



ACPA

American Cleft Palate
Craniofacial Association

acpacares.org



Your Baby's First Year

2026 Edition

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Scan the QR code to be directed to the ACPA Family Resource Center webpage:



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Cleft Lip and Cleft Palate: What Is the Difference?

A cleft is a split or opening that occurs when parts of the skin, muscle, and bone of the mouth do not come together during facial development between weeks 5 and 12 of a pregnancy.

A cleft lip is an opening in the lip, most commonly the upper lip, that can occur on one or both sides. If it occurs on one side, it is called a unilateral cleft lip (Figure 2a). If the cleft occurs on both sides of the lip, it is called a bilateral cleft lip (Figure 2b).

The cleft lip opening varies in size from baby to baby. There may be a slight notch in the red portion of the lip (called the vermillion) or a complete separation of the lip that extends into the tip and side of the nose. A cleft lip can extend into the nasal cavity and often presents with changes to the shape of the tip of the nose.

A cleft palate is an opening in the roof of the mouth. When a baby is born with a cleft palate, the roof of the mouth may appear missing. In fact, the two sides of the palate didn't join during development. A cleft palate does not cause pain or discomfort for the baby, but it may affect feeding.

A cleft that occurs only in the palate (not the lip or the gumline) is called an isolated cleft palate, or cleft palate only. At its smallest, an isolated cleft palate may look like a notch or slit at the very back of the palate, or it may extend somewhat into the soft palate. In severe cases, the cleft may involve the entire soft palate and part of the back of the hard palate. A complete cleft palate extends through both the soft and hard palates.

Because the lip and palate develop separately while the baby is still in the womb, a baby may have a cleft lip only, a cleft palate only, or both. Figure 3 shows the palate anatomy when no cleft is present. When cleft lip and cleft palate occur together, they can involve one side (unilateral - Figure 4a) or both sides (bilateral - Figure 4b) of the lip, gum, and/or palate.



Figure 1: Typical Lip and Nose



Figure 2a: The Unilateral Cleft Lip and Nose



Figure 2b: The Bilateral Cleft Lip and Nose



Figure 3: The Typical Palate



Figure 4a: The Unilateral Cleft Lip and Palate



Figure 4b: The Bilateral Cleft Lip and Palate

What Causes Cleft in Babies

Most cases of cleft lip result from a combination of inherited information (genes) interacting with specific, often unknown, environmental factors. Clefts occur very early in pregnancy and are often out of the control of the pregnant person.

Clefts are one of the most common birth differences in the United States. Cleft lip and/or palate occur in about 1 in every 700 births. Clefts have a multifactorial etiology, meaning several factors may increase the risk. Prenatal vitamins can decrease the risk and are strongly recommended for all women of childbearing age.

Choosing a Cleft Care Team

Those born with cleft lip, cleft palate, and/or other craniofacial differences may require individualized treatment into adulthood. A team of specialists can best manage their care by working with the family to develop and follow a treatment plan. The American Cleft Palate Craniofacial Association (ACPA) is dedicated to team care and improving patient outcomes.

You can find an ACPA Approved Team in your area by visiting www.ACPAcares.org or scanning this QR code.



Members of the Cleft Care Team

Team care begins at prenatal diagnosis and continues through the first days of a baby's life. Your team will support you and your child throughout childhood, the teenage years, and beyond.

Cleft specialists who contribute to team care may include:

- A surgeon (such as a plastic surgeon, an oral and maxillofacial surgeon, a craniofacial surgeon, or a neurosurgeon)
- A speech-language pathologist, who assesses speech and feeding problems
- A pediatric dentist, who works with children, or another dental specialist
- An orthodontist, who straightens the teeth and aligns the jaws
- A geneticist, who has training in human genes and screens patients for syndromes, including craniofacial syndromes (see the Glossary on page 10), and helps parents and adult patients understand the chances of having more babies with these conditions
- A nurse who helps with feeding education and monitors the child's health
- A psychologist or other mental health professional who supports your child's and your family's emotional needs

- An audiologist, who assesses hearing
- An otolaryngologist, also called a head and neck surgeon or an ear, nose, and throat (ENT) specialist
- A pediatrician, a physician who specializes in monitoring your child's overall health and development
- Other specialists

Questions to Ask When Selecting a Cleft Care Team

Your first visit with the team will include a consultation and an examination. Then the team will organize a full treatment plan for the short-term and long-term care of your child.

When you meet with the team, be prepared to ask questions and request additional information. Your questions may include:

- Which specialists are on the team?
- Do the surgeon, orthodontist, and speech therapist all see the patient on the same day in a coordinated fashion?
- What are the qualifications of the individual members of the team?
- What kind of experience does the team have?
- How do the team members communicate?
 - With each other?
 - With patients and families?
- Who will be the team contact person after our baby is born or after surgeries?
- Does the team prefer that parents use a particular type of modified cleft palate bottle instead of another type?
- Who can assist with feeding, if necessary, at the birth hospital? During the first year of life?
- Who are the specialists who will help my child once they enter high school?
- How does my child transition to adult providers?

Treatment needs can change over time as children grow and develop. Evaluation and treatment can focus on appearance, speech, hearing, ear health, dental development, overall health, and overall well-being.

Caring for a Baby with a Cleft

Your job is to support your baby's growth and health. All babies need love, care, and attention. While caring for an infant with a cleft is similar in many ways to caring for a baby without a cleft, your baby may require special treatment.

Bottle-Feeding

A baby born with an opening in the palate can't seal their mouth and create the suction needed to keep the breast (or bottle) in place and pull the nipple to the back of their mouth.

The American Academy of Pediatrics (AAP) recommends that babies consume breast milk or formula as their primary nutrition until their first birthday. After this time, infants born with a cleft lip and/or cleft palate are usually ready to eat solid foods at the same age as any other baby.

Lactation consultants (see the Glossary on page 10) have found that exclusive breastfeeding is a difficult goal for all but a few babies with a cleft palate. As a result, even though babies with a cleft have normal sucking and swallowing reflexes, they need to take formula or pumped breast milk from special bottles and nipples that allow the liquid to flow because of the lack of suction.

Regardless of what feeding system you choose, the AAP recommends breast milk supplementation for newborns if possible. If using breast milk is not an option, your health-care provider will help you select the most appropriate formula for your baby based on nutritional composition and compatibility with your baby's digestive system.

Mothers can still share many benefits of breastfeeding with their child:

- Express breast milk with a pump, then feed it to your baby with a special bottle.
- Make eye-to-eye and skin-to-skin contact whenever your baby is feeding.
- Once your baby has become successful at feeding on a bottle, the baby may be put to the breast for non-nutritive sucking.
- Non-nutritive sucking at the breast can stimulate important muscles in your baby's mouth and tongue that will help the baby achieve future tasks such as drinking from a cup, chewing, and producing sounds and speech.
- It can also facilitate the bonding experience and stimulate milk production for those mothers who continue to pump breast milk.

Your treatment team will provide guidance about feeding, types of bottles to use, and other related topics. It is also important to build a good relationship with your baby's primary care provider (pediatrician), who can answer questions about weight gain, formula intake, and transition to solid foods. The pediatrician can also help you understand the information you've heard from other specialists.

Scan this QR code to see ACPA's website pages on feeding your baby.



DRINKING FROM A CUP

Most babies born with cleft lip and/or cleft palate can learn to use a cup at the same age as other infants. All babies, regardless of cleft type, should be drinking exclusively from a cup (not a bottle) by 12 months of age. Some cleft care teams recommend using open cups typically by a baby's first

birthday. Others suggest sippy cups modified to eliminate suction. Before you choose a cup and start helping your baby use it, ask your cleft care team which one is best for your baby. You may need to experiment with several styles to suit your baby's needs or preferences.

Caring for the Ears and Hearing

Children born with a cleft palate are more likely to have ear infections because the palate muscles are abnormally oriented and may not work as they should. Normally, the palatal muscles open the Eustachian tubes, the small tubes connecting the throat to the middle ear. When the Eustachian tubes do not open properly, air cannot enter the middle ear and fluid may build up, sometimes causing infections. Because this problem often occurs in children born with a cleft palate, the ACPA recommends that these children see their primary care physician or the otolaryngologist (ENT) on the team for an ear exam within the first few weeks of life.

Fluid in the middle ear can be hard to detect at home because it does not always result in symptoms like earaches or fevers. A child born with a cleft palate should have frequent ear exams because middle-ear fluid can cause hearing loss. Unfortunately, even mild hearing loss can affect a child's speech and language development.

If the fluid persists or if the baby has repeated ear infections requiring antibiotics, the baby's physician may recommend a minor surgical procedure called a myringotomy. For this procedure, a surgeon makes a small slit in the eardrum to drain the fluid, then inserts tiny plastic or metal tubes called pressure equalization tubes (also called PE tubes). PE tubes let air into the middle ear and prevent fluid buildup. As a child grows, PE tubes usually fall out on their own after several months. This operation is often coordinated with the cleft palate surgery. Some children with cleft may require more than one set of tubes. Some children also need long-lasting tubes that stay in place longer.

Tests for Hearing

Hearing tests are an important part of early treatment. Certain hearing tests can be performed on babies as early as 1 day of life. An audiologist with specialized training and equipment for testing infants should perform these tests.

Hearing screenings are early, general tests performed by audiologists, speech-language pathologists, or other professionals. One type of screening, called acoustic emission testing or tympanometry, measures the middle ear's response to sound. Otoacoustic emissions testing (OAE) is a screening that measures the response of the cochlear nerve, the hearing nerve in the innermost part of the ear. Depending on the results of these early screenings, a professional may recommend further testing. For example, an auditory brainstem response test shows how the brain reacts to sound.

For more information on hearing tests, talk to your baby's health-care provider and see the ACPA resource, "Help With Hearing."



SPEECH DEVELOPMENT

Children with cleft lip and/or cleft palate may present with many types of speech issues. Some may relate to their cleft condition, some to their teeth or bite relationship, and others may not relate to their cleft condition.

A child with a cleft palate should have frequent speech evaluations during the first year of life and throughout childhood. Speech and language skills begin to develop even before a baby uses real words. Months before babies say their first words, they coo and babble. Babbling usually starts at around age 6 to 8 months.

Children with a cleft palate may develop babbling sounds differently than other children. They typically produce nasal sounds (M and N sounds, as in mama and nana) and vowels (in combinations such as yaya, nana, nini, and mama), but they may not babble with other sounds (B, P, D, T, G, K) until after palate surgery. Sometimes, children with a cleft palate produce sounds in their throat (for example, they may grunt or growl the uh sound in uh-oh) or seem to leave sounds off words. If these issues are present or if your child is not producing a variety of sounds several months after palate surgery, speech therapy may be needed.

Children with a cleft palate may produce fewer words or use shorter phrases or sentences than their peers. They may also have difficulty following instructions or producing longer phrases and sentences. If you have questions about your child's speech, discuss them with the speech-language pathologist and other members of the care team.

Most children born with a cleft palate develop speech normally once the palate is repaired. As the cleft care team plans your child's palate surgery, the speech-language pathologist will work with the surgeon and other specialists to determine the best timing for surgery to support speech and language development.

DENTAL CARE

A baby should have their first dental appointment after the first tooth erupts, and no later than 12 months. At the first appointment, the dentist will examine the baby's mouth and talk with the parents about lifelong oral health habits. The dentist may also recommend a home fluoride treatment. The American Dental Association recommends early brushing and topical fluoride use for infants and toddlers.

Children with clefts are at increased risk for cavities, so brushing is very important. Also, avoid sugary foods and drinks at bedtime.

Children born with clefts that involve the upper jaw may have all their normal teeth. At times, however, the teeth may be turned, misshapen, or missing. During preschool or school-age years, a dentist may recommend X-rays to identify missing tooth buds. As your child grows, the dental specialists on the cleft care team will talk with you about any needs and their treatment.

Surgical Procedures

Most children born with cleft lip and/or cleft palate undergo surgery within the first year of life. It is important that you feel comfortable with your baby's surgeon and confident in the surgeon's skills, experience, education, and training. The timing and technique of surgical repair can vary from one surgeon to another. As your child grows and matures, they may need additional surgery on the lip, nose, gums, and/or palate.

Lip Surgery (Average Age Range: 2-4 Months Old)

The goals of cleft lip surgery are to close a cleft lip with minimal scarring, create a natural appearance, and ensure typical facial growth.

Cleft teams in the United States usually recommend performing this procedure after a baby has gained enough weight, has been screened for other health problems, and is strong enough to undergo general anesthesia.

Lip surgery can be accomplished in one procedure but is sometimes done in two stages. Some treatment centers use presurgical tapes or appliances to narrow the cleft and improve nasal shape and form before the first cleft lip and nose repair surgery. Lip surgery usually requires a hospital stay of 1 or 2 days, but in some cases, the operation can be performed without an overnight stay.

Your baby's surgeon and/or treatment team will give you instructions for caring for the baby after surgery. The team may recommend that your baby wear elbow restraints so they don't accidentally rub their face or nose after surgery. They are designed to keep the baby's hands away from the surgical site so it can heal. Most teams recommend that a baby return to bottle-feeding or breastfeeding immediately after surgery.

The scar on the lip may be red and stiff at first, but within several months it will look less noticeable and soften. A scar takes more than a full year to heal completely and will always be present. If you have concerns about healing or scar changes, you should discuss them with your baby's surgical team.

Palate Surgery (Average Age Range: 6-18 Months Old)

The goal of cleft palate surgery is to close the cleft palate so it functions normally during eating, drinking, and talking.

Cleft surgeons in the United States typically close the palate when the child is between 6 and 18 months of age, but a surgeon may recommend operating earlier or later in life depending on a variety of factors. Palate surgery may be performed in one or two stages, depending on the child's needs and the cleft team's recommendations. The operation usually involves a 1- to 3-day hospital stay.

After palate repair surgery, you will need to follow special feeding instructions. The cleft team may require the baby to drink from a cup that will not harm the surgical site and may recommend that all foods be puréed or liquefied. As with lip repair, the cleft team may recommend that a baby wear elbow restraints for a while after surgery. Ask questions as they come up, and be sure you have a contact phone number for your child's team in case you need support in the early days after surgery.

Paying for Surgery

Private or group health insurance policies usually cover at least a portion of the cost of cleft treatment. If an insurance company initially says it won't pay for a treatment, you should discuss the case with the company. In some cases, the reviewers are not aware of the problems associated with unrepaired clefts. They may authorize payment once they learn more.

Also, many states have laws prohibiting insurance companies from denying payment for medical needs due to congenital (birth) differences such as cleft lip and/or palate. Some children and families are eligible for federal or state programs such as TRICARE, Medicaid, and Children's Special Health Services. Ask your cleft care team or pediatrician about financial assistance in your area. Some private and nonprofit agencies provide funds or special services for children born with clefts.

Support Groups

Parents of children with clefts often find it helpful to connect with other families with similar experiences. Several support groups are available online. ACPA partners with organizations such as myFace, Children's Craniofacial Association, CleftProud, and Smile Train; you can find their contact information and support groups on the [ACPA website](#).

Many families also find ongoing support through in-person groups. Parent/patient support groups are organizations of individuals and families who meet to share common concerns and ideas. Ask your cleft team, your local health-care providers, or explore ACPA Family Resources to find a group in your area.

ACPA Online Resource Center

The ACPA maintains a growing collection of booklets, fact sheets, videos and webpages that introduce and explain many elements of cleft and craniofacial care and treatment. Representatives of professional health care providers serving the field of cleft and craniofacial care and treatment author and revise all resources. Visit our website at www.ACPAcares.org, or scan the QR code on the right to be directed to our website.
<https://acpacares.org/resource/cleft-home/>



Glossary

ACOUSTIC EMISSION TESTING - Also known as **tympanometry**; a type of hearing test that measures the response to sound in the middle ear cavity.

ALVEOLAR RIDGE - The bony ridges of the maxilla (upper jaw) and mandible (lower jaw) containing the teeth, commonly referred to as the gum.

AUDIOLOGY - An area of health care concerned with hearing. An audiologist is an individual with a degree, license, and certification in audiology who measures hearing, identifies hearing loss, and participates in rehabilitation of hearing impairment.

AUDITORY BRAINSTEM RESPONSE TEST - A test that shows how the brain reacts to sounds.

BOTTLE CARIES - Sometimes referred to as **bottle rot** or **bottle mouth**; Cavities caused by milk or formula left on a baby's teeth. These cavities often form when babies are put to sleep with a bottle of milk in their mouth.

CLEFT PALATE TEAM OR CRANIOFACIAL TEAM - Any team of specialists from several disciplines who work together, and with a family, to create, carry out, and update an individual's care plan as it relates to cleft lip and/or cleft palate.

COCHLEA - The innermost portion of the ear which is responsible for hearing.

CONGENITAL - A disease or deficiency existing at the time of birth.

CRANIOFACIAL - Involving or related to the **cranium** and the face.

EARDRUM (TYMPANIC MEMBRANE) - The membrane located at the end of the ear canal which separates the canal from the inner ear cavity. This membrane vibrates and transmits sound to the middle ear.

ENT (EAR, NOSE, AND THROAT) - Also called **otolaryngologist** and **head and neck surgeon**; an individual who specializes in the diagnosis and treatment of Ear, Nose and Throat disorders.

EUSTACHIAN TUBE - A structure that connects the middle part of the ear with the back of the nose and equalizes pressure between those two spaces. Some children born with cleft palate have problems with Eustachian tube function. PE tubes (defined below) can help a child avoid ear infections and hearing problems.

GENETICS - The study of heredity and how characteristics are passed down from one generation to the next.

LACTATION CONSULTANT - A health-care professional who provides guidance about breastfeeding and about bottle-feeding babies.

MAXILLA - The upper jaw.

MIDDLE EAR - The part of the ear located behind the eardrum. The middle ear contains three small bones that transfer sound from the eardrum to the inner ear.

MYRINGOTOMY - A minor surgical procedure in which a small cut is made in the eardrum to allow fluid to drain from the middle ear.

NASOALVEOLAR MOLDING – Also called **NAM (nasopalveolar molding) therapy**, which is also referred to as a type of **presurgical orthopedics**: A nonsurgical method for reshaping the lip, gums, and nostrils before surgery for cleft lip and cleft palate. A NAM device is made of wire and acrylic nasal stents attached to a plastic plate.

ORAL-MAXILLOFACIAL SURGERY – The branch of dentistry concerned with managing differences of the dental and facial bones and soft tissue.

ORTHODONTICS – The branch of dentistry concerned with the correction and prevention of irregularities and misalignment of the teeth and jaws.

OTITIS MEDIA – Inflammation of the middle ear with accumulation of thick, mucous-like fluid.

OTOACOUSTIC EMISSIONS TESTING – Also called **OAE** (an abbreviation for **otoacoustic emissions**): A type of hearing test that measures the response of the cochlea.

OTOLARYNGOLOGY – Also called **ENT (ear, nose, and throat)**; also called **head and neck surgery**: The branch of medicine concerned with diagnosis and treatment of patients with ear, nose, and throat disorders.

PE TUBES – Also called **pressure equalization tubes, ventilation tubes, grommets, and tympanostomy tubes**: Tiny tubes inserted into the eardrum during a myringotomy (see the definition for that term above) that allow air to enter the middle ear and fluid to drain from behind the eardrum.

PEDIATRIC DENTISTRY – The branch of dentistry concerned with the care of children's teeth.

PLASTIC SURGERY – The branch of surgery concerned with surgical repairs to establish appearance and function for both conditions present at birth and that appear later.

PROSTHODONTICS – The branch of dentistry concerned with the replacement of teeth and related mouth or jaw structures with artificial devices.

PSYCHIATRY – The branch of medicine dealing with the diagnosis and treatment of mental disorders.

PSYCHOLOGY – The branch of medicine concerned with the study of the mind and mental processes, especially in relation to behavior.

SOCIAL WORK – A human service field that may involve specialized training in social welfare and in individual, family, group, and community health services.

SPEECH-LANGUAGE PATHOLOGY – An area of health care focused on disorders of speech, language, cognition, voice, resonance, and swallowing (dysphagia). A licensed and/or certified speech-language pathologist has had the academic training and experience necessary to diagnose and treat disorders of speech, language, resonance, and feeding.

SYNDROME – A group of physical conditions that occur together as part of a pattern

TYMPANOMETRY – Also called **acoustic emission testing**: A type of screening that measures the response to sound in the middle ear cavity. It measures how well the eardrum moves when air pressure is applied to the ear canal.



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FOR MORE INFORMATION

This booklet and many others have been produced by:

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The information in this resource is not a substitute for medical advice provided by a physician. It is intended for use by parents, caregivers, and nurses caring for babies with cleft lip and/or cleft palate, not for babies with more complicated craniofacial conditions.

This content does not represent the only, or necessarily the best, feeding method or equipment appropriate for your baby's situation. You should consult your health-care provider before using any of the information presented here.