siblings = 28) of 567 invited (17.6%) were re-consented.

Parents were more likely to respond for a proband than an unaffected sibling (Proband: n=95 (31.3%); Sibling: n=53 (20.2%); p=0.03; Fischer Exact Test (FET)). No significant difference in parental invitation percentages between independent probands (n=41/48; 89.1%) and unaffected siblings (n=46/53; 86.8%). No significant difference in re-consenting percentages between invited independent probands (n=23/41; 56.1%) and unaffected siblings (n=28/46; 60.9%).

Engaging the Next Generation in ASD Research—Experiences of the SSC@IAN Family Registry

Jaimie S. Toroney, MHS
J. Kiely Law, MD, MPH
Allison R. Marvin, PhD
Casey White, MA, MS
Elizabeth Brooks
Elizabeth M. Mekosh
Wendy K. Chung, MD, PhD
Paul H. Lipkin, MD

Background

The key to engaging young adult probands and siblings is parental engagement.

Parents of adult offspring are more likely to engage with respect to their ASD-affected child than an unaffected adult sibling.

Once engaged, there was no significant difference in the rate in which parents invited their independent young adult offspring to re-consent between probands and siblings.

For those independent young adults for whom parents had provided an email address, more than half re-consented to participate in autism research. There was no significant difference in re-consent rate between those with and without ASD.

Support

This study was funded by the Simons Foundation. IAN is a partnership project of the Kennedy Krieger Institute and the Simons Foundation.

Conclusions

Table 1. Comparing Parental Response Rates for Probands by Age Category

<table>
<thead>
<tr>
<th>Proband Age Category</th>
<th>Number of Invitations</th>
<th>Number of Responses</th>
<th>Response Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult (18 years or older)</td>
<td>304</td>
<td>95</td>
<td>49.4%</td>
</tr>
</tbody>
</table>

Results: Children (Under 18 years)

49.4% of parents of child probands responded to the SSC Family Update Study. This is statistically significantly higher compared to the 31.3% response rate from parents of adult probands. (χ²(1, N=1290) = 30.88; p<0.001 (Yates correction). See Table 1.

Support

Thank you to SSC@IAN Families for making this study possible. To learn more about IAN, visit www.IANproject.org