

Cleft Lip or Palate



Healthy



Cleft Palate



Cleft Lip and Palate



Cleft Lip Bilateral



Cleft Lip Unilateral

What is a cleft lip or palate?

Cleft lip and cleft palate are the most common surgical birth defects, occurring in 1 in 600 births nationally.

Both conditions develop in the first trimester of a pregnancy, and the cause is often unknown.

- » Cleft lip is a condition where the two sides of the top lip do not fuse together during development, it also causes clefting of the nose leading to a wide abnormal nose that needs reconstruction.
- » Cleft palate is a condition where the roof of the mouth does not form completely, it also typically causes clefting of the gum (alveolus) and upper jaw (maxilla).

A Cardinal Glennon St. Louis Fetal Care Institute nurse is available 24 hours a day, seven days a week to discuss referrals with physicians and potential families by calling 314-268-4037, option 2.

Phone 314-268-4037, option 2
Toll-free 1-877-SSM-FETL (776-3385)
Web stlouisfetalcare.com
Email fetalcare@ssmhealth.com
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Cleft Lip or Palate

They can occur on one (unilateral) or both (bilateral) sides of the mouth and face. The lips and palate form separately as a baby develops, so a child can have one or both of the conditions. The size and position of the cleft is different in every child.

Both conditions are treatable, but they have the potential to cause:

- » Facial deformities
- » Dental problems-orthodontic needs
- » Feeding problems
- » Hearing impairment
- » Speech and language challenges
- » Sleep apnea

We know this diagnosis can be scary, but the SSM Health Cardinal Glennon St. Louis Fetal Care Institute can help. We work hand in hand with the St. Louis Cleft-Craniofacial Center at SSM Health Cardinal Glennon Children's Hospital to provide seamless care from prenatal diagnosis and delivery, to surgery and care through adulthood.

How are cleft lip and palate diagnosed?

Cleft lip and cleft palate can be diagnosed via ultrasound as early as 16 weeks into a pregnancy. There are rare occurrences of mild cleft palate that are not diagnosed until after delivery when an infant has difficulty feeding.

How are cleft lip and palate managed during pregnancy?

During your pregnancy we will help you and your family prepare for delivery and monitor the well-being of your baby. We will also perform a Level II ultrasound and a fetal echocardiogram to see if there are any other abnormalities. Depending on your unique situation, you may meet with members of our multidisciplinary team from:

- » Maternal-fetal medicine
- » Social Work
- » Fetal Heart Program
- » Neonatology
- » Genetics
- » The Cardinal Glennon
St. Louis Cleft-Craniofacial Center Team

This team will work with you to decide the best treatment for your child after delivery.

How does cleft lip affect my baby after delivery?

Each child is different and so is their cleft, this is why every child's care plan is unique. Babies with cleft lip and cleft palate can typically go home after delivery, but will require surgery to repair the cleft during their first year of life.

Initially, your baby might have difficulty feeding; special cleft bottles, along with proper positioning, can help ease the feeding process. Our cleft-craniofacial team and lactation specialists have a wealth of knowledge and experience in feeding babies with cleft lip and palate, and can help you learn how to properly feed your baby.

After delivery, you and your baby will meet with the team from the Cardinal Glennon St. Louis Cleft-Craniofacial

Center, who will help finalize a specialized care plan for your little one.

The team at the Cleft-Craniofacial Center includes:

- » A Nurse Coordinator
- » Plastic Surgeons
- » Speech/Feeding Therapists
- » Audiologists
- » Ear, Nose and Throat Specialists
- » Orthodontists
- » Pediatric Dentists and Prosthodontists
- » Sleep Medicine Specialists
- » Genetic Specialists
- » Psychology Specialists

The team is designated an Affiliated Team by the American Cleft Palate-Craniofacial Association (ACPA), the governing association of cleft-craniofacial centers.

How are cleft lip and palate treated?

The treatment of cleft lip and cleft palate require a collaborative approach involving a team of specialists.

Proper treatment will help restore normal functions, create a more typical appearance and help your child reach his or her full potential.

Our plastic surgeons are specialists in cleft lip and palate surgery and can reshape the bones of the face to improve the normal shape and function of the face. During your child's reconstruction, we can also repair the cartilage and soft tissues of the face, lips, palate, nose and tongue.

If your baby was born with a cleft lip we recommend lip repair surgery when your baby is between three and six months old. We typically repair a cleft palate when your child is 9 to 12 months of age. As your child continues to age and develop, additional surgeries might be required to enhance their function and appearance. You will learn more details about these surgeries during visits with the Cleft Team.

Working closely with you and your child, our goal is to restore the unique elements of your child's appearance, so they can speak and function more normally, achieving their best life.

We understand that a Cleft Lip or Palate can be a scary diagnosis. That's why we're available to help 24 hours a day, 7 days a week. For more information or to schedule an appointment, call us at 314-268-4037, opt. 2 or toll free at 877-SSM-FETL (877-776-3385).

While we can't change the diagnosis, we can provide you expert care and support, helping your baby get the most out of treatment - and life.

Feeding Your Baby With Cleft Lip and/or Cleft Palate

Cleft lip and cleft palate can present a unique set of feeding challenges. A baby with a cleft palate typically has normal sucking and swallowing reflexes, but is unable to create negative pressure to efficiently suck or extract liquid from a bottle or breast. This is similar to when you try to drink from a straw with a crack in it. A baby with a cleft lip may have a hard time making a good seal around the nipple.

Our team of cleft lip and palate specialists and lactation consultants are here to help provide you with the support and resources to successfully feed your little one.

Breastfeeding

Even though you may not be able to traditionally breastfeed, there are alternative ways to provide your baby with breast milk. Pumping your breast milk and feeding your baby with special bottles is a successful feeding solution for many families.

Learning you cannot breastfeed can be disappointing for many mothers, but you can still provide many of the benefits of breastfeeding to your baby. In addition to pumping breastmilk, you can have skin to skin and eye to eye contact with your baby while feeding. The Cleft Palate-Craniofacial Association also recommends non-nutritive sucking once your baby has become successful feeding from a bottle. These exercises can stimulate your baby's mouth and tongue muscles, enhance the bonding process and can help stimulate milk production for mothers who are pumping breast milk.

Bottle feeding

Finding the best bottle for your baby can be challenging for any parent, even those whose baby does not have a cleft lip or palate. You may need to try various bottles and nipples to see which one works best for you. We recommend giving your baby up to 48 hours to adjust to a new bottle or nipple before switching. Our team is here to help, and guide you through this process, oftentimes with the help of your pediatrician.

Feeding Your Baby

When you are feeding your baby remember that the goal is to provide them with the right amount of milk in around 30 minutes or less without taking in too much air. If feeding is taking longer than 30 minutes, your baby may be using too much energy to eat, burning calories they need to grow.

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Feeding Your Baby With Cleft Lip and/or Cleft Palate

When you begin feeding, make sure you hold your baby upright, this will help your baby swallow more easily and can prevent the milk from flowing back into the nose or middle ear area.

Start the feeding by touching your baby's lips with the nipple. Once your baby latches on to the nipple, keep the bottle tilted down so the nipple is full of milk and pointed away from the cleft. Your baby will adjust the nipple to the most comfortable position.

As you feed your baby they should develop a rhythm of sucking, swallowing then taking a short rest. Watch for this pattern and make sure there is a swallow followed by a breath. If you are using an assisted-delivery bottle, where you can adjust the flow of milk, make sure to not squeeze the bottle while your baby is swallowing or taking a breath. This process will become easier with time.

Babies with a cleft lip or palate take in more air while they are feeding. This simply means they need to be burped more often, typically after every half to one ounce. Follow the cues and signs from your baby and burp them when needed.

As you feed your baby you may notice milk escaping from the nose. This is called nasal regurgitation, and is common for babies with cleft lip and palate. Do not be alarmed, your baby is not choking, and this is not dangerous. Your baby may also cough or sneeze when this happens. This is your baby's way of clearing and cleaning their nose. If this is happening frequently, try holding your baby more upright while feeding. At the end of the feeding, it may be beneficial to gently suck the milk from the baby's nose with a bulb sucker.

We know this is a new journey for many of our families. If you have any questions about your baby's feeding, growth or development we are here to help.

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