

A Guide about Cleft Lip & Palate

Texas Children's Hospital
Plastic & Craniofacial Surgery

texaschildrens.org/cleft

Dear Families,

Welcome to the Cleft Lip and Palate Clinic at Texas Children's Hospital. The Cleft Team offers comprehensive, specialized care for children with a cleft lip and/or palate. Since we began treating patients almost 50 years ago, we have helped thousands of families affected by this condition.

Each year, we see many new babies with a cleft lip and/or palate in our clinic. Most of these patients are followed in our clinic from infancy until adulthood. This guide will help understand clefts and learn when your child will need specific treatments.

Our cleft team consists of plastic surgeons, physician assistants/nurse practitioners, speech-language pathologists, craniofacial orthodontists, Ear, Nose and Throat doctors (ENT), social workers, geneticist, psychologists and dietitians. We work together with you to develop the best plan of care for your child.

All of our team members are dedicated to helping children with clefts achieve their full potential. Parents and caregivers are important members of the team. We encourage you to participate in your child's care by asking questions and following recommendations. All of us working together will lead to a better outcome for your child.

Sincerely,

The Texas Children's Cleft Lip and Palate Team

What is Cleft Lip and Palate?

A cleft lip and/or cleft palate happens when a child's upper lip, upper gums and palate (roof of the mouth) don't come together in the womb – leaving an open space. It is one of the most common birth conditions in the United States. About 1 out of every 1,000 babies in the United States are born with a cleft. Clefts can be repaired with surgery.

What causes clefts?

We do not fully understand why clefts occur. Most of the time, a cleft spontaneously occurs and is **not** the result of anything occurring during pregnancy. Sometimes clefts can be related to a family history or genetic condition.

Where is the cleft?

A cleft can impact any combination of these 3 areas:

1. **Lip:** Outside part of the cleft.
2. **Alveolus:** Gum and bone of the upper jaw.
3. **Palate:** The roof of the mouth. There are 2 parts of the palate – the hard palate (bone in the front) and the soft palate (muscles in the back).

How clefts are named

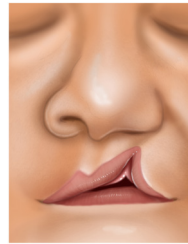
Unilateral – a cleft that is only on one side.

Bilateral – a cleft that impacts both sides

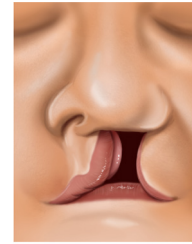
Incomplete – cleft involving a portion of the lip only

Complete – the gap extends from the lip to the nose

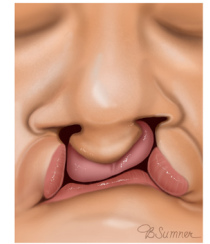
Types of clefts



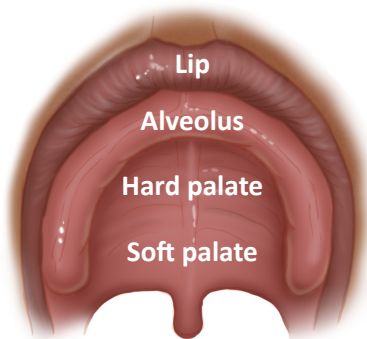
Incomplete
cleft lip and alveolus



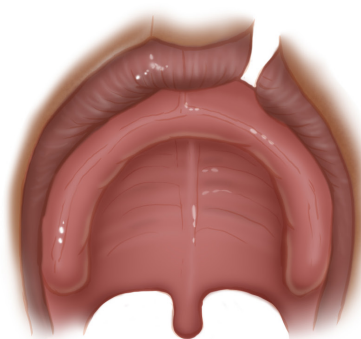
Complete
cleft lip and alveolus



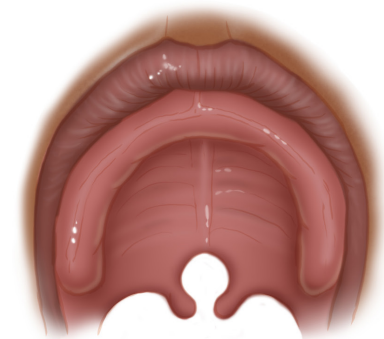
Bilateral complete
cleft lip and alveolus



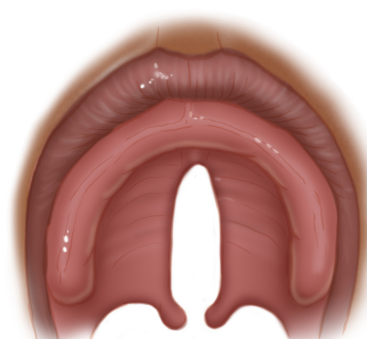
1. No cleft



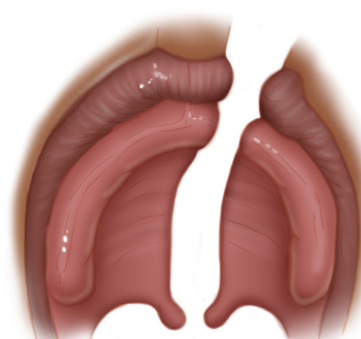
2. Cleft lip



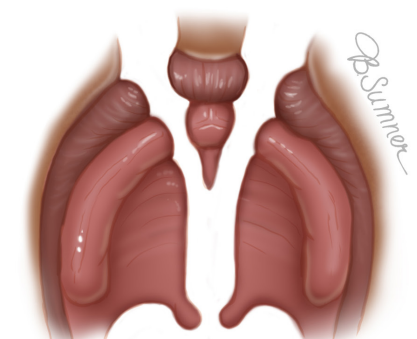
3. Cleft of the soft palate
(also known as Veau 1 cleft)



4. Cleft of the soft and hard palate
(also known as Veau 2 cleft)



5. Left unilateral cleft lip and palate
(also known as Veau 3 cleft)



6. Bilateral cleft lip and palate
(also known as Veau 4 cleft)

The Cleft Lip and Palate Team

Your child's care team is made up of many specialists who care for your child as they grow. Each specialist has unique knowledge and experience helping children with clefts. During your baby's first year of life you, will have appointments to plan for surgeries and check healing. Then, your baby will have appointments with the team once a year.

Plastic Surgery

The plastic surgery team consists of Plastic Surgeons and Plastic Surgery Advanced Practice Providers (APPs). The plastic surgery team leads and coordinates your child's treatment and communicates with all the other specialists to make sure your child is getting the best care possible. The plastic surgery team performs your child's cleft surgeries, including cleft repair, bone grafting, jaw surgery and others.



Dietitians

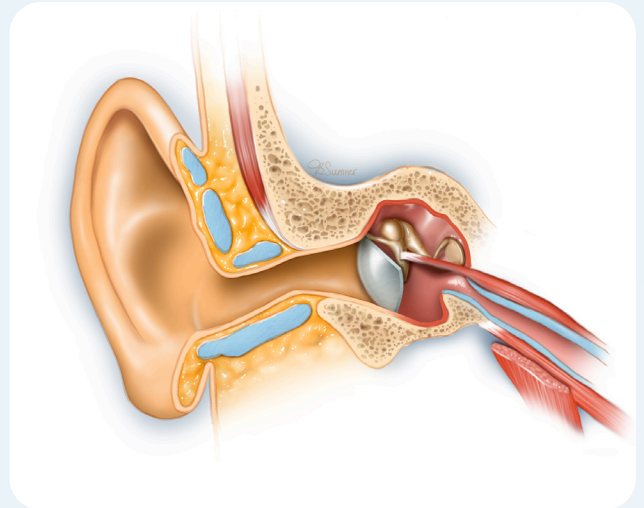
Many children with clefts, especially those with a cleft palate, have difficulty feeding early in life. They require extra attention, special bottles and feeding techniques. The dietitian team works with the speech-language pathology team to assess your child's feeding needs and give you resources to make their feeding as efficient and pleasant as possible. They will help your baby get big enough to make their first surgery as safe as possible. Follow their recommendations about the amount or type of formula your baby needs.

ENT (Ear, Nose and Throat)

The ENT provider takes care of your child's ears and airway. They check your child's hearing, and may perform surgery on your child's ears, tonsils or adenoids. Often these surgeries can be combined with a surgery needed for your child's cleft.

Speech-Language Pathology

A Speech-Language Pathologist (SLP) specializes in helping children speak and form words. During infancy, they help your child feed efficiently by recommending bottles or feeding positions. As your child grows, they assess your child's speech and language skills. They help develop treatment and therapy plans.



Orthodontics

The orthodontic team specializes in aligning your child's teeth. There are several periods in your child's life when they will likely come into contact with the orthodontic team, if needed: early in life for nasoalveolar molding, before and after bone grafting, and before and after possible jaw surgery. Texas Children's orthodontic team helps coordinate your child's dental care to make sure they are getting what they need.

Dentistry

Children with clefts often have missing, extra or irregular teeth. It is essential to work closely with your child's dentist, and to supervise your child's brushing and flossing, to make sure your child's teeth are as healthy and clean as possible.

Psychology

Being born with a facial difference can cause psychosocial concerns. The psychology team can help assess any stressors that your family may encounter as your child grows and can help provide resources.

Social Work

A social worker helps you navigate the healthcare system as an advocate, provides emotional and family support and shows you what resources are available.

Genetics

Some clefts (but not all) may be due to a genetic condition. In those cases, it is important to diagnose that genetic condition to make sure your child is getting the appropriate care. A genetic counselor can help assess your child and investigate whether their cleft is due to a syndrome. In addition, our genetic counselor can assist with family planning to discuss future pregnancies that might be affected by a cleft.

Primary Care

In addition to the primary care provider you choose, a Texas Children's Hospital primary care nurse practitioner follows your child throughout the infancy and toddlerhood stages. They help monitor feeding and growth to get your child ready for each surgery. They also help with the common issues that children with cleft may encounter.

Common Challenges for Children with Clefts

Feeding

The first priority in babies with clefts, especially those with cleft palate, is making sure they are getting the nutrition that they need to grow. It is important to see the cleft team within 1 to 2 weeks of your baby's birth to make sure feeding is going well. Babies with cleft palate are usually unable to feed from a regular bottle or breastfeed because they can't form suction. The team will recommend special bottles to help your baby feed better. Babies with cleft *lip (without cleft palate)* are usually able to feed without special modifications.

Congestion

Babies with cleft palate may sound congested all the time because milk gets into their nasal canals. Nasal saline or salt water nose drops and suction can be used to help clear the congestion.

Ear infections and hearing loss

Children with clefts are more likely to develop ear infections. Many children with clefts eventually need ear tubes. It is important to follow up with the Ear, Nose & Throat team to check your child's hearing.

Reflux

Gastroesophageal reflux is more common in children with cleft palate. Keeping your child at an incline during feeding, burping frequently and keeping them at a slight incline for 30-40 minutes after the feeding can help prevent reflux.

Reflux medication may be prescribed, if your baby:

- Has large amounts of spit-up
- Vomits after most feedings
- Seems irritable during feeding
- Has trouble gaining weight

Gas

Increased gas is common in babies with cleft palate because they swallow more air with feedings. Frequent burping during feedings can help, as well as over the counter drops like simethicone.

Speech and language delays

Children with clefts may have difficulty pronouncing certain words or making certain sounds. This can happen in any child with a cleft but is more likely if there is a cleft *palate*. It is important to work closely with the speech-language pathologist to detect speech difficulty and start speech therapy when recommended.

Dental issues

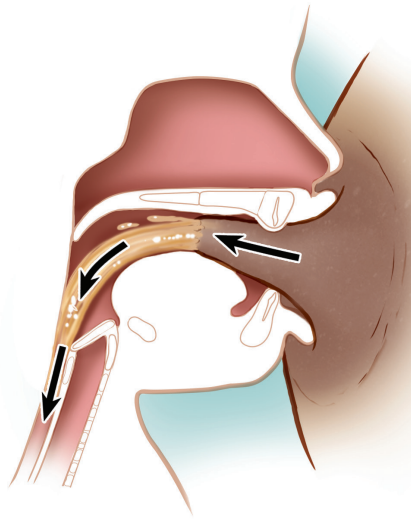
It is important to keep your child's mouth clean and follow up with your child's dentist. Children with clefts may have missing, extra or teeth in atypical positions, such as very close together. The orthodontist can help move the teeth with braces or other techniques. In addition, children with a cleft may have an underbite. A plastic surgeon may recommend jaw surgery when your child has finished growing.

Feeding

What about breastfeeding?

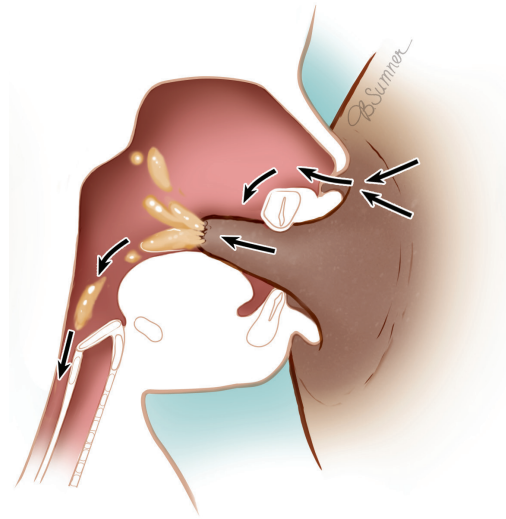
Babies with cleft palate have difficulty producing enough suction with their mouth to breastfeed. If your baby has a cleft palate, breastfeeding most likely is not possible. They may latch but will most likely have difficulty staying on the breast. They may end up frustrated and losing weight. Breast milk is especially important, so we recommend that you pump and give expressed breast milk to your baby through a specialty bottle. If you wish to breastfeed for bonding, we recommend feeding your baby first with a specialty bottle for nutrition and then putting them to your breast after.

Breastfeeding without a cleft palate



The baby is able to generate suction inside their mouth, allowing for the milk to be expressed from the nipple.

Breastfeeding with a cleft palate



Due to the connection between the mouth and the nose, air rushes in through the nose during suction, and the baby is unable to generate enough suction to express milk from the nipple.

Special bottles for Babies with Cleft Palate

- Medela “Special Needs” Feeder (formerly called a Haberman Bottle)
- Pigeon Bottle
- Dr. Brown’s Specialty Feeding System



Where to Get Bottles

- Bottles are available from online retailers
- The American Cleft Palate Craniofacial Association also has ordering information and videos showing the assembly and use of bottles at acpacares.org/resource/feeding-your-baby.

For specific feeding questions, feel free to contact the speech-language pathologist on your Cleft Palate Team.

Speech Development

Learning to talk is an important step in your child's growth. Speech development varies from child to child and depends on the type of cleft. Some babies have no speech difficulty and some may require help from a speech therapist. Your child's speech will be assessed every year to monitor language development and how your child produces sounds.

Cleft lip

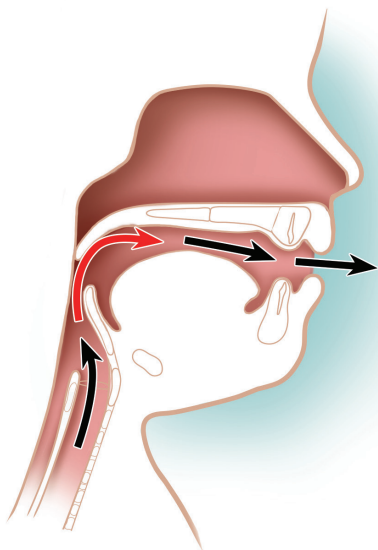
If your child's cleft is limited to their lip, speech will likely develop normally. Sometimes there are changes in how they pronounce sounds requiring the tongue right behind the teeth, like /t/ or /s/.

Cleft palate

Children with cleft palate are more likely to have speech difficulties. This can be caused by air leaking from the mouth into the nose during speech. This is known as velopharyngeal insufficiency (VPI). In this condition, the palate is not able to fully touch the back of the throat (pharynx) during speech. Children with VPI may have difficulty pronouncing sounds like /b/, /d/, /f/, /k/, /p/, /s/ and /t/. These sounds may come out muffled, or they may sound like /m/ or /n/.

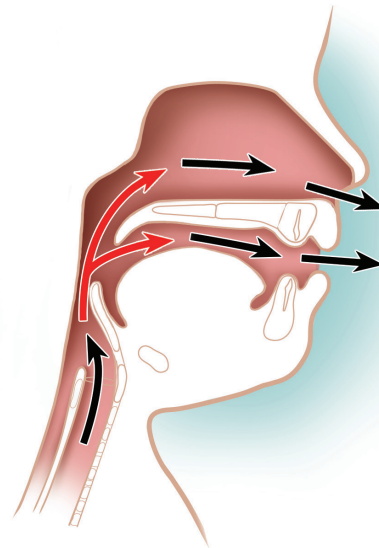
We repair the cleft palate around 1 year of age to place the muscles (soft palate) in the proper position. This positioning helps children be able to pronounce sounds correctly as they learn them. Having a speech evaluation every year is important. Your child's speech will be assessed at your annual team visit by our speech-language pathologist.

Speech with normal palate function



During speech, the soft palate (muscles) can touch the back of the throat (pharynx), allowing the air to go into the mouth and allowing air pressure to build up in the mouth.

Speech with VPI

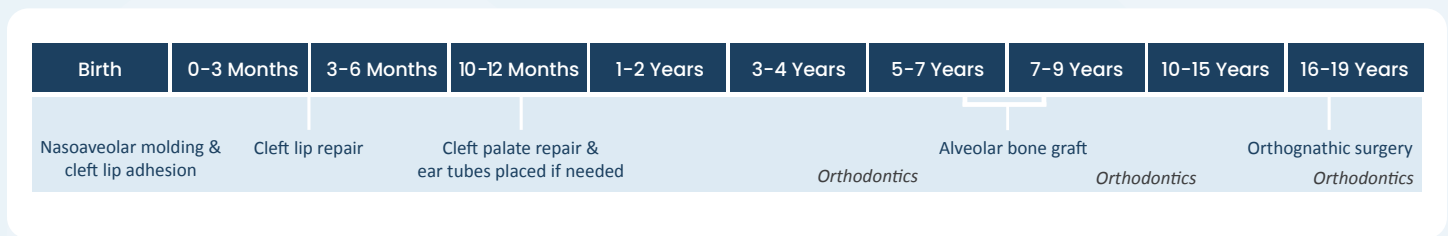


The palate is unable to touch the back of the throat during speech. Therefore, air rushes into both the mouth and the nose during speech, creating what is called "hypernasal speech."

Speech therapy may be recommended if your child's speech and language skills are delayed. Some families will choose to come to speech therapy at Texas Children's, while other families may prefer to be seen for therapy closer to their home. Texas Children's speech-language pathologists can work closely with any treating speech-language pathologists to ensure your child's speech develops appropriately. We will see them for their first speech-language evaluation several months after their palate has been repaired. During that visit, we monitor language development and listen closely to how your child produces sounds.

Timing of Surgical Repairs

The following is a simplified timeline and description of the most common surgeries that children with cleft might need. Not every child will require all these surgeries. On the other hand, some children might require more procedures than what is outlined here.

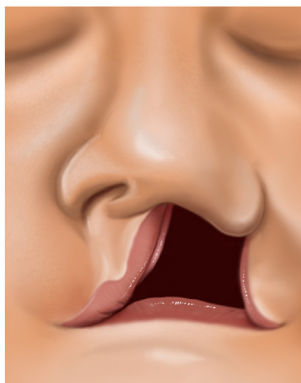


Molding therapy

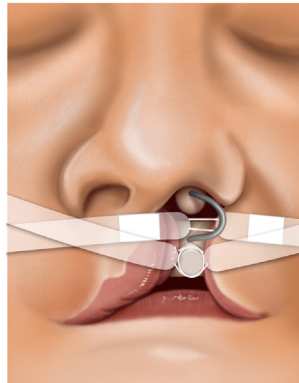
Before some babies can have surgery to repair a cleft they need molding therapy to bring the left and right sides closer together. Some molding therapies require surgery, however their purpose is still to prepare the structures for a surgeries that can close the gaps.

Nasoalveolar molding (NAM)

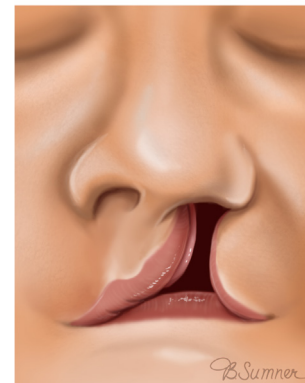
This type of molding therapy is a surgery performed by our orthodontist and plastic surgeon for newborns with a wide, complete cleft lip and cleft palate. NAM is an appliance, similar to a retainer, that helps bring the parts of the cleft closer together. NAM helps reshape the nose in preparation for cleft lip/nasal repair. After you child has NAM, they will have appointments every 1 to 2 weeks for until they are ready for cleft lip repair.



Wide complete cleft lip and Veau 3 cleft palate



The NAM device is used to progressively narrow the gap in the lip, alveolus, palate and to reshape the left nostril



Cleft after NAM and before surgery. The cleft is narrower, and the left nostril shape is more similar to the right nostril

Lip taping

This is an alternative to NAM for smaller clefts or for babies in the neonatal intensive care unit (NICU). Lip taping brings the lips and gums closer together. Our team will show caregivers how to apply the tape and other details to help this therapy prepare the baby for surgical repair of the cleft.

Cleft lip adhesion

This is an alternative to NAM in children with wide, complete clefts. It is a surgery that brings the parts of the cleft closer together in preparation for cleft lip repair. During a cleft lip adhesion, silicone stents can be placed in the nose and kept in place until cleft repair. This surgery usually requires a 1-night stay in the hospital.

Dynacleft

Dynacleft is for babies that have wide or nostrils that are very flat and a small or intact palate. This combination of stickers and mold guide the nostrils into a better position to improve facial symmetry before surgery

Cleft lip repair

When your baby reaches 10 lbs and is between 3 to 6 months of age, this surgery can be undertaken safely. This is the surgery where the lip and the nose are repaired directly. For some babies with narrow or incomplete clefts this may be their first surgery. Others will need a molding therapy before cleft lip repair.

At your post operative follow up, you will be instructed on how to take care of the scar. The team will meet with you before the surgery and then you will have appointments 1 week, 1 month and 6 months after surgery to check healing.

Cleft palate repair

When your baby is around 1 year of age, and after the cleft *lip* has been repaired, the cleft *palate* can be closed surgically. Before this surgery, you can see the open space, however, all the structures that are needed to repair the cleft palate are already available within the palate. The surgeon rotates the muscle and portions of the hard palate to improve the alignment and close the cleft. Most children are able to go home after 1 night in the hospital. Some children may not be interested in food after this surgery and may need to stay longer so the team can make sure they get used to eating again.

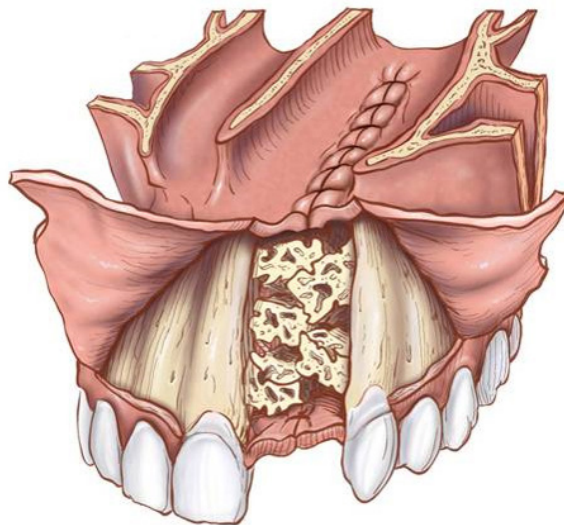
After this surgery, please adhere to dietary restrictions provided by your team in order to assist with healing of the palate. No hard objects (fingers or toys) or cruchy foods (crackers and baby puffs) in the mouth until approved by your team.

Alveolar bone graft (ABG)

An ABG is performed in children with an alveolar cleft.

A small incision is made over one of the hip bones, and some bone marrow is taken. The tissues of the alveolar cleft are then opened, the bone placed inside, and the incisions closed. After this surgery, please adhere to dietary restrictions provided by your team in order to assist with healing of the palate.

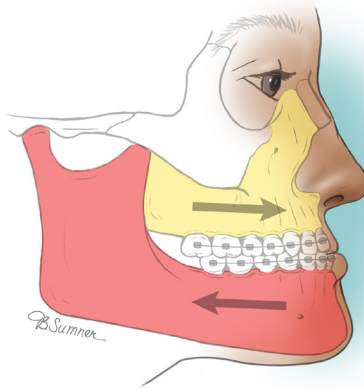
Alveolar bone graft



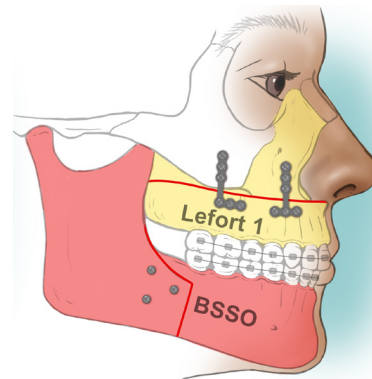
The mucosa of the gum is opened, bone is packed into the cleft, then the mucosa is closed with stitches

Orthognathic surgery

This is also known as jaw surgery. It is performed in adolescents whose jaws do not line up correctly when the bite cannot be fixed with orthodontics alone. The surgeon may move the upper jaw (LeFort 1), lower jaw (bilateral sagittal split-osteotomy or BSSO), or both. This surgery usually requires several nights in the hospital. There will be dietary restrictions that your team will discuss with you.



Example of a patient with an underbite, where the lower jaw is more forward. This is a typical jaw position that may occur in children with cleft lip and palate



Jaw position after orthognathic surgery. A surgeon moves the maxilla (yellow) forward and/or the mandible (red) back.

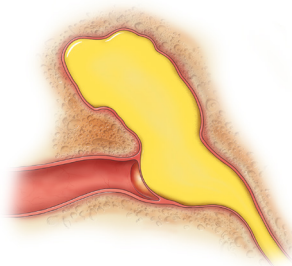
Septorhinoplasty

This is often the final surgery for children with cleft lip and palate. From the outside, it helps improve the shape and symmetry of the nose. Inside the nose, it will correct the cartilage that divides the nostrils in two, if needed (deviated septum).

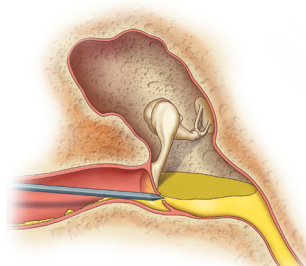
Other Procedures

Sometimes, children with clefts may need other surgeries. The most common other surgeries are:

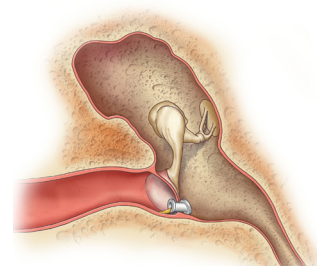
- **Ear tubes (also known as tympanostomy or myringotomy tubes):** These are small tubes that the ENT inserts through your child's eardrum to allow fluid to drain and to decrease the risk of ear infections.



Fluid filled middle ear



Myringotomy/Draining



Ear tube in place

- **Cleft lip and nose revision:** Sometimes the cleft lip and nose repair needs a touch-up as your child grows, and a revision can help improve the scar and the shape of the nose and lip.
- **Palate revision:** Sometimes, a child with a history of cleft palate repair continues to leak air through their nose (VPI) when they speak. Your plastic surgeon, in conjunction with the speech-language pathologist, may recommend a palate revision to improve your child's speech.

Patient and Family Resources

- **American Cleft Palate Craniofacial Association:** Read more about cleft lip and palate and learn about team-based care and family experiences at acpacares.org. You can also find many booklets about what to expect at each stage of your child's life there.
 - Financial resources to help pay all or part of the costs of treating a person with a cleft lip and/or palate fall into three categories: 1) health insurance; 2) federal and state resources; 3) and private and non-profit agencies, foundations, and service organizations. Information is in your folder and available online.
- **Children's Craniofacial Association:** Find out more about syndromes and join a network of other families touched by a craniofacial condition at ccakids.org
- **MyFace:** myFace is a non-profit organization dedicated to changing the faces – and transforming the lives – of children and adults with facial differences.
myface.org/craniofacial-conditions/cleft-lip-and-or-palate/
- **Smile Train:** Smile Train is the world's largest cleft-focused organization, with a sustainable and local model of supporting surgery and other forms of essential care. Over the last 20+ years, we have supported safe and quality cleft care for 1.5+ million children and will continue to do so until every child in need with a cleft has access to the care they deserve.
smiletrain.org/events

Visit us online at <https://www.texaschildrens.org/departments/cleft-lip-and-palate-clinic>

Our locations:

ADD ALL CLEFT LOCATIONS HERE

