Quality of Life in Mass Screening-Identified Pediatric Celiac Disease
Camryn Slosky, Tiffany Phu, MA, Marisa Stahl, MD,1 Edwin Liu, MD,1 Mary Shull MD,1 & Monique Germonde, PhD1
1Children’s Hospital Colorado

BACKGROUND
• Celiac disease (CD) is common and affects at least 1 in 134 adolescents in the US1
• CD is a gluten-induced enteropathy with significant complications when untreated2
• A strict lifelong gluten-free diet (GFD) is the only treatment2
• Autoimmune Screening for Kids (ASK) is the first US mass pediatric screening for Type 1 Diabetes (T1D) and CD3
• The Outcomes of Screening-Identified Celiac Autoimmunity Research (OSCAR) study examines biological and psychosocial outcomes of ASK participants with a positive screen for CD

OBJECTIVE
This study uses a subset of data from OSCAR to examine changes in health-related quality of life (HRQoL) pre- and post-CD diagnosis in screening-identified children

METHODS
Participants:
• 19 screening-identified children with CD and their caregivers
• Child age (in years): M (SD) = 11.46 (3.94)
Measures:
• Prospective administration of Pediatric Quality of Life Inventory Generic Core Scales (PedsQL™) questionnaire (self- and parent proxy-reports) prior to confirmation of diagnosis and at 12 months post-diagnosis
Analyses:
• Paired sample t-test evaluation of differences in PedsQL scores pre- and post-CD diagnosis in both child and parent proxy-reports

RESULTS

<table>
<thead>
<tr>
<th>PedsQL Scale</th>
<th>Pre-diagnosis</th>
<th>Post-diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>66.6</td>
<td>69.4</td>
</tr>
<tr>
<td>Social</td>
<td>46.2</td>
<td>46.0</td>
</tr>
<tr>
<td>Emotional</td>
<td>55.9</td>
<td>48.1</td>
</tr>
<tr>
<td>Academics</td>
<td>60.5</td>
<td>52.3</td>
</tr>
<tr>
<td>Total</td>
<td>56.5</td>
<td>48.1</td>
</tr>
</tbody>
</table>

Note: PedsQL scores range from 0 – 100, with higher scores indicating better functioning

CONCLUSIONS
• Despite a large representation of diverse participants in the ASK study, those that go on to be diagnosed with CD remain predominantly White5
• Children who participate in general screening for T1D and CD and subsequently are diagnosed with CD show improvements in self-reported and parent proxy-reported HRQoL one year after diagnosis
• Parents reported statistically significant increases in physical, emotional, and academic functioning with starting GFD
• Children reported statistically significant increases in social and academic functioning

IMPLICATIONS
Increase in self- and parent proxy-reports of HRQoL from pre- to post-diagnosis indicates that participating in the screening process and subsequent diagnosis with CD, and initiation of the GFD, may result in positive outcomes.

ACKNOWLEDGEMENTS
Research supported by the Bea Taplin Endowment Fund for Celiac Disease and the SSCD-Beyond Celiac Early Career Research Award and conducted at the Colorado Center for Celiac Disease at Children’s Hospital Colorado

REFERENCES


Child Reported HRQoL

<table>
<thead>
<tr>
<th>PedsQL Scale</th>
<th>Pre-diagnosis</th>
<th>Post-diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>70.6</td>
<td>74.3</td>
</tr>
<tr>
<td>Social</td>
<td>49.7</td>
<td>54.6</td>
</tr>
<tr>
<td>Emotional</td>
<td>56.6</td>
<td>59.9</td>
</tr>
<tr>
<td>Academics</td>
<td>68.3</td>
<td>69.7</td>
</tr>
<tr>
<td>Total</td>
<td>63.9</td>
<td>69.7</td>
</tr>
</tbody>
</table>

Note: PedsQL scores range from 0 – 100, with higher scores indicating better functioning

* p<0.05