

# Cleft Lip and Palate

A GUIDE FOR FAMILIES



**Boston  
Children's  
Hospital**  
Until every child is well™

Plastic and  
Oral Surgery

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## Our Program

Boston Children's Hospital Cleft Lip and Palate Program is one of the largest and most experienced in the world for cleft lip and/or palate diagnoses, treatment and follow-up care.

We are committed to providing the highest quality medical and surgical care for all patients, and supporting families throughout the treatment process.

Proper cleft lip and/or palate treatment often requires the skills of many specialists. Our multidisciplinary team includes plastic and oral maxillofacial surgeons, dentists, otolaryngologists, speech-language pathologists, audiologists, psychologists, social workers and clinical geneticists with the pediatric expertise needed to get your child on the road to recovery.

This multidisciplinary team works together to address the individual needs of each patient and family in treating and managing cleft lip and/or palate.

As one of the largest cleft lip and palate programs of its kind, we provide a wide range of diagnostic, treatment and follow-up services for cleft lip and/or cleft palate. Services include:

- surgical cleft lip and/or palate repair
- dental and orthodontic treatment
- feeding guidance and nutritional support
- evaluation and management of hearing loss
- speech therapy
- psychosocial support and counseling

**To schedule an appointment or speak to a member of our team, email [samantha.hall@childrens.harvard.edu](mailto:samantha.hall@childrens.harvard.edu) or call 617-355-6309.**

## Our Team of Specialists

The Cleft Lip and Palate Program at Boston Children's is one of the largest and most experienced treatment centers in the country, caring for nearly 600 infants, children and adolescents every year.

Our combination of specialized training, innovative treatments and compassionate, family-centered care has made us a national leader in the field.

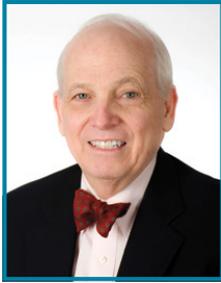
Because a cleft can involve the lip, nose and palate (the roof of the mouth), a child's hearing, feeding, speech and dental functions may all be affected. A dedicated and knowledgeable team of specialists from several disciplines is necessary to give these patients—and their families—the care and long-term support they need.

Our expert team includes:

- plastic surgeons
- oral and maxillofacial surgeons
- orthodontists
- dentists
- feeding specialists
- nurses
- nurse practitioners
- physician assistants
- psychologists and social workers
- otolaryngologists
- speech-language pathologists
- audiologists
- clinical geneticists

**To schedule an appointment with a member of our team, call 617-355-6309 or email [samantha.hall@childrens.harvard.edu](mailto:samantha.hall@childrens.harvard.edu).**

## Our Surgeons



**John B. Mulliken, MD**  
*Director, Craniofacial Program  
Attending Surgeon,  
Plastic Surgery*



**John G. Meara, MD, DMD, MBA**  
*Surgeon-in-Chief,  
Plastic Surgery*



**Carolyn R. Rogers-Vizena, MD**  
*Attending Surgeon,  
Plastic Surgery*



**Ingrid Ganske, MD**  
*Attending Surgeon,  
Plastic Surgery*

## Insurance Information

Understanding and maneuvering through the insurance coverage process can be challenging.

Here are some tips to assist you throughout the process:

- Ask your child’s doctor which dental and medical procedures are likely to be necessary. A list of possible procedures is provided on page 29, “What to Expect.”
- Be sure to enroll your child in your dental insurance plan in addition to a medical plan. Dental procedures are usually not covered by medical insurance.
- Check with your insurance provider to make sure all of the procedures are covered by your plan.
- Ask your doctor whether there will be additional referrals needed down the line.

If you have other questions, please contact your insurance provider directly by calling the phone number on the back of your insurance card.

As of August 26, 2012, a bill was passed to support patients with cleft lip/palate diagnoses.

The bill—entitled “**An Act Relative to the Treatment of Cleft Lip and Cleft Palate, Acts 2012, Chapter 234**”—allows patients to receive insurance coverage for any services or treatment related to these diagnoses.

## **Insurance FAQs:**

### **What are the age limits?**

The law applies to children under the age of 18. It may cover any treatment started before your child's 18<sup>th</sup> birthday, but it is not clear whether it will support work started before 18 but completed later.

### **When will the coverage begin?**

The bill, effective January 1, 2013, only covers treatment under your insurance after the date of renewal. If your insurance renews on the first of January, it will immediately go into effect, but if it renews at a later date, it will not go into effect until that date, i.e., April 1, if that is the date of renewal for your policy. State employee plans renew on July 1.

### **Are all insurance plans included?**

No, only "state-regulated" plans are mandated to cover these services. If you are self-insured, it is technically not covered under this law. Some larger employers may consider providing coverage; however, it is not required. If the plan is regulated outside of Massachusetts, this law does not apply.

### **Do deductibles in my policy still apply?**

Cost sharing, deductibles and your plan's rules regarding cost tiers and networks will still apply.

### **How will I know if I am covered?**

Please contact your employer's human resources department to determine whether or not your plan is self-insured. If it is, you will need to know from your employer whether or not they will cover the treatment mandated under the state law. They are not required to do so under this law.

### **What do I need to provide the dental department to assure they will be paid?**

A prior authorization should be obtained in writing for any care which will be covered by a third party. You must pay any and all co-payments at the time services are rendered. If the third party does not pay the invoice within 120 days, you, as the parent/legal guardian, will be expected to fulfill the financial obligation of paying the bill. Duplicate payments later received by the Hospital will be refunded.

## Overview of Cleft Lip

### What is a cleft lip?

A cleft lip is a separation in the skin and muscle between a baby's nose and lip. Cleft lips are congenital, which means they present at birth.

### Do all children with cleft lips also have a cleft palate?

No. A child can be born with just a cleft lip, just a cleft palate or a combination of both.

### What causes a cleft lip?

Between the fourth and sixth weeks of pregnancy, a developing baby's lip begins to form. During this time, skin and muscle normally grow in from both sides of the baby's face to join with the skin that grows down from the tip of the nose. When this tissue and muscle fail to connect all the way, a cleft lip occurs.

Experts believe that cleft lip may be a genetic condition—meaning it is caused by an error in the genes. Cleft lip (as well as cleft palate) can run in families, but many children with a cleft have no known family history of the condition.

### What are my chances of having another child with a cleft lip/palate?

The chance of having more than one child with a cleft lip/palate is different for each family. During your child's care, members of Boston Children's cleft lip and palate team, including a geneticist, will provide detailed answers to this question.

Once a genetic syndrome has been ruled out, the condition is referred to as an isolated cleft lip/palate. Currently, there are no tests to determine the genetic changes in the absence of a recognized syndrome.

If there is one affected person in the family with a cleft, the likelihood of having a child with a cleft lip and/or palate is 2 to 5 percent. If there is a second affected person in the family, possibly a sibling or parent, the chance for future children to have a cleft lip increases to 10 to 14 percent, and the risk for isolated cleft palate rises to 8 percent.

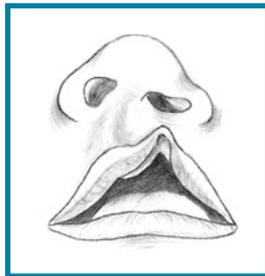
## Are all cleft lips the same?

No. There are different types of cleft lip that can also involve the nose and the palate. The major types are:

- unilateral (affecting only one side of the face)
- bilateral (affecting both sides)

Within these two categories, there are three subtypes:

- incomplete (the two sides of the lip are partially fused)
- complete (the sides of the lip do not connect at all)
- asymmetrical (the cleft is complete on one side and incomplete on the other)



unilateral incomplete  
cleft lip



unilateral complete  
cleft lip/palate



bilateral complete  
cleft lip/palate

## How is a cleft lip diagnosed?

An ultrasound can detect a cleft lip as early as the 12<sup>th</sup> week of pregnancy. The diagnosis will then be confirmed with a detailed exam when the baby is born.

# Dentofacial Orthopedic

## Is pre-surgical orthopedic treatment recommended?

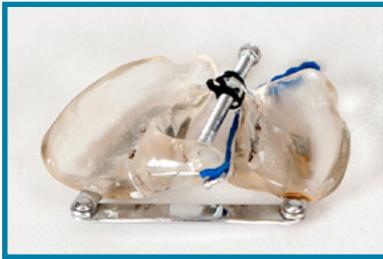
If your child has a unilateral or bilateral complete cleft lip (associated with a complete cleft palate), then treatment with a dentofacial appliance is usually recommended. The dentofacial appliance (referred to as a Latham-type device) will bring the segments of the palate closer together to optimize the outcome of the cleft lip repair. This is done in four steps:

**Step 1:** At 3-to-6 weeks old, the pediatric dentist makes an impression of your child's gums, which is then used to make the appliance.

**Step 2:** At 6-to-12 weeks old, the dentist inserts the appliance in your child's mouth; this is done in the operating room under general anesthesia.

**Step 3:** The appliance is then manipulated gently every day by the parent to slowly bring the gums closer together and improve surgical repair of the lip. The appliance stays in the mouth for 6-to-8 weeks.

**Step 4:** The appliance will be removed in the operating room just before the closure of the cleft lip or cleft lip/nasal adhesion, if recommended.



Most unilateral complete cleft lips will require a dentofacial maxillary appliance (DMA)



Most bilateral complete cleft lips will require an elastic chain premaxillary retraction appliance (ECPR)

To schedule an appointment with a member of our team, call our program coordinator at 617-355-6309 or email [samantha.hall@childrens.harvard.edu](mailto:samantha.hall@childrens.harvard.edu).

# Cleft Lip Repair

## How is a cleft lip treated?

All cleft lips require some form of surgical treatment. There are different operations that may be used for a cleft lip:

- If your child has a bilateral complete cleft lip or a unilateral complete cleft lip, the use of dentofacial orthopedics is often recommended as a step.
- An incomplete cleft lip (either unilateral or bilateral) is usually repaired in a single operation when the child is between 3 and 5 months of age. During the operation, a plastic surgeon uses the existing muscle and tissues of the child's lip and nose to close the cleft and corrects the baby's nasal asymmetry (unevenness in the shape of the nose).

Before they have a repair operation, some children first need a procedure called a lip-nasal adhesion. This procedure is between the ages of 1 to 4 months and involves three steps:

- closing the gap in the lip
- taking the first step to correct the positioning of the nose
- if possible, closing the gap in the gum (this step is also referred to as a gingivoperiosteoplasty)

## **Will my child need to be admitted to the hospital for the repair?**

Yes. Because all cleft lip repair procedures are performed in the operating room under general anesthesia, your child will need to stay in the hospital for one or two nights to recover.

You (or your child's other guardian) will be able to stay at the bedside, and our nursing team will be here to guide you through the process of feeding and caring for your baby during recovery. See page 17, "Feeding Children with Cleft Lip - Cleft Palate".

## **How will my child look after the cleft lip is repaired?**

Your child's lip, nose and face will be swollen and bruised for a few days right after the operation. The area around the incision may be red for several weeks, and the resulting scar may take as long as a year to soften and fade. Although the scar will never completely disappear, it will become almost invisible over time.

## **As my child gets older, will another operation of the lip or nose be necessary?**

Lip or nasal revisions are always an option but not required. However, some children with a cleft lip that involves the alveolus (gum line) will need another procedure when they are between 8 and 10 years old. In these cases, an operation called an alveolar bone graft is needed to help the permanent teeth erupt and make it possible for the child to wear orthodontics (braces).

You can read more about orthodontics and the alveolar bone graft operation on pages 25 and 27.

**Before**



**After**



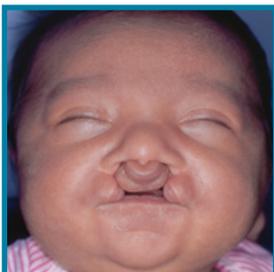
Unilateral incomplete cleft lip, before and after repair



Unilateral complete cleft lip, before and after repair



Bilateral incomplete cleft lip, before and after repair



Bilateral complete cleft lip/palate, before and after repair

## Overview of Cleft Palate

### What is a cleft palate?

A cleft palate is a separation in the palate (the roof of the mouth).

### What causes a cleft palate?

A developing baby's palate forms between the 8<sup>th</sup> and 12<sup>th</sup> week of pregnancy. During this time, bone and muscle grow in from both sides of the upper jaw and join to form the roof of the mouth and the bottom of the nose. If the fusion of these two shelves of bone and muscle is not complete, the baby is born with a cleft palate.

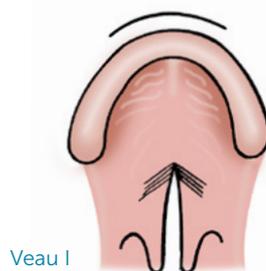
Similar to cleft lip, cleft palate may be a genetic condition. Some children with a cleft palate have other family members with the defect, but many others do not. Experts are still working to determine the exact causes of cleft palate.

### Are all cleft palates the same?

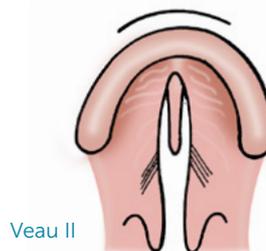
No. The palate is made of two parts, a muscular part (called the soft palate) and a bony part (the hard palate). A cleft can involve one or both parts of the palate. The Veau classification system is used in differentiating between types of cleft palates.

### How is a cleft palate diagnosed?

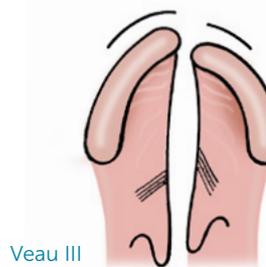
A prenatal MRI can detect a cleft palate as early as the 15<sup>th</sup> or 16<sup>th</sup> week of pregnancy. The diagnosis will then be confirmed with an exam when the baby is born.



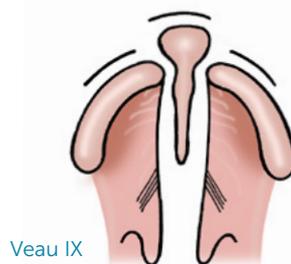
Veau I



Veau II



Veau III

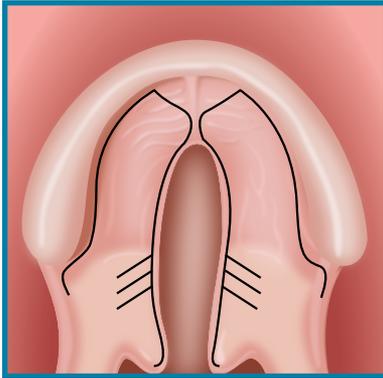


Veau IX

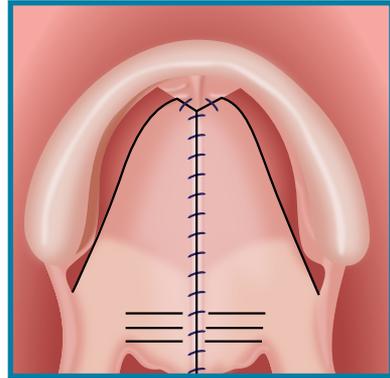
# Repairing a Cleft Palate

## How is a cleft palate repaired?

A cleft palate needs to be repaired surgically. During the operation, a plastic surgeon brings together the separated muscles and tissue from the two halves of the palate, closing the opening.



unrepaired palate



repaired palate

## When will my child's cleft palate be repaired?

The repair operation usually takes place between the ages of 8 and 12 months (before a baby's first attempts at speech).

## Will my child need to be admitted to the hospital for the repair?

Yes. All cleft palate repair procedures are performed in the operating room and require general anesthesia. Your child will need to stay overnight for one to two nights to recover.

You (or your child's guardian) will be able to stay at the bedside, and our nursing team will help you learn the best ways to feed and care for your baby during recovery.

## How should I feed my child in preparation for cleft palate repair?

Your baby's nurse will give you specific recommendations including the following general guidelines:

- If the nurse approves cup feeding before the cleft repair, you should start by introducing the cup to your child around the age of 6 months.

- The cup can be used for one feeding a day and then gradually used more often until your child is completely weaned from his or her cleft feeder.
- Begin spoon feedings around the age of 6 months. Use a soft-tipped spoon to give your baby liquids, as well as cereal, fruits, vegetables and other foods as directed by your pediatrician.

## How should I feed my child after cleft palate repair?

Our cleft nurses will review detailed feeding instructions, customized to meet your baby's needs, at the time of the cleft palate repair. Here are some of the basics:

Your child should use a cup that either does not have a spout or has a very short one. (Your nurses will advise you which type is best.)

You will need to use a cup for all feedings during the first 10 to 14 days after the repair procedure.

Your baby is safe to use a Haberman® feeder or a specialty cleft feeder after palate repair.

- After 10 to 14 days, you can start giving your baby soft foods, using the side of a soft-tipped baby spoon.
- After each feeding, rinse your baby's mouth with a sip of water from a cup or bottle. Rinsing is very important, especially while your baby's mouth heals.
- You may be taught how to use a special syringe to rinse the palate post-operatively. Another option would be rinsing your baby's palate with water from a bottle or cup.
- Your baby may regurgitate some food and liquid through the nose for as long as three months after the operation. This is normal while the swelling goes down and your baby's palate starts to work properly.

## As my child gets older, will another operation on the palate be needed?

Approximately 5 to 15 percent of all children who have undergone a cleft palate repair will need a second operation to correct "nasal-sounding" speech. The most common procedure used to fix this problem is by using a pharyngeal flap when the child is about 5 years old. Learn more in the "Speech and Language Development" section.

**For a more in-depth overview of the surgical procedure, email [samantha.hall@childrens.harvard.edu](mailto:samantha.hall@childrens.harvard.edu) or call us at 617-355-6309.**

## Feeding Children with Cleft Lip – Cleft Palate

### Can I breastfeed my child?

Your baby's ability to feed, whether by breast or bottle, depends on the severity of your child's cleft. Right after birth, your care team will help you determine the type of feeding method that's best for you and your baby.

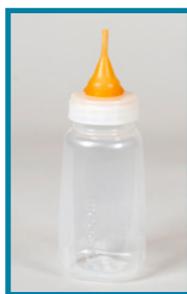
- If your baby has a cleft lip only, breastfeeding is usually fine as long as the cleft is covered during feeding.
- If your baby is working too hard to suckle, or if the cleft palate involves the hard palate, a specialty feeder such as the Pigeon nipple, Haberman feeder, or Dr. Brown's Specialty Feeder may be needed. These bottles are designed to help your baby feed easily through compression of the nipple, and don't require suction to express milk.
- You may still provide breast milk to your baby if you desire by pumping and giving it by bottle.
- If your baby has both a cleft lip and a cleft palate, a special feeding device will be necessary. A Haberman feeder is usually recommended because it allows milk to be pumped in time with the baby's suck-swallow sequence. A Ross nipple might be added to help deliver the flow of milk.



Dr. Brown's Specialty Feeder



Haberman Feeder



Ross Nipple



Pigeon Nipple

### How long should my baby's feeding sessions be, and how much milk should be consumed in a session?

- Feedings should last no more than 30 minutes at a time, every three to four hours. Prolonged feeding can exhaust both you and the baby.
- Infants burn calories very quickly. Your nursing team will determine the total amount of milk your child needs over a 24-hour period.
- Never let your baby go more than four hours without a feeding—unless you are close to exceeding the amount of milk your nursing team has recommended for a 24-hour period.

- Establishing a rhythm with your baby is key. Watch for any hunger cues and do not interrupt the suck/swallow/breathe pattern. When the baby takes a long pause, use that time to burp the baby.

## **Is there a positioning technique I should use when bottle feeding?**

Yes. We have found this approach to be very beneficial:

- Wrap your infant, enclosing the hands, in a blanket. This is called swaddling.
- Sit in a comfortable chair, like a rocking chair or a glider chair, with a footstool.
- Hold the baby upright in your arm or hold his or her head from behind.
- Relax both arms and place the nipple gently into the baby's mouth.
- Lay the nipple on top of your baby's tongue. If your infant has both a cleft lip and a cleft palate, position the nipple so that his or her upper and lower gums connect with it.
- Rotate your arm so that the underside of your hand is holding the bottle.
- Put your ring or small finger under the baby's chin.
- With firm pressure, keep your ring finger in place so that, as the baby suckles, you feel pressure against your finger.
- With gentle pressure under the chin, push up to start the baby's sucking.
- Your baby should feel comfortable while suckling (meaning no straining or squirming to access the nipple and to swallow).
- Maintain pressure. If, after a minute of sucking, there is little flow of milk, rotate the nipple to a longer line if using the Haberman Feeder or compress the nipple with gentle pressure to match your baby's suck-swallow reflex.
- Watch for cues that your baby is either full or needs burping.

## **What should my baby and I do right after feeding?**

- Keep your baby upright for about 20 minutes after you are finished with feeding. This can be accomplished either by holding the baby or placing him or her in a seat.
- If you place your baby in bed, slightly turn him or her to the side with some type of "wedge."
- Elevate the bed by 20 degrees, so that the baby's head is higher than his or her stomach.

- If your baby has a cleft palate, he or she may exhibit what is called esophageal or nasopharyngeal reflux—meaning milk either comes out of the nose or is regurgitated shortly after feeding has ended. Always keep a suction bulb handy in case this happens.
- Record the time, length and amount of milk consumed during the feeding.
- Keep a log so you can track the baby’s progress.

### **How can I ensure my baby is gaining sufficient weight?**

- Weigh your baby once a week. If he or she is not gaining more than one ounce per day, you should talk to your pediatrician about increasing the calories in the milk.
- Calories can easily be added by concentrating formula or adding powdered milk to breast milk. Your pediatrician or cleft nursing team can advise you on the right approach.
- If your baby has still not gained enough weight even after increasing calories, your pediatrician may recommend an appointment with a gastrointestinal or nutritional specialist.

### **Are there ways to supplement or replace oral feedings?**

Yes. When oral feedings are not enough to meet your baby’s nutritional needs, there are other methods that can be used to deliver the needed calories.

Sometimes, a device called a naso-gastric tube—a tube connected to a special syringe—is inserted through the child’s nostril down into the stomach. This is a temporary solution to help the baby absorb enough calories until he or she can do so by mouth.

Another type of tube used in feeding is a gastrostomy tube. This tube is inserted directly into the stomach from the outside of the abdomen. This procedure requires anesthesia and is used when a child has trouble with breathing as well as eating or is at risk of aspiration (inhaling food, liquids or other materials into the lungs and trachea). As a child grows and learns to eat by mouth, the gastrostomy tube can be removed.

## How can I ensure that my baby is properly nurtured, as well as nourished?

It's essential to remember that your child is a normal baby, and his or her cleft can be surgically corrected.

It is also very important to have at least two to three people supporting you who feel comfortable feeding your child. Your infant will sense their confidence with feedings and will be more relaxed as a result.

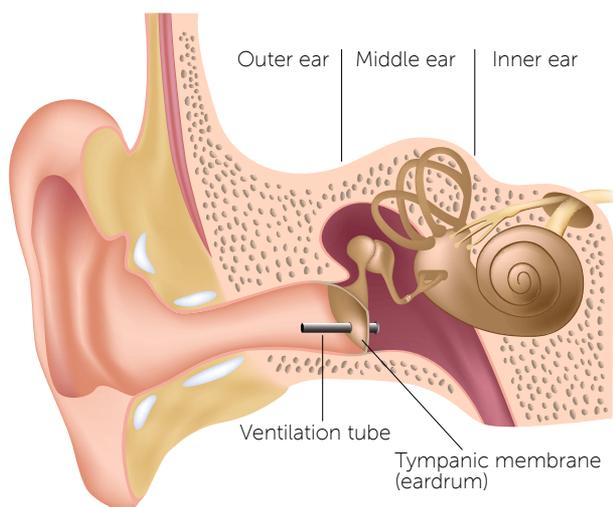
Once you feel comfortable with the feeding method recommended by your treatment team, you will find it easier to nurture your baby. You'll see him or her thriving, smiling and responding to your touch.



## Hearing in Children with Cleft Lip – Cleft Palate

### Will my child have difficulty hearing because of the cleft?

A cleft lip does not affect hearing, but children born with a cleft palate often have temporary hearing loss because the tube that connects the middle ear to the throat (called the Eustachian tube) does not drain normally. Fluid in the middle ear space (also known as effusion) affects almost all babies under the age of one year with an unrepaired cleft palate and can cause frequent infections—as well as hearing loss that can interfere with speech and language development.



### How and when will my child's hearing be evaluated?

Your child's age and other health circumstances will determine which hearing tests are used and when. In general:

- Newborns to 6-month-olds usually require a special hearing evaluation called an auditory brainstem response (ABR). This test measures how well sound travels to the baby's brainstem. This is done after a feeding and while your infant is sleeping.
- After the age of 6 months, babies may go through what is known as behavioral audiometric testing, which prompts them to turn their heads in response to certain sounds.

- Children between 7 months and 2½ years usually have a visual reinforcement audiometric (VRA) test, which uses special light-up toys and particular sounds to gauge how well they hear. A child who is between 2½ and 5 years old is likely to have an audiometric test, in which he or she will be asked to raise a hand in response to specific sounds.
- In addition to all of these tests, your child may also undergo tympanometric testing—an evaluation of middle ear function that can also check how well the ear tubes are functioning and can detect any signs of a hole in the eardrum.

Here at Boston Children’s, one of our audiologists (hearing specialists) will evaluate your child’s hearing every 6 to 12 months and will work closely with an otolaryngologist (ear, nose and throat specialist/ORL) to assist with any hearing issues related to the cleft. Your child’s first hearing test and ORL consultation **must** be prior to his or her palate repair.

### **What treatment is available for persistent fluid in the middle ear and associated hearing loss?**

Babies with middle ear fluid and related hearing loss need an operation to drain the fluid and insert ventilation tubes—which are very important in protecting long-term hearing and allowing children to master normal speech. This operation is performed under general anesthesia and is usually done at the same time as the cleft palate repair.

If your child has this procedure, the ventilation tubes will likely need to stay in place for nine to 12 months, with checkups by the ORL specialist every six months. The tubes usually fall out on their own and so do not require another operation to remove them. There is a 50 percent chance that your child will need to have ventilation tubes re-inserted at some point.

# Speech and Language Development in Children with Cleft Lip – Cleft Palate

## Does a cleft lip affect speech?

A cleft lip alone does not cause speech problems.

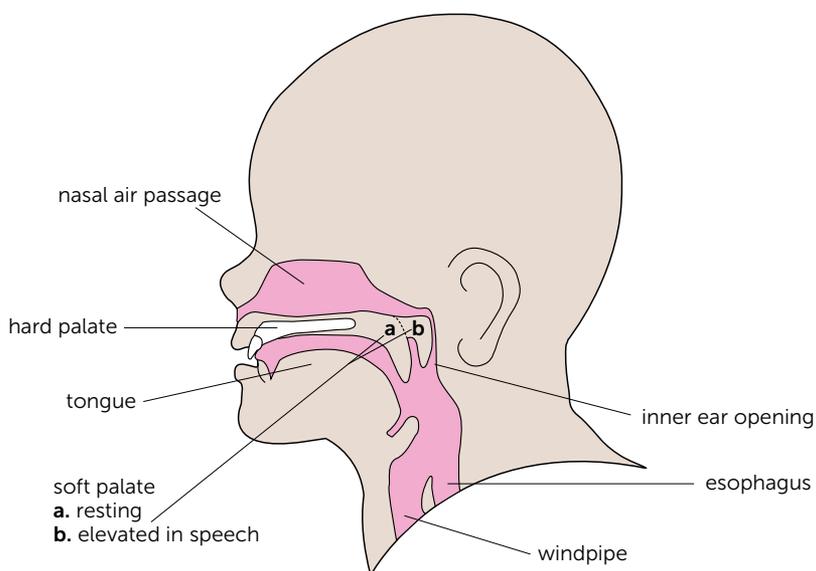
## Does a cleft palate affect speech?

The hard and soft palate separates the mouth from the nose. During normal breathing, the air flows in and out of a child's lungs through the nose and throat. During normal speech, the muscles in the soft palate move the palate to the back of the throat to seal off the nose (this process is called velopharyngeal closure). Such movement allows the air to flow through the mouth, and only the mouth, during speech. By contrast, there are only three English speech sounds ("m," "n" and "ng") that are made through the nose.

A child born with a cleft palate is unable to make normal speech sounds other than "m," "n" and "ng" until after the palate is closed.

The good news is that many of these patients acquire speech and language skills at a normal pace once the palate is closed and ear tubes are placed for drainage.

## Pharynx Anatomy Diagram



## Will my child need speech therapy? What will this involve?

At Boston Children's, your child will be evaluated by one of our speech therapists shortly after cleft palate repair to determine whether further treatment is needed. If speech therapy is recommended, we will help you connect with services in your community. Once your child's palate is closed, you may notice that he or she vocalizes less often and in fewer ways. It may take up to six weeks to resume normal vocalization.

Your child's speech therapist will offer suggestions for home activities to help develop normal speech and language skills. For example, your baby should be encouraged to make lip sounds ("p" and "b") and front-of-the-tongue sounds ("t" and "d"). You can do this with playful lip-popping games (like mimicking a fish) and tongue-clicking games (mimicking a trotting horse). Sounds made in the throat, such as "uh oh," or animal roaring sounds should be discouraged; they can cause poor speech habits in children with a repaired cleft palate.

Your child's speech will be evaluated every six months until the age of 3 and on a yearly basis thereafter. You are encouraged to call our team's speech therapist at any time if you have questions or concerns.

## Will my child need additional surgery on the palate?

Approximately 5 to 15 percent of children will not be able to adequately seal off their nose during speech, even after the palate is repaired. This results in hypernasal speech (too much nasal airflow), a problem called velopharyngeal insufficiency (VPI).

Velopharyngeal insufficiency may require another operation, such as a pharyngeal flap. When needed, this procedure is performed when the child is approximately 5 years old, following a complete speech evaluation by a speech therapist, otolaryngologist and plastic surgeon.

## Will my child need other operations, like an adenoidectomy or tonsillectomy?

The adenoids naturally assist children in sealing off the nose during speech; they should only be removed after consultation with our Cleft Lip and Palate Program team.

The tonsils do not help in sealing off the nose from the mouth and can be removed if there is a medical need to do so. Tonsils and adenoids must be evaluated, and often removed, by an otolaryngologist prior to a pharyngeal flap procedure.

# Oral and Dental Health in Children with Cleft Lip – Cleft Palate

## Will my child’s teeth be affected by a cleft lip or palate?

Your child’s first tooth (usually the lower incisor) will probably appear between 4 and 14 months of age. At 3 years, he or she will likely have all the primary (baby) teeth.

Children with a cleft lip/palate often have poorly formed enamel (the outer tooth layer) on some of their teeth, especially those that are closest to the cleft. The teeth in this region may also be out of alignment and only partially erupted—and, therefore, difficult to clean. All of these factors will make your child’s teeth more susceptible to cavities, so good dental hygiene is very important.

## How should I keep my child’s teeth clean and protected?

To minimize the risk of cavities:

- Brush your child’s teeth at least twice a day. (Fluoride toothpaste should be used, but only in very small amounts.)
- Avoid foods with a lot of sugars and starches.
- Don’t allow frequent snacking, which is especially harmful to the teeth since the bacteria in dental plaque produce cavity-causing acids each time food enters the mouth.
- Put your child on the fluoride dosage recommended by your dentist early in life. Fluoride, whether through the water supply or through prescribed supplements, has been proven to reduce the amount of decay in both baby teeth and permanent teeth. The greatest benefits from fluoride occur between 6 months and 8 years of age.

## When should my child see the dentist for the first time?

If your child has a complete cleft lip/palate and has needed any type of dental appliance, you probably have already met our dental team. Either way, your child should visit a pediatric dentist by the age of 12 months, or earlier if you have specific concerns.

## **What other dental issues should I expect as my child gets older, and how can these be treated?**

Common problems can include missing, malformed or extra teeth in the area of the cleft. Absent teeth may need to be replaced by a dental implant once the child has finished growing, or by moving natural teeth into the space with orthodontics (braces).

As your child grows, his or her pediatric dentist and orthodontist (a dental specialist who corrects teeth and jaw alignment) will determine whether any additional treatment is needed.

## **Will my child require orthodontic therapy (braces)?**

Children with a cleft lip/palate almost always have some type of problem with their "bite" (teeth alignment), and most will need one or more phases of orthodontic treatment (braces).

The decision to treat the teeth and/or bite should be made by a pediatric dentist and/or orthodontist who has special expertise working with children born with a cleft.

## Will any other orthodontic treatments be necessary later in my child's life?

A second phase of orthodontics may be required when your child is a teenager. This will ensure permanent teeth are properly aligned. In addition to braces, this phase can also include the use of a headgear to correct an underbite.

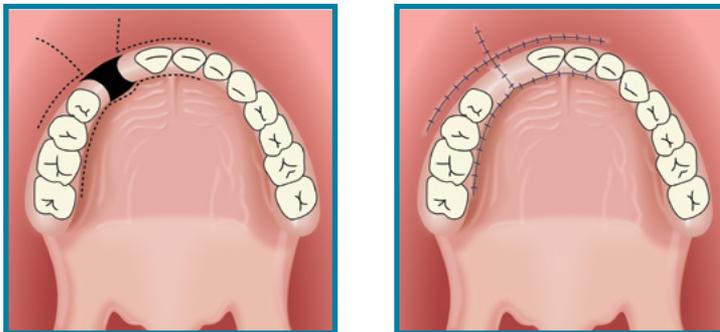
Although children with a repaired cleft lip (either incomplete or complete) who have an intact palate usually have normal facial growth, children with a complete cleft lip/palate frequently have abnormal upper jaw growth. These patients can benefit from a third phase of orthodontics between the ages of 13 to 15 for girls and 16 to 18 for boys.

## What is an alveolar bone graft, and how can it help my child?

If your child has both a cleft lip and a cleft palate, a procedure called an alveolar bone graft may be very helpful in adding bone to the gum line. This operation makes it easier for dentists to insert a dental implant, if needed, and provides extra support for the rest of the teeth.

The alveolar bone graft can take place once the first stage of orthodontic therapy is complete—usually between the ages of 8 and 10 years. During the procedure, bone is taken from the hip area and used to connect the soft tissue and bony gap in the upper jaw. The grafted bone will heal and solidify over time. Surgeons can also make minor corrections to the child's lip and nose during the same operation.

For these children, the first phase of orthodontics involves an appliance placed in the maxilla (part of the upper jaw) to widen the palate before the alveolar bone graft procedure.

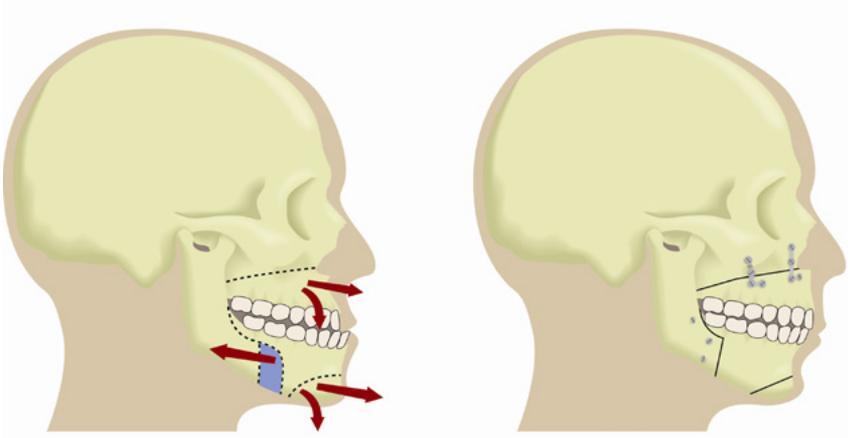


Grafting alveolar cleft (left) and closure of fistula (right)

## Will my child need any other type of oral surgery?

It is possible that your child may need an additional operation to properly align the jaws and bite after he or she has finished growing. This procedure, called a Le Fort I maxillary advancement, takes place in the late teen years.

Other types of orthognathic (jaw) surgery can reposition parts of the jaw to fix both cosmetic and functional problems—making the child’s face look more balanced and helping him or her to eat, speak and breathe more comfortably.



Repositioning of upper and lower jaws to correct the bite and provide facial balance

# What to Expect

Here is a general guide to the different steps that may be required during your child’s cleft care. Because every child is different, each case is treated individually and your child’s treatment plan may vary.

## TIMELINE FOR THE CARE OF CLEFT LIP AND CLEFT PALATE

Age	Cleft lip	Cleft palate	Cleft lip and palate
6 weeks to 3 months		Consider ABR test *	Dentofacial orthopedics for complete cleft lip and palate
1 to 4 months	Cleft lip/nasal adhesion		Cleft lip/nasal adhesion considered
4 to 6 months	Repair cleft lip and nasal deformity		Repair cleft lip, nasal deformity and alveolar cle
6 to 8 months		Hearing test and ear exam	Hearing test and ear exam
8 to 12 months		Repair cleft palate; place ear tubes if needed	Repair cleft palate; place ear tubes if needed
18 to 24 months	First annual cleft lip/palate clinic visit	First annual cleft lip/palate clinic visit, speech/language evaluation	First annual cleft lip/palate clinic visit, speech/language evaluation
18 to 36 months	First dental evaluation	Dental evaluation	Dental evaluation
1 to 5 years		Hearing test every 6 to 12 months	Hearing test every 6 to 12 months
4 to 6 years	Consider revision of lip/nose	Consider pharyngeal flap (VPI) **	Consider pharyngeal flap (VPI) consider revision of lip/nose
7 to 10 years			Phase I orthodontics: premaxillary expansion, removal of retained baby teeth; alveolar bone graft to close gum cleft and/or premaxillary osteotomy
12 to 14 years	Consider revision of nasal tip		Consider revision of nasal tip: Phase II orthodontics; full orthodontic treatment to coordinate bite and relieve crowding rotations
15 to 20 years	Final correction of external nose and septum		Final correction of external nose and septum: Phase III orthodontics; orthodontic treatment with orthognathic correction

\* ABR: auditory brainstem response hearing evaluation  
 \*\* VPI: velopharyngeal insufficiency; persistent nasal speech

# Resources and Notes

## Appointments

Email [samantha.hall@childrens.harvard.edu](mailto:samantha.hall@childrens.harvard.edu) or call **617-355-6309**.

Our dedicated Cleft Lip and Cleft Palate Program team is here to answer your important questions and assist you with decision-making.

## For additional information:

Boston Children's Hospital  
Cleft Lip and Palate Program  
[bostonchildrens.org/cleftlip](http://bostonchildrens.org/cleftlip)  
617-355-6309

### **John B. Mulliken, MD**

617-355-7686

### **John G. Meara, MD, DMD**

617-355-4401

### **Carolyn R. Rogers-Vizena, MD**

617-355-8509

### **Ingrid Ganske, MD**

617-355-1463

### **Contact a nurse**

617-355-4513

## Online Resources

Facebook: [facebook.com/bostoncleft](https://facebook.com/bostoncleft)

Mobile App: [bit.ly/bostoncleftapp](https://bit.ly/bostoncleftapp)

Foundation for Faces: [facesofchildren.org](https://facesofchildren.org)

*Photos and drawings courtesy of John B. Mulliken, MD, John G. Meara, MD, DMD and Alexander Allori, MD.*





# Cleft Lip and Palate

A GUIDE FOR FAMILIES



**Boston  
Children's  
Hospital**

Until every child is well™

Plastic and  
Oral Surgery