

Oral Facial Clefts

Last Reviewed Revised 3/03

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Definition: An oral-facial cleft is an opening in a structure around the mouth and face. Clefts may occur in the lip, the roof of the mouth (hard palate) or the tissue in the back of the mouth (soft palate). There are two major types of oral-facial clefts. In one, the baby has a cleft lip which usually is accompanied by cleft palate. This is called **cleft lip/palate**. In the other, called **isolated cleft palate**, cleft palate occurs by itself, without cleft lip. The two forms of oral-facial clefts are considered separate birth defects.

Causes

The causes of cleft lip/palate are not well understood. Studies suggest that a number of genes, as well as environmental factors, such as drugs (including anti-seizure drugs), infections, maternal illnesses, maternal alcohol use and possible deficiency of B vitamin folic acid may be involved.

Up to 13 percent of babies with cleft lip/palate have other birth defects. Some involve genetic syndromes that may pose additional problems for the affected baby. Babies with cleft lip/palate should be thoroughly examined by a doctor soon after birth.

Health Problems

There may be problems with feeding, ear disease and speech development, as well as dental problems. These may differ between children with cleft lip/palate and those with isolated cleft palate; the problems also will differ depending on the specific cleft and its severity. Each child with cleft lip/palate or isolated cleft palate requires an individualized treatment plan.

Children with oral-facial clefts usually are treated by a team of specialists so that all aspects of treatment can be coordinated. Most teams include a pediatrician, a plastic surgeon, dental specialists, an otolaryngologist (ear, nose and throat specialist), a speech-language pathologist, an audiologist (hearing specialist), a geneticist, a psychologist, a nurse and a social worker. This team approach can be found through the Maine Cleft Lip and Palate Clinic at MMC and EMMC.

Speech

Children with cleft lip generally have normal or near-normal speech. Some children with cleft palate (isolated or as part of cleft lip/palate) may develop speech a little more slowly than other children. Their words may sound nasal and they may have difficulty producing some consonant sounds. However, after cleft palate repair, most children eventually catch up and develop normal speech, though some will require speech therapy.

Prevention

While little is known about how to prevent oral-facial clefts, a 1995 study suggested that taking multivitamins containing folic acid before conception and during the first two months of pregnancy may help prevent cleft lip/palate and isolated cleft palate. The study showed that women who took multivitamins had a 50 percent lower risk of having a baby with cleft lip/palate and a 25 percent lower risk of having a baby with isolated cleft palate.

Other studies have shown that fetuses with a certain predisposing gene may be at increased risk for isolated cleft palate if their mother smokes.

Studies have shown that maternal alcohol use may increase the risk of cleft lip/palate. Women who are planning pregnancy or who are pregnant should avoid alcohol, which also can cause a number of mental and physical birth defects. Because some types of medications (such as some drugs used to treat epilepsy) have been linked to increased risk of cleft lip/palate, women who take medications for chronic illnesses should check with their doctors before they become pregnant. In some cases, the doctor may recommend stopping the medication or switching to a medication that is safer during pregnancy. All pregnant women should use only medications prescribed by a physician who knows of the pregnancy, and get early and regular prenatal care, beginning with a pre-pregnancy visit. Families with a history of cleft lip/palate, isolated cleft palate, or any other condition of which clefting is a part, may wish to discuss the chances of recurrence with a genetic counselor.

(The text above is adapted from the March of Dimes fact sheet on Oral Facial Clefts)

Considerations for the School Aged Child

During the early school years (ages 5 to 12 years), the child's focus widens to include not only the family, but the larger world of neighborhood and school as well. Children with cleft lip/palate may become concerned about how they look and talk. They may worry about making friends, being teased, doing well in school, and being included in activities. Parents want their children to be successful and to develop a good self-concept. However, children born with clefts sometimes need help to achieve these goals. Some times of particular crisis for the parents are at the time of birth, during periods of surgery, when the child begins to talk and when the child starts school.

A significant percentage of children with cleft lip/palate experience difficulty in the classroom. Most children with cleft lip/palate will experience at least some social discrimination and teasing. Other children with cleft lip/palate have delayed language development with an associated language-based learning disability. Psychosocial adaptation should also be monitored.

A child born with cleft lip/palate may be faced with multiple and complex problems such as achieving the best possible appearance, speech, hearing, teeth, and intellectual abilities.

The American Cleft Palate-Craniofacial Association has developed standards of care for children with clefts and other craniofacial anomalies and recommends that treatment of cleft and craniofacial conditions occur in a team setting.

Interdisciplinary team care should begin shortly after birth and continue until the physical growth of an individual has been completed - around 21 years of age.

The optimal time for the first evaluation is at or shortly after birth, however, referral for team evaluation and management can be considered for individuals of any age.

Although the habilitative process for children with cleft lip/palate can be a lengthy one, the availability of coordinated, interdisciplinary team care has enabled most children to become functioning and contributing members of society.

Role of the School Nurse

There are many ways a School Nurse can help families on this journey, as it is a journey that often lasts throughout the child's adolescent years.

Develop an IHP for the student, as appropriate.

Offer in-service to staff and students as appropriate.

Children with cleft lip/palate require many medical appointments/surgeries and will miss school time. The school nurse is encouraged to meet with the child and family to obtain a medical history and assure continued assessment through specialized clinical services.

A cleft palate increases a child's susceptibility to ear infections indicating the need for regular audiological evaluations. A yearly hearing screening could be recommended in the IHP.

If a child has any visible signs of the cleft, they may be experiencing teasing from other students. The School Nurse could provide an educational activity with the child's peers about the various ways that we are all different.

• The School Nurse can advocate to ensure that the child is receiving appropriate educational assessments, counseling, speech/language services and other services as needed.

The School Nurse can serve as a liaison between the family and the Cleft Lip/Palate Clinic team by translating medical terminology into understandable language. The team discusses all aspects of the individual, identifies problems, and together develops an integrated, multidisciplinary treatment plan. When appropriate, the School Nurse could attend clinic with the child and family.

Referrals to the Department of Human Services/Bureau of Health/Cleft lip/palate Program should be made.

Be aware of the needs of students even though the repair is complete.

Resources:

Department of Human Services, Coordinator, Oral-Facial Cleft, Elizabeth Boothby, 287-5348, elizabeth.m.boothby@Maine.gov

March of Dimes, PO Box 1657, Wilkes-Barre, PA, 18703, 888-MODIMES, www.modimes.org

The Cleft Palate Foundation – 1829 E. Franklin Street., Suite 1022, Chapel Hill, NC 27514, 800-242-5338, www.cleftline.org

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