

# The Care of a Child with Cleft Lip and Palate



## A Guide for Parents



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**THE GREATER BROOKLYN  
CLEFT AND CRANIOFACIAL TEAM**



### ***The Greater Brooklyn Cleft and Craniofacial Team***

*is a multidisciplinary network of experienced and qualified physicians and allied healthcare professionals coordinated through SUNY Downstate Medical Center, the only academic medical center in Brooklyn. It represents specialists from many hospitals in Brooklyn, including Kingsbrook Jewish Medical Center, Brooklyn Hospital and New York Methodist Hospital, who work together to coordinate the care of children with cleft and craniofacial disorders.*

*Medical care for children with cleft lip and palate requires a team approach. Each clinician plays a unique and necessary role.*

### **Services provided:**

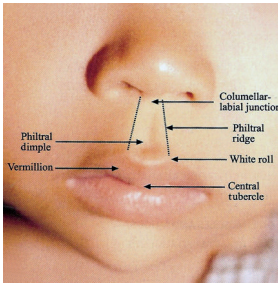
- **OTOLARYNGOLOGY/FACIAL PLASTIC SURGERY**  
*Cleft lip and palate repair; rhinoplasty surgery*
- **PEDIATRIC OTOLARYNGOLOGY**  
*Upper airway management*
- **SPEECH/LANGUAGE PATHOLOGY**  
*Feeding therapy; speech evaluation/therapy*
- **DENTAL MEDICINE**  
*Orthodontic care; upper and lower jaw surgery*
- **GENETICS**  
*Syndrome identification; genetic counseling*
- **AUDIOLOGY**  
*Hearing evaluation*
- **PLASTIC SURGERY**
- **NEONATOLOGY**
- **PEDIATRICS**

### ***The team also accepts referrals for:***

- Microtia (small, underdeveloped ears)
- Velopharyngeal insufficiency
- Micrognathia (small jaw)/Pierre Robin Sequence
- Other craniofacial syndromes: 22q11.2 deletion syndrome (VCFS/DiGeorge); Hemifacial microsomia, Treacher Collins syndrome

## What is cleft lip?

When a child is born with a gap in the upper lip, the lip is described as cleft. The skin, muscle and inner lining of the lip may be missing in one part of the lip. In addition, the upper gum may also be cleft.



Normal Upper Lip



Completely Cleft Lip

In some children, the entire upper lip and gum are cleft (complete cleft). In other children, part of the height of the lip is intact and the cleft does not extend to the nose (partial or incomplete cleft). The cleft may involve one or both sides of the lip.

## Why do children get cleft lip?

Doctors and researchers do not know the complete answer to this question. There are some factors that are associated with a higher risk of cleft lip, but in many instances, a direct cause is never found. What we do know is that early in the first trimester, events occur that prevent the tissues of the upper lip from developing properly. In utero exposure to certain medications, cigarette smoke, alcohol and other factors are known risk factors. In some children, the cleft lip will be associated with other developmental problems and, if it is suspected, the physicians caring for the child will need to do several tests to determine this.

## How is a cleft lip repaired?

Surgery to repair cleft lip is performed between four and twelve weeks of age, and may be done in one or two stages, typically completed by age six months. Prior to surgery, the surgeon may apply tape to the upper lip to narrow the width of the gap, and in some instances, dental appliances are utilized to line up the gum tissues. When the child is older, additional surgery will be performed to improve the shape and space within the nostril.



3 Years After Repair of Completely Cleft Lip  
(see photo on left-facing page)

## What is cleft palate?

Cleft palate is a condition that occurs when there is a gap in the roof of the mouth. This is often seen in conjunction with a cleft lip, but may also occur alone in a child whose lip is normal.

## What effect does a cleft lip and/or palate have on the child?

The gap in the upper lip may make it difficult for the child to feed with a standard nipple, especially if a cleft palate is also present. If only the lip is cleft, feeding may progress fairly normally, and breastfeeding should be attempted by mothers who wish to do so.

A child with a cleft palate will have problems feeding because he or she cannot form a seal around the nipple. In the hospital, the nursing staff will demonstrate how to feed the child with a special bottle. The child will need to be fed with formula or breast milk that is pumped. The child may also experience food or formula coming through the nose, but this can be avoided with the right feeding technique.

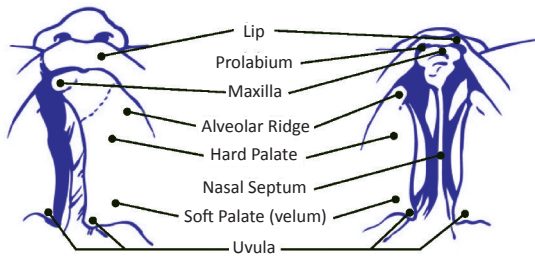
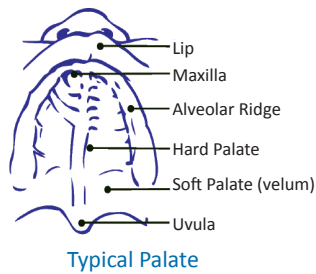


The nursing staff will demonstrate how to feed the child with a special bottle.

Some children with cleft palate may have problems with breathing and swallowing, also related to the development of the cleft. The physicians will address these issues prior to discharge from the hospital. Parents will meet many specialists who will be involved in the treatment of the cleft, including the cleft surgeon and other pediatrics specialists.

## How is a cleft palate repaired?

Cleft palate surgery is performed when the child is older, between 9 and 15 months of age. It is safer to wait until the child is older for this operation, which takes longer than the cleft lip repair. Most children with cleft palate also have hearing loss related to fluid behind the eardrum. This develops because the cleft palate muscles cannot open the tube that drains the middle ear. At the same time that the palate is repaired, ear tubes are placed to correct the hearing loss.

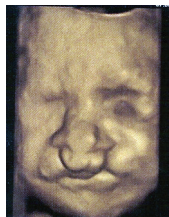


Unilateral Cleft Palate

Bilateral Cleft Palate

## Can cleft lip be diagnosed prior to birth?

Ultrasound imaging in the second trimester can show many details of the child's face. If he or she has a cleft lip, it may be detected. The obstetrician can refer the family to the cleft team prior to delivery so they can meet the surgical team and begin to prepare for treatment.



Prenatal ultrasound showing clefts of both sides of the upper lip

## Can older children be treated?

Sometimes minor clefts might not be diagnosed until later in life. Treatment recommendations will vary depending on the type and severity of the cleft, the presence of associated syndromes or other birth defects, and the child's age and needs. Although surgical repair can improve the look and appearance of a child's face, it may also improve breathing, hearing and speech. Children born with orofacial clefts might also require treatments such as special dental or orthodontic care or speech therapy.

## How is the surgery and care coordinated?

Within seven to ten days after discharge from the hospital, the child's parents will meet with the surgeon who will repair their child's cleft. Additional follow-up appointments will also include the child's pediatrician, a feeding specialist, a genetic specialist, and possibly other pediatric specialists, depending on any other medical issues discovered during the child's initial evaluation in the hospital.

## Each patient receives individualized care.

A team of specialists, coordinated through SUNY Downstate Medical Center, will devise a comprehensive, individualized plan of treatment for the child. These experts will meet on a regular basis to organize the specific follow-up appointments each child will need. All recommendations made by the cleft team will be discussed with the parents.

## Quick Facts

### Cleft Lip and/or Cleft Palate:

- Affect approximately 1 in every 700 babies—they are the most common birth defects in the U.S.
- Are more common in boys than in girls.
- Are more common in children of Asian, Latino or Native American descent.
- Can occur unilaterally—involving only one side of the mouth—or bilaterally, involving both sides.
- Can be successfully treated with surgery, especially when conducted soon after birth or in early childhood.

### According to the Centers for Disease Control:

- Women who smoke during pregnancy are more likely to have a baby with an orofacial cleft than women who do not smoke.
- Women with diabetes diagnosed before pregnancy have been shown to be at increased risk of having a child with a cleft lip with or without cleft palate.

## References

Photos of Normal Upper Lip, Prenatal Ultrasound and Feeding Bottles courtesy of: Losee JE and Kirschner RE, eds. Comprehensive Cleft Care. New York: McGraw Hill, 2009. Typical Palate, Unilateral and Bilateral Cleft Palate illustrations reprinted with permission from the Cleft Palate Foundation – [www.cleftline.org](http://www.cleftline.org).



**To make an appointment** with the Greater Brooklyn Cleft and Craniofacial Team, please contact:

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