**Introduction**

Cleft lip and cleft palate are birth defects that result from improper formation of the mouth and lip by about 10 weeks after conception. Together, these birth defects commonly are called “orofacial clefts”.

**Figure 1: Cleft Palate**

**Figure 2: Cleft Lip**

The Centers for Disease Control and Prevention (CDC) recently estimated there are 2,651 live births each year in the United States with cleft palate and 4,437 live births with cleft lip (with or without cleft palate).

Michigan statistics regarding orofacial clefts come from the Michigan Birth Defects Registry, a statewide population-based, passive system. In Michigan, from 1992 to 2010, the overall rate of orofacial clefts was 15.7 cases per 10,000 live births. From 2001 to 2010, a total of 1,981 infants were reported with an orofacial cleft, or 1 in 633 Michigan newborns. Children with oral clefts require specialized health care services during childhood. Families may benefit from additional financial and emotional support.

**Objective**

- To assess the experience, needs, and utilization of services by families, parents, and caregivers of children with orofacial clefts (OFC) in Michigan.
- To identify and address gaps in the information and support services provided to families of children with OFC.

**Methods**

**Population:**
- Parents of children with OFC, including isolated cleft palate and cleft lip (with or without cleft palate), born from 2009 through 2011.
- Identified from the Michigan Birth Defects Registry (MBDR).
- **Inclusion criteria:** Children with OFC born in Michigan, not deceased, and not adopted.

**Survey:**
- 420 families were invited in up to three mailings.
- Access to an Internet “Survey Monkey” iteration was provided in every mailing.
- Paper surveys were also provided in the second and third mailing.
- Participants were asked to complete the survey for their oldest child with OFC.

**Analysis:**
- Results were analyzed using Statistical Analysis Software (SAS) version 9.2.
- Descriptive statistics were calculated as well as statistical significance where applicable.

**Results**

**Demographics**
- Response rate: 34% (104 respondents); 82% online and 18% on paper.
- The majority of respondents were 25 years or older (92.9%), white (90.8%), and had more than a high school education (84.7%).
- Thirty-seven out of 83 MI counties were represented, with 55% in the Southeastern lower region.
- Children ranged in age from 1-11 years; the average age was 3 years.
- Cleft lip and palate was the most common type of OFC among respondents’ children (50.5%). About 23% had cleft lip only, and about 27% had cleft palate only.

**Table 1: Family history of OFC and other children born with OFC (n=101).**

<table>
<thead>
<tr>
<th>Other children with OFC</th>
<th>Maternal side</th>
<th>Paternal side</th>
<th>Both</th>
<th>No</th>
<th>Not sure</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>2 (2.0%)</td>
<td>2 (2.0%)</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>10 (9.9%)</td>
<td>6 (5.9%)</td>
<td>2</td>
<td>75</td>
<td>3</td>
<td>96</td>
</tr>
<tr>
<td>Total</td>
<td>12 (11.9%)</td>
<td>8 (7.9%)</td>
<td>2</td>
<td>76</td>
<td>3</td>
<td>101</td>
</tr>
</tbody>
</table>

**Table 2: Issues related to having a child with cleft, whether addressed by a health professional (HP) and perceived importance (n=99).**

<table>
<thead>
<tr>
<th>Issues</th>
<th>Addressed by HP</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ways to cope with struggles</td>
<td>41.8%</td>
<td>43.8%</td>
</tr>
<tr>
<td>How having a child with cleft may affect family</td>
<td>40.4%</td>
<td>44.4%</td>
</tr>
<tr>
<td>Ways to contact other families/support groups</td>
<td>35.7%</td>
<td>56.1%</td>
</tr>
</tbody>
</table>

**Table 3: Family received emotional/social support and reported ability to cope with struggles (n=97).**

<table>
<thead>
<tr>
<th>Emotional/social support</th>
<th>Coping with struggles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very well</td>
<td>Fair</td>
</tr>
<tr>
<td>Total</td>
<td>70 (72.3%)</td>
</tr>
<tr>
<td>Yes</td>
<td>62 (63.9%)</td>
</tr>
<tr>
<td>No</td>
<td>5 (5.2%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>3 (3.1%)</td>
</tr>
<tr>
<td>Total</td>
<td>78 (80.4%)</td>
</tr>
</tbody>
</table>

**Discussion**

- Most families (over 80%) provided positive feedback about accessing the follow-up care needed for their child and receiving information on needed specialists. Most did not currently need help finding any information, services, or support. However, several gaps were identified.
- Most children with cleft lip and palate had experienced at least two surgeries; more than a third had undergone 3 or more surgeries before age 3 (Figure 3).
- The association between family history and OFC (Table 1) underscores the importance of referrers to genetics.
- Less than 50% of respondents indicated that a health professional had addressed issues surrounding the potential stress of raising a child with OFC that most families identified as important (Table 2).
- Results suggested an association between receiving emotional/social support and the caregiver’s ability to cope with struggles (Table 3). The majority of respondents who saw a social worker or counselor reported that their emotional and/or social support needs were met (68.6%).

**Public Health Impact**

- New parents of children with OFC can benefit from receiving information and assistance beyond specialized medical care. Families identified needs related to care coordination, financial assistance, their ability to contact the health care provider with questions, coping with potential struggles, and contact with other families who had a child with an OFC or support groups.
- The MBDR has the opportunity to increase awareness among health care providers of family needs and available services.

**Acknowledgements**

- We would like to thank the MBDR for their assistance in administering this survey.
- We acknowledge and thank the staff of the clinical care teams, support groups and parents for their assistance and contribution.

This publication was supported by Cooperative Agreement Number 5U50DD000615-05 from the CDC. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.