

# Congenital Cleft Lip and Palate

Image 1  
Cleft in lip

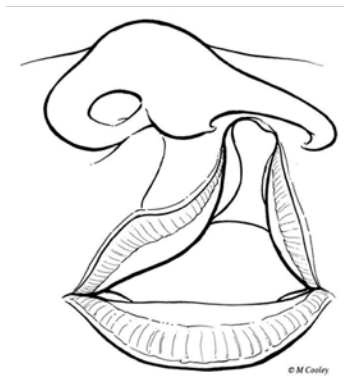
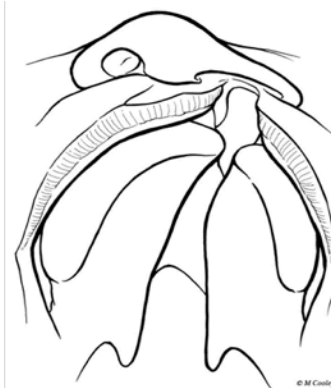


Image 2  
Cleft in palate



## Overview

Cleft lip and/or cleft palate is one of the most common birth defects in the U.S., affecting approximately one in 700 babies. Cleft lip and palate may occur as part of an underlying syndrome or be an isolated birth defect. A cleft lip is the result of the lip not joining together completely during the first few months of fetal development. This often includes the separation of the upper gum line. A cleft palate, which also occurs during the first few months of fetal development, is a separation in the roof of the mouth caused by the sides of the palate not completely joining together.

The severity of cleft lip and cleft palate can vary. A baby can be born with a cleft lip, a cleft palate, or both a cleft lip and palate. A unilateral cleft lip or palate affects just one side of the mouth. A bilateral cleft lip or palate affects both sides of the mouth.

## Causes

A variety of factors can come into play to determine if a baby is born with a cleft lip or cleft palate. In most instances, there is no single explanation, but a combination of many factors acting together that results in clefting. There are cases in which a cleft is due to a more comprehensive genetic syndrome that includes other birth defects as well. A geneticist evaluates every new patient to determine if the cleft is isolated or part of an underlying syndrome. Isolated cleft lip with or without cleft palate and isolated cleft palate may be caused by a variety of both genetic and non-genetic factors. Non-genetic factors include prenatal exposure to alcohol, cigarettes, and some medications and drugs. In most cases, however, a causative factor is not identified.

## How Cleft Lip is Diagnosed

Cleft lip may be found during routine prenatal ultrasound or may be discovered after the baby is born. If your doctor suspects a problem, additional tests may be ordered. These may include:

- **Fetal echocardiogram:** A fetal echocardiogram is a special ultrasound used by a pediatric heart doctor (cardiologist) to look closely at your baby's heart and surrounding blood vessels.
- **Fetal MRI** (magnetic resonance imaging): This type of imaging gives more detailed pictures of your baby's organs.

## Other Tests

Some congenital conditions are because of changes in DNA, or a baby's genetic make-up. The doctors may suggest genetic testing to find out more about your baby's DNA.

- **Cell-Free Fetal DNA testing:** Your doctor can take a sample of your blood to look for copies of fetal (baby) DNA. This is only a screening test. A positive result means that there could be problems with the DNA. This should be confirmed with another test to be sure of the result. Other testing can be done before or after birth depending on the needs of the baby.
- **Amniocentesis:** A small sample of the amniotic fluid that surrounds the baby in the womb is taken and tested for DNA problems. This test is usually done in the middle of the second trimester. An amniocentesis can be used to confirm findings on the cell-free fetal DNA test.
- **Testing the baby:** After birth, a test is done with a sample of your baby's blood to look for chromosome problems. This is called either a "karyotype" (basic chromosome study), or microarray (a more detailed look and all genes).

## Care During Your Pregnancy

Your doctor will monitor your pregnancy closely, and the presence of a cleft in your child should not alter its course. It is important to call your doctor if you have any questions or concerns during your pregnancy.

If a cleft lip and/or palate is found while you are pregnant, you will continue to receive care from your doctor and may be referred to the Ohio Fetal Medicine Collaborative (OFMC).

Through the OFMC, you will see a doctor who specializes in taking care of high-risk patients. You will also meet with the Cleft Lip and Palate Center Team at Nationwide Children's Hospital to learn more about your baby's care after he or she is born. Nurse coordinators and other members of the team will be available to help answer questions and concerns, to guide you through your pregnancy, and to prepare you for your child's birth.

## Care After Your Baby Is Born

The treatment of a child born with cleft lip and/or cleft palate begins at birth and continues into young adulthood. You will be referred to Nationwide Children's Hospital Cleft Lip and Palate Center for the care for your baby. A comprehensive team of specialists will care for your child, providing attention to feeding and development, surgical repair, speech and hearing, dental and orthodontic needs, and psychosocial well-being.

**Clinical Feeding Evaluation.** If the cleft involved the lip alone, your baby may be able to feed well enough to go home from the delivery hospital without any special intervention. If a cleft palate is present, you will learn special feeding techniques to ensure that your baby receives enough calories to grow and gain weight. A comprehensive feeding evaluation is an integral component of team care. Infants born with a cleft palate may face feeding challenges that will require modifications in feeding techniques. There are several types of special bottles and nipples that are specially designed for cleft-affected infants. The craniofacial feeding team works closely with each family to determine the feeding system that is best for their infant and monitors each infant's weight gain and development.

**Hearing Testing (Audiometry) and Tympanometry.** Children born with cleft palate are at risk for hearing loss due to abnormal function of the muscular tube (Eustachian tube) that helps clear fluid from behind your child's eardrum. Because fluid can collect behind the eardrum, many children with cleft palate will need frequent monitoring of their hearing, even after palate repair. The most common type of hearing problem associated with cleft palate is usually temporary and treatable. In most cases, infants will require placement of special tubes into their eardrums (called ventilation tubes or pressure-equalization tubes) in order to prevent fluid from accumulating in the middle ear space and to reduce the risk of hearing loss.

**Cleft Lip Surgery.** The goal of cleft lip surgery is to restore normal appearance and function to the upper lip. Cleft lip repair may be performed in one or two stages, usually beginning at three months of age. In some cases, lip repair may be preceded by pre-surgical orthopedics, such as lip taping or nasoalveolar molding (NAM), a procedure designed to lessen the severity of the cleft prior to surgical repair.

**Cleft Palate Surgery.** Cleft palate repair is typically performed on infants that are between 10 and 12 months of age. Since the primary goal of repairing the palate is to provide for normal speech, the surgery is performed early during language development. As with cleft lip surgery, the tissues of the palate are detached and rearranged in order to close the cleft. The muscles of the soft palate are also repositioned to allow for the best possible function for speech.

## **Looking Ahead**

Your baby will require regular follow-up appointments to monitor feeding, growth, and development. You will want to find a local pediatrician to take care of routine checkups, immunizations, and other doctor's visits.

Our nationally-recognized Cleft Lip and Palate Center team has a single, clear mission: to work together as a team to ensure that you and your child receive the very best care and quality outcomes. The children and families who turn to us receive comprehensive care from a multi-disciplinary team of expert clinicians who have come together to ensure that every child born with a facial difference enjoys the best possible quality of life.

## **About the Ohio Fetal Medicine Collaborative**

The Ohio Fetal Medicine Collaborative (OFMC) is a group of care providers and hospitals committed to achieving optimal outcomes for high-risk expectant mothers and their babies with suspected fetal diagnoses. Members of the OFMC include:

- Dayton Children's Hospital
- Miami Valley Hospital
- Mount Carmel Health Systems
- Nationwide Children's Hospital
- OhioHealth
- The Ohio State University Wexner Medical Center

For more information about OFMC visit our website at [OhioFetalMedicine.org](http://OhioFetalMedicine.org)

**For more information about the Cleft Lip and Palate Center at Nationwide Children's, call (614) 962-6366 or visit our website at [NationwideChildrens.org/Cleft-Lip-Palate-Center](http://NationwideChildrens.org/Cleft-Lip-Palate-Center).**