ENThealth℠
POWERED BY AMERICAN ACADEMY OF OTOLARYNGOLOGY–HEAD AND NECK SURGERY

CLEFT LIP AND CLEFT PALATE

A "cleft" means a split or separation. A cleft palate refers to the roof of your mouth with or without the lip being split as well. Oral clefts are one of the most common birth defects. A child can be born with both a cleft lip and cleft palate, or a cleft in just one area. During normal fetal development between the sixth and eleventh week of pregnancy, the two sides of the lip and palate fuse together. In babies born with cleft lip or cleft palate, one or both of these splits fail to come together.

There are three primary types of clefts. *Cleft lip/palate* is when both the palate and lip are cleft, which represents about 50 percent of all clefts. About one in 1,000 babies are born with cleft lip/palate. Up to 13 percent of cases involve other birth defects, and occur more often in male children. It is more common in Asian populations and certain groups of American Indians, but less common in African American populations.

Isolated cleft palate is the term used when a cleft occurs only in the palate. About one in 2,000 babies are born with this type of cleft (the incidence of submucous cleft palate, a type of isolated cleft palate, is one in 1,200). This represents about 30 percent of all clefts. All ethnic groups have a similar risk for this type of cleft, but it occurs more often in female children.

Isolated cleft lip refers to a cleft in the lip only accounting for 20 percent of all clefts.

What Are the Symptoms of Clefts?

Symptoms of cleft lip/palate include:

- A tiny notch in the upper lip, or up to a split that extends into the nose (cleft in the lip)
- Small malformation that results in minimal problems, up to a large separation of the palate that interferes with eating, leaking into the nose, speaking with a nasal-sounding voice, and even breathing (cleft palate)
- Unilateral, a split on one side, or bilateral, one split on both sides

What Causes Clefts?

No one knows exactly what causes clefts, but most believe they are caused by one or more of three main factors: (1) an inherited characteristic (gene) from one or both parents; (2) poor early pregnancy health or exposure to toxins such as alcohol or cocaine; and/or (3) genetic syndromes. A syndrome is an abnormality in genes or chromosomes that result in multiple malformations in a recognizable pattern occurring together.

Cleft lip/palate is a part of more than 400 syndromes including Waardenburg, Pierre Robin, and Down syndromes. Approximately 30 percent of cleft deformities are associated with a syndrome, so a thorough medical evaluation and genetic counseling is recommended for cleft patients.

Clefting of the lip and palate is usually visible during the baby's first examination. One exception is a submucous cleft where there are abnormalities in the hard or soft palate that remain covered by a smooth, unbroken lining of the mouth. A child with cleft lip or palate is often referred to a multidisciplinary team of experts for treatment. The team may include: an ENT (ear, nose, and throat) specialist (or otolaryngologist), plastic surgeon, oral surgeon, speech pathologist, pediatric dentist, orthodontist, audiologist, geneticist, pediatrician, nutritionist, and psychologist/social worker.

The complications of cleft lip and cleft palate can vary greatly depending on the degree and location of the cleft. They can include some or all the following:

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- *Breathing*—When the palate and jaw are malformed, breathing becomes difficult. Treatments include surgery and oral appliances.
- *Feeding*—Problems with feeding are more common in cleft children. A nutritionist and speech therapist that specializes in swallowing may be helpful. Special feeding devices are also available.
- *Ear infections and hearing loss*—Any malformation of the upper airway can affect the function of the Eustachian tube and increase the possibility of persistent fluid in the middle ear, which is a primary cause of repeat ear infections. Hearing loss can be a consequence of repeat ear infections and persistent middle ear fluid. Tubes can be inserted in the ear by an ENT specialist to alleviate fluid build-up and restore hearing.
- *Speech and language delays*—Normal development of the lips and palate are essential for a child to properly form sounds and speak clearly. Cleft surgery repairs these structures; speech therapy helps with language development.
- *Dental problems*—Sometimes a cleft involves the gums and jaw, affecting the proper growth of teeth and alignment of the jaw. A pediatric dentist or orthodontist can assist with this problem.

What Are the Treatment Options?

Treatment of clefts is highly individual, depending on the overall health of the child and the severity and location of the cleft(s). Multiple surgeries and long-term follow up are often necessary. Because clefts can interfere with physical, language, and psychological development, treatment is recommended as early as possible.

Surgery to repair a cleft lip is usually done between 10- and 12-weeks-old. The cleft palate repair procedure, called "palatoplasty," is done between nine and 18 months. Additional surgeries are often needed to achieve the best results. In addition to surgery, the child may receive follow-up care from members of the multidisciplinary team for speech, dental, or other developmental issues.

What Questions Should I Ask My Doctor?

1. When should I have my child evaluated for possible corrective surgery?
2. Are any secondary surgeries or procedures required?
3. What are the chances that my future children could have cleft lip/palate?
4. What are possible problems after cleft lip repair that I should look for?