Let's Talk ABOUT...

As a child's body is forming before birth, the left and right areas of the face are separate parts. Early in the pregnancy, these areas grow toward each other. They meet and fuse together to become one. The nose, lips and mouth are formed. The lip fuses at about four weeks, and the palate fuses at eight to twelve weeks. Sometimes, the lip or the palate does not fuse together completely. The area remains split, or cleft. At this time, doctors are not sure what causes clefts.

The roof of the mouth, called the palate (PAL-et), has two parts. The hard palate is in the front of the mouth. Above it is the skull. The soft palate is at the back of the mouth (see Figure 1).

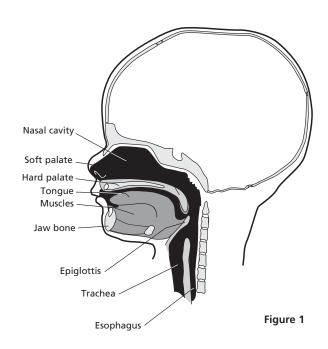
How often does this happen?

For every 700 babies born in the U.S., one of them will have a cleft. More boys than girls are born with a cleft lip and palate, but more girls than boys are born with just a cleft palate.

Are there different kinds of clefts?

Clefting can occur in several different combinations. The most common types of clefts are: unilateral (one-sided), bilateral (two-sided), cleft of the hard palate, or cleft of the soft palate only (see Figure 2).

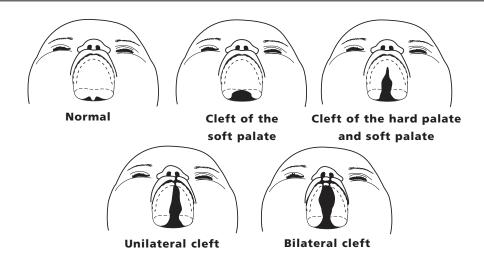
Cleft lip and palate



How does having a cleft affect my baby?

Although a baby born with a cleft is usually very healthy, the cleft can present challenges. Every child is different. Your child may have problems with feeding, hearing, and speech. The cleft may interfere with jaw growth and development or cause dental problems.

Figure 2



What about feeding?

Babies born with just a cleft lip can usually nurse like other babies. Babies born with a cleft palate will have a hard time making a seal around the nipple to create suction. If your baby is unable to breastfeed, you can use a breast pump and a special bottle designed to make feeding easier. Members of the cleft palate/craniofacial (cray-nee-o-FAY-shall) team can show you the choices available. You may have to try different products to find the one that works best for you and your child.

When feeding, milk may run out of the nose of a baby with a cleft palate. This is not a health risk. Have a soft cloth on hand to wipe the milk away. Feed your baby in an upright position to help milk to flow down the throat. This will lessen the amount of milk reaching the nose. Babies with clefts tend to swallow more air and need to be burped more often than other children. With a little time and patience, you will become an expert at feeding your baby.

Are the ears affected?

The eustachian (you-STAY-shan) tube connects the middle ear to the nose and throat. It drains fluids from the ear. Often, the unusual muscle structure of a cleft prevents the eustachian tubes from draining normally. Fluids build up and bacteria can grow in the middle ear, causing infections. Tympanostomy (tim-pan-OSS-toe-mee) tubes can be placed to help drain the middle ear. (see *Let's Talk About...*

Tympanostomy tubes.)

What about speech?

The roof of the mouth directs sound from the vocal cords out through the open mouth. If the palate is cleft, sound can be directed into the nose. A child with a cleft can sound nasal and be hard to understand. Speech therapy can help your child to form sounds that can be understood by others. Being able to communicate well will help your child to be more social, both at home and in school.

What about my child's teeth?

The cleft often causes problems with teeth. Some children may need a bone graft if a part of their jaw is missing. X-rays will help see if your child's teeth have been affected. Sometimes they may be in the wrong place. As with many children, your child may need orthodontics (orth-o-DON-ticks), or braces.

How can I find support?

Most hospitals in large cities have cleft palate-craniofacial teams. Check with your local health care facility for information. The American Cleft Palate-Craniofacial Association can be reached on the internet at **www.cleftline.org** or by calling (919) 933-9044.

How is the cleft repaired?

Clefts can be repaired by surgery. The American Cleft Palate-Craniofacial Association (ACPA) recommends a team approach to treating children with clefts. Usually, a team is made up of the following:

- A craniofacial plastic surgeon, a specialist in facial repair
- An otolaryngologist (oh-toe-lar-in-GOLL-o-jist), an ear, nose and throat specialist
- An audiologist (aw-dee-ol-o-jist), a specialist in hearing
- A pediatric orthodontist
- An audiologist
- A pediatric dentist
- A speech therapist
- A pediatrician
- A social worker
- A geneticist (gen-ET-eh-sist), who studies the baby's genes
- A registered nurse
- You the most important member of the team.

The team will work together to plan therapies and surgeries that will promote a happy, healthy life for your baby.

When should the cleft be repaired?

The timing of surgical repairs and the number of surgeries needed depend on the type and severity of cleft your child has. The surgical repair of your child's cleft may be planned over a period of time. Your surgeon will give you a timeline for your baby's repairs.

Lip repair

At eight to twelve weeks, or when your baby weighs about ten pounds, his lip will probably be repaired. The usual hospital stay is one to three days.

Protecting the surgery site

When your baby returns from surgery, he may have an arch of metal, called a Logan's Bow, over the surgery site (see Figure 3). The bow is taped to the cheeks. This will protect the surgery site from injury. It will have to stay in place at least until you have a follow-up visit with your surgeon.

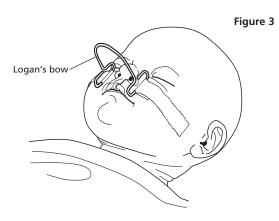
When your child is in the recovery room, he will have fabric restraints placed on his arms These are called Snuggle WrapsTM or "No-No's"TM. The wraps will prevent him from touching the surgical site. He will have to wear the arm restraints for two or three weeks. The restraints should be removed every four to six hours so your child can exercise his arms. Be sure he moves his arms in all directions. It is very important that you hold your baby while the splints are off to make sure the surgical site is not touched. Care should be taken with a toddler who is attempting to walk. The arm restraints will throw him off balance. Supervise the child carefully to prevent him from falling

Feeding

Your baby will first be given clear liquids when he returns from the recovery room. When he is ready, he can return to his usual method of feeding. Never put hard objects such as fingers, spoons, or forks in your child's mouth until it heals.

Pain control

Your baby will probably need pain medicine for the first few days after surgery. Your surgeon may also prescribe pain medicine to help keep your child comfortable at home. Follow the instructions carefully. Call your pharmacist if you have any questions.



Infection prevention

You will receive specific instructions about cleaning the surgery site for the type of surgery that was performed. Never pull or put pressure on the site during cleaning. Most often, you will be told to keep the area clean using a mild soap and water. You may be told to use a weak solution of hydrogen peroxide to wipe the site and then apply a prescription ointment. Use a Q-tip® and and gently roll the ointment over the area. You will be given additional instructions on how to care for your child's lip when you go for your follow-up visit to the surgeon.

Remember! Always follow your surgeon's instructions if they are different from the information you read here!

Palate Repair

Every child's cleft palate is different in size, shape, and severity. The type of surgical repair and the healing process of cleft palate repair will be different for each child.

The surgeon may decide to perform a one-stage palate repair, depending on the size and severity of the cleft. This surgery is usually done when your child is about nine months of age. Both the hard and soft palate are closed. Your child will be in the hospital for two to three days.

If your surgeon decides on a two-stage repair, the first surgery will take place at about nine months. The soft palate is closed. The surgeon then will place a prosthesis (pros-THEE-sis), a plastic shield, over

the cleft in the hard palate. The hard palate will be repaired when your child is older and the cleft in his palate is narrower.

The recovery room

After surgery, your child will go to the recovery room. He will have fabric restraints, or Snuggle Wraps™, on his arms. This will stop him from touching the surgery site. He may also have a stitch through his tongue. It will help him to breathe easier if there is swelling in the back of the throat. The stitch will be removed in a day or two. There may be some blood coming from his mouth and nose. This is not unusual. It will decrease in 24 hours. Your child will be given clear liquids for the next day or two, and then can return to his usual method of feeding.

Fabric restraints

Your child will have to wear fabric arm restraints for two to three weeks after surgery, or until the surgeon tells you that it is all right to stop using them. These restraints are called Snuggle Wraps™, or "No-No's"™. The arm restraints will prevent him from touching the surgical site. The restraints should be removed every four to six hours so your child can exercise his arms. Be sure he moves his arms in all directions. It is very important that you hold your baby while the splints are off to make sure the surgical site is not touched. Care should be taken with a toddler who is attempting to walk. The arm restraints will throw him off balance. Supervise the child carefully to prevent him from falling.

Feeding

Your child can use the bottle and nipple with which he is comfortable. If he ate soft foods before surgery, he can likely start having them again in about four weeks. Do not give your child hard foods like chips, crackers, and hard candies. Never put spoons, forks, straws, or fingers in his mouth. Give him soft toys with which to play. Your surgeon will give you more detailed information on feeding your child after surgery.

Pain control

As with lip surgery, your surgeon may prescribe pain medicine for your child when he goes home. Follow the instructions carefully. Call your pharmacist if you have any questions.

Infection prevention

Your surgeon will give you instructions about wound care. You must keep the surgical site as clean as possible and protect the area from harm.

Remember! Always follow your surgeon's instructions if they are different from the information you read here!

Call your doctor if. . .

- Your child has a temperature over 101°, or 38.4°C, that does not come down with Tylenol™.
- There is increased drainage or bleeding.
- There is increased swelling.
- Nausea or vomiting increases or is uncontrolled.
- There are signs of dehydration: dry mouth, less than six to eight wet diapers in 24 hours.
- Your child doesn't want to eat.
- Diarrhea or constipation increases.
- He has chest pain or difficulty breathing.

If you are unable to wake your child, GO TO THE EMERGENCY DEPARTMENT OR CALL 911.



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All of the information contained in the *Let's Talk About*... series is for educational purposes only. This educational information is not a substitute for medical advice or for care from a physician or other health care professional. If you have questions about your child's health, contact your health care provider.