Congenital Cleft Lip and Palate

A cleft lip is an opening in the lip. It can be a small opening in the lip or extend to the nose (Image 1). The cleft can be on one side or both sides of the lip and may extend through the gums and the palate as well. A cleft in the lip forms because the lip does not join during early development in pregnancy.

Some babies with cleft lip also have a cleft palate. A cleft palate is an opening in the roof of the mouth. The palate is the top, or “roof,” of the mouth. It separates the mouth from the nose and is made up of 2 parts: the bony hard palate at the front of the mouth and the soft palate at the rear of the mouth. This happens when the sides of the palate do not completely join. A cleft palate occurs early in development during pregnancy.

Cleft palate may occur with or without cleft lip. An opening or separation on one side of the child’s mouth is a unilateral cleft palate; an opening in both sides of the palate is a bilateral cleft palate. The opening may be just in the soft palate or may involve both the soft and hard palate (Image 2).

Cause

The exact cause of cleft lip and palate is not always known. Cleft lip can run in families, so there may be a genetic cause in affected children. Cleft lip and palate may occur along with other syndromes or birth defects. Cleft lip/palate is one of the most common birth defects in the U.S., affecting about one in 700 babies. It is congenital, meaning that it happens before your baby is born.

How a cleft lip or cleft palate is found

You may have a prenatal ultrasound done while you are pregnant to learn about the health of your baby. A cleft lip and/or palate may be found during a routine prenatal ultrasound. A cleft palate is often difficult to diagnose prenatally; it is often found at the time of birth of your baby.
Care during your pregnancy

Your doctor will watch your pregnancy closely. Ideally, you will be able to have a normal vaginal delivery. If a cesarean section (C-section) is needed your doctor will discuss this with you. It is important to call your doctor if you have any questions or concerns during your pregnancy.

Ohio Fetal Medicine Collaborative

If this problem 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 will be available to help answer questions and concerns; guide you through your pregnancy; and prepare you for what to expect.

Care after your baby is born

If the cleft is mild, your baby may be able to feed well enough to go home from the delivery hospital. You will be referred to Nationwide Children’s Hospital Cleft Lip and Palate Center for continuing care for your baby’s cleft lip or palate.

Problems your baby may have because of a cleft lip or palate are:

- Failure to gain weight
- Feeding problems
- Flow of milk through the nose during feeding
- Poor growth
- Repeated ear infections
- Speech delay
- Dental problems

You will learn special feeding techniques to ensure that your baby receives enough calories to grow and gain weight. A therapist may also help to improve your baby’s feeding and swallowing skills. You will learn about several types of special bottles and nipples that are specially designed for infants with cleft lip and palate.

At Nationwide Children’s, a team of specialists will care for your child with cleft lip and/or palate, providing attention to surgical repair, speech and hearing, dental and orthodontic needs, and psychosocial well-being.

Surgery

Cleft lip surgery is usually done when the baby is three to four months of age. The goal of cleft lip surgery is to restore normal appearance and use of the upper lip (Image 3).

Surgery to repair a cleft palate is generally done when your infant is between 9 and 12 months of age (Image 4). The primary goal of repairing the palate is to avoid any abnormal speech development, so the surgery is scheduled before the child’s speech develops.
**Care after surgery**

Most babies heal after surgery without problems. Your child will probably be in the hospital for 1 or 2 days after surgery. Complete recovery can take up to 4 weeks.

The surgical wound must be kept very clean as it heals. It must not be stretched or have any pressure put on it for 3 to 4 weeks. Your child’s nurse should show you how to take care of the wound.

Until the wound heals, it is important for your child not to put hands or toys in the mouth.

**Follow up**

Your baby will need regular follow-up appointments to measure growth, development and nutrition. You will want to find a local pediatrician to take care of the routine checkups, immunizations and doctor’s visits. The program coordinator can help if needed.

A team of doctors and other specialists at the nationally recognized Nationwide Children’s Cleft Lip and Palate Center is involved in your child’s ongoing care.

As your child grows, additional procedures may be needed in order to restore normal form and function of his cleft lip or palate. Treatment for a child born with cleft palate begins at birth and may continue into young adulthood.