OBJECTIVE
Survey Design and Analysis
Survey questions were developed and beta-tested in consultation with communities of patients with EE and healthcare professionals – Study protocol approved by Western Institutional Review Board (IRB), Puyallup, WA – Open for response from July 19–December 31, 2017 – Participants were recruited through social media, patient advocacy websites, and parent community events – Participants responded to 1 of 4 online, IRB-approved, cohort-specific surveys – Respondents or caregiver/patient gave consent to participate – Carers, parents, siblings 9-12 years old (y/o), siblings 13-17 y/o, and adult siblings ≥18 y/o – Adult siblings surveyed both currently and retrospectively
Survey Design and Analysis
Quality-of-life (QoL) metrics used visual analog scale scores, with 0-10 or 0-3 response options – Four questions assessed potential depressed mood – Two questions assessed potential anxiety symptoms – Additional questions assessed QoL, parameters
RESULTS
Sibling Voices Survey: Respondents and Demographics (Table 1)
Parent and sibling respondents represented 115 and 107 patients with EEs, respectively (Table 2)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>9-12 y/o</th>
<th>13-17 y/o</th>
<th>18+ y/o</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex, n (%): Male</td>
<td>54 (41)</td>
<td>32 (52)</td>
<td>15 (56)</td>
</tr>
<tr>
<td>Patient diagnosis</td>
<td>56 (42)</td>
<td>34 (55)</td>
<td>16 (56)</td>
</tr>
<tr>
<td>Lennox-Gastaut syndrome</td>
<td>54 (41)</td>
<td>34 (52)</td>
<td>16 (56)</td>
</tr>
<tr>
<td>Other EEs</td>
<td>10 (8)</td>
<td>3 (5)</td>
<td>0</td>
</tr>
<tr>
<td>Median age (years)</td>
<td>11 (0-16)</td>
<td>14 (0-21)</td>
<td>25 (18-63)</td>
</tr>
<tr>
<td>Siblings, n (%): Female</td>
<td>52 (40)</td>
<td>23 (36)</td>
<td>10</td>
</tr>
</tbody>
</table>

SEVERE EPILEPTIC ENCEPHALOPATHIES (EEs) OF CHILDHOOD (EG, DRAVET SYNDROME [DS], SERIES-OCCULT) PLACE SUBSTANTIAL HUMANISTIC BURDENS ON THE ENTIRE FAMILY UNIT

INTRODUCTION
Severe epileptic encephalopathies (EEs) of childhood (eg, Dravet syndrome [DS], Lennox-Gastaut syndrome [LGS]) present developmental delays, neurocognitive impairment, and motor deficiencies.

METHODS
Survey Development and Recruitment
Survey questions were developed and betatested in consultation with communities of patients with DS and LGS and healthcare professionals – Study protocol approved by Western Institutional Review Board (IRB), Puyallup, WA – Open for response from July 19–December 31, 2017 – Participants were recruited through social media, patient advocacy websites, and parent community events – Participants responded to 1 of 4 online, IRB-approved, cohort-specific surveys – Respondents or caregiver/patient gave consent to participate – Carers, parents, siblings 9-12 years old (y/o), siblings 13-17 y/o, and adult siblings ≥18 y/o – Adult siblings surveyed both currently and retrospectively

Table 1. Demographic Characteristics of Sibling Voices Survey Respondents

Siblings 9-12 and 13-17 y/o reported lower ratings for stress and worry/fear (stress, scores 5, 4-7, 8-10) than adults (scores 5, 4-7, 8-10) (Figure 2).

CONCLUSIONS
The Sibling Voices Survey data support recent survey studies that report parents/caregivers concerns regarding the emotional impact of EEs on siblings of children with EEs.

Siblings 9-12 and 13-17 y/o reported lower ratings for stress and worry/fear (stress, scores 5, 4-7, 8-10) than adults (scores 5, 4-7, 8-10) (Figure 2).

Substantial differences were observed in ratings for sadness and anger between siblings and parent reports (Figure 3).

Figure 1: Reports of Potential Symptoms of (A) Anxious or (B) Depressed Mood

Figure 2: Ratings of Stress and Worry/Fear Over Sibling’s Diagnosis

Figure 3: Ratings of Sadness and Anger Over Sibling’s Diagnosis

The Sibling Voices Survey was developed and is owned by Zogenix, Inc. and was funded by Zogenix, Inc.

REFERENCES