



The Michigan Monitor

Following trends, promoting prevention
and linking families to resources

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Orofacial Clefts

Background

Cleft lip or cleft palate occurs when a baby’s lip or mouth does not form properly before birth. Together, these conditions are commonly called “orofacial clefts” or “oral clefts” (OFCs). Affecting 1 or 2 in every 1,000 newborns, together they are among the more common birth defects; and the most common affecting the face.

OFC happens early in pregnancy, by 5 to 6 weeks after conception (cleft lip) and by about 10 weeks after conception (cleft palate). A baby can have a cleft lip, a cleft palate, or both.¹ An OFC may affect one side of the lip and/or palate (unilateral) or both sides (bilateral). The OFC may disrupt the formation of the nose and may extend into the gum or upper jawbone.

Occurrence

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 a cleft palate).¹ Michigan statistics for OFC come from the Michigan Birth Defects Registry (MBDR); a statewide population-based surveillance system. In Michigan, from 1992-2010, the incidence of OFC was about 1 in 637 live births (15.7 cases per 10,000 live births) with an average number of 75 cases of cleft palate and 130 cases of cleft lip (with or without cleft palate) each year.

Children with OFC often have trouble with feeding and talking. Recurrent ear infections, hearing loss, and problems with their teeth are common.¹ OFCs usually require one or more surgeries early in life. Before and after OFC surgical repair, a child may need special feeding techniques, orthodontic care and/or speech therapy. OFC severity varies with the degree of clefting and with the presence of other birth defects; in extreme cases, death may result.¹ Most babies with an oral cleft have a good outlook for a long, healthy life.

We conducted a study called: *A Needs Assessment Survey of Parents of Children with Oral Clefts in Michigan*. A summary of results is presented in the following pages.

Figure 1: Cleft Palate¹

Figure 2: Cleft Lip¹



Causes

Previous research has identified that the causes of OFC are complex, involving both environmental and genetic factors.² As featured in the 2014 Surgeon General’s Report, maternal smoking in early pregnancy increases the chance of orofacial clefts in offspring.³ Studies have shown a protective effect with folic acid supplementation starting around the time of conception. However, this has not been proven conclusively.⁴

Points of Interest

- ◇ Children with orofacial clefts (OFC) often have problems with feeding and talking.¹
- ◇ They may have ear infections, hearing loss and problems with their teeth.¹
- ◇ OFCs are more likely to occur when a primary relative (parent or sibling) has an OFC.⁵

Diagnosis and Follow-up Care

Most families (over 80%) provided positive feedback about accessing the follow-up care information needed. Most did not currently need help finding information, services, or support. However, several gaps were identified.

Over half (54.5%) reported that a health professional did not talk with them about future expenses and planning how to pay for the medical care of their child with an oral cleft. The majority (84.4%) said this is important. A third (33.3%) indicated that their health care provider did not give them a contact number to call with questions, although the majority felt it is important (96.7%).

Most children with cleft lip and palate had experienced at least two surgeries; more than a third had undergone 3 or more surgeries before 3 years of age. Children with cleft lip and palate had more surgeries than those with cleft lip or cleft palate alone. Nearly half (47.8%) did not receive assistance with managing, planning and scheduling specialist appointments.

Respondents were asked to indicate whether they had other children born with OFC and about their family history of OFCs. Nearly a quarter (22%) indicated that they had a family history of clefts (Table 2).

Table 2: Family history of OFC and other children born with OFC: A Needs Assessment Survey of Parents of Children with Oral Clefts in Michigan

Other children with OFC	Family History (n=101)					
	Mother	Father	Both	No	Not sure	Total
Yes	2 (2%)	2 (2%)	0 (0%)	1 (1%)	0 (0%)	5 (5%)
No	10 (10%)	6 (5%)	2 (2%)	75 (74%)	3 (3%)	96 (95%)
Total	12 (12%)	8 (8%)	2 (2%)	76 (75%)	3 (3%)	101

We assessed the association between family history and having a child born with OFC. Analysis suggested a statistically significant relationship ($p=0.0187$). This underscores the importance of genetic referral.

Emotional and Social Support

Less than half of respondents indicated that a health professional had addressed important issues surrounding the potential stress of raising a child with OFC (Table 3).

Table 3: Issues related to having a child with OFC, whether addressed by a health provider and perceived importance (n=99): A Needs Assessment Survey of Parents of Children with Oral Clefts in Michigan

Issues	Health Provider Addressed			Important
	Yes	No	Not sure	Yes
Ways to cope with struggles	42%	44%	14%	89%
How having a child with cleft may affect family	40%	44%	15%	80%
Ways to contact other families/support groups	36%	56%	8%	70%

Overall, 76% of respondents reported that they had received the emotional/social support they needed (Table 4). Results suggest a significant association between receiving emotional/social support and caregiver coping ($p < 0.001$).

A greater percentage of respondents who met with a social worker or counselor (68.6%) reported that their emotional and/or social support needs were met.

Table 4: Family received emotional/social support and reported ability to cope with struggles (n=97): A Needs Assessment Survey of Parents of Children with Oral Clefts in Michigan

Emotional/social support	Coping with struggles		
	Very well	Fair	Total
Yes	62 (64%)	12 (12%)	74 (76%)
No	5 (5%)	9 (9%)	14 (14%)
Not sure	3 (3%)	6 (6%)	9 (9%)
Total	70 (72%)	27 (28%)	97

Public Health Implications and Future Directions

New parents of children with OFC can benefit from receiving information and assistance beyond specialized medical care. Families identified their needs related to care coordination, financial assistance, their ability to contact the health care provider, 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.

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For more information please contact:
Birth Defects Education and Outreach Program,
Lifecourse Epidemiology and Genomics Division
201 Townsend St, CV-4
Lansing, MI 48913

Call Toll Free: 1-866-852-1247
E-mail: BDRFollowup@michigan.gov
Website: www.michigan.gov/birthdefectsinfo

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The *Michigan Monitor* is online at www.michigan.gov/mchepi

Find information about MBDR reporting at:
www.michigan.gov/mbdr

MBDR Reporting: ICD10 live October 2015!

With the implementation of ICD-10-CM coding on the horizon for health care institutions, MDCH looks forward to the more detailed and enhanced classification of reportable birth defects that the new coding system provides.

An example of the ICD-10-CM classification for Cleft Palate with Cleft Lip is seen below.

International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM)
<http://www.cdc.gov/nchs/icd/icd10cm.htm>

ICD10	DEFINITION (CLEFT PALATE with CLEFT LIP)
Q37.9	UNSPECIFIED CLEFT PALATE with UNILATERAL CLEFT LIP
Q37.1	CLEFT HARD PALATE with UNILATERAL CLEFT LIP
Q37.3	CLEFT SOFT PALATE with UNILATERAL CLEFT LIP
Q37.5	CLEFT HARD and SOFT PALATE with UNILATERAL CLEFT LIP
Q37.0	CLEFT HARD PALATE with BILATERAL CLEFT LIP
Q37.2	CLEFT SOFT PALATE with BILATERAL CLEFT LIP
Q37.4	CLEFT HARD and SOFT PALATE with BILATERAL CLEFT LIP
Q37.8	UNSPECIFIED CLEFT PALATE with BILATERAL CLEFT LIP

Helpful websites for health professionals and families:

Michigan Cleft Network: www.micleft.com

Cleft Lip and Palate Foundation of Smiles: www.cleftsmile.org

Cleft Palate Foundation: www.cleftline.org

Ameriface: www.ameriface.org

EndBirthDefects.org

Michigan Family to Family Health Information Center: f2fmichigan.org

References

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