



The Vanderbilt Cleft and Craniofacial Team

Why choose Vanderbilt Children’s Hospital for cleft care?

Our department, approved by the American Cleft-Palate Craniofacial Association, has been caring for children with clefts for over 30 years. Team members offer unique educational backgrounds focused on cleft care, have extensive experience due to our high volume and complexity of cases, and corroborate with other institutions to ensure we offer the best care to our patients.

We often use the phrase “from prenatal to prom” as our motto because our providers care for children with clefts throughout their entire course of treatment. We treat more than 50 new infants with cleft per year and hundreds more older children, who are at different stages of cleft care.

Our center doesn’t just treat and care for children with a cleft. Equally important to our mission are education, research and giving back to the community here and abroad. Because of our high volume and the complexity of our cleft cases, we have two fellowships, Pediatric Otolaryngology – Head and Neck Surgery and Craniofacial Plastic Surgery, to help train the next generation of cleft surgeons. Our providers regularly attend national and international meetings to further their education and to remain current on the latest developments in cleft care. Our research program maintains a registry of every cleft patient and conducts studies to improve clinical outcomes and the quality of life for children with a cleft. Finally, our surgeons have extensive international experience and routinely volunteer their time and surgical skill to help underserved communities abroad.

Cleft Care

Vanderbilt Children’s Cleft and Craniofacial Program

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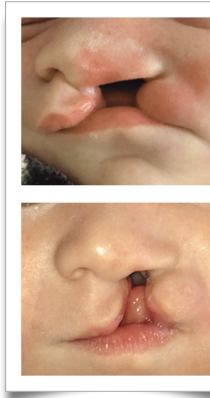


What does it mean if a baby is born with a cleft lip and palate?

Cleft lip and/or palate occurs in about 1 in 700 live births. It is the most common facial difference for babies at birth. Diagnosis typically occurs during a prenatal ultrasound visit, as early as 20 weeks.

Learning a baby has cleft lip or palate can come as a surprise to parents and cause them to feel uncertain about the future. At Children’s Hospital, we reassure and guide parents even before their baby is born. Once we diagnose a cleft, parents meet their surgeon, the cleft team coordinator, Clare Gargaro, and, in most cases, their pediatric dentist, to discuss a care plan and treatment options.

If a cleft is wide, parents may discuss with the pediatric dentist a potential orthopedics treatment called naso-alveolar molding (NAM). NAM is used to actively mold and reposition nose and mouth tissues. Over time, NAM can decrease the size of the cleft prior to the first lip repair surgery. Ours is one of the few programs in the region performing this molding therapy.



Before and after NAM treatment

Benefits of NAM include:

- Molding the gums and bone into a better position, which makes surgery easier and quicker
- Helping a child have better, healthier teeth as they grow
- Improving the ability to feed and breathe
- Becoming something like a pacifier, meaning children tend to adapt well to the procedure

If a baby with a cleft is delivered at Vanderbilt, a member of our team visits with the parents while in the hospital, assesses the cleft and provides information on feeding and care. If a baby is delivered elsewhere, we meet with parents in our outpatient clinic in the first few weeks of the baby’s life. Parents and the baby meet all needed providers at one convenient visit, either onsite or via telehealth.

Cleft care timeline

Every child is unique, so we adapt care to individual needs. While this information may not apply to every baby, this surgical timeline helps families understand what to expect.

Birth through 3-to-5 months of age – Pre-surgical molding and cleft lip/nose repair: Conducting a feeding assessment is probably the most important need in the days after delivery. Our speech and language pathologists meet with families to teach feeding techniques. This may include the use of specialty bottle systems or supplemental devices. Together with the pediatrician, we closely monitor the baby’s weight gain and implement treatment changes as needed.

Our surgeon then sets the date of the cleft lip repair, typically at 3 to 5 months of age. We also offer many pre-surgery treatments to make the cleft smaller and improve the nasal shape, such as NAM therapy. This option can be performed weekly on campus or at an offsite dental office, offering convenience for families. We also may discuss other treatments, such as lip taping or lip adhesion.

11 to 13 months old – Cleft palate repair and ear tubes: Before a cleft palate repair, a feeding specialist meets with the family to help the baby transition from using a bottle to a free-flow “sippy” cup. Our team will likely recommend ear tube placement at the same time as the palate repair to prevent any hearing problems. These two procedures help repair the cleft by separating



An infant with a right unilateral cleft treated with pre-surgical molding before surgery and at 2 years old.

the mouth from the nose and repairing the important speech muscles in the soft palate.

One year to kindergarten age – Lip or nose revision, speech surgery: The American Academy of Pediatric Dentistry recommends all children have their first visit with a dentist around their first birthday. This especially applies to children with cleft lip and palate, who have unique and complex dental needs. Regular and routine dental visits are important throughout the next several years of rapid facial growth.

With the initial repairs complete, the next few years require at least annual clinic visits with the surgeon as children develop speech. We recommend a formal speech evaluation around at least 18 months of age to ensure the palate is working the way it should.

If there is a hypernasal quality to speech (a sound like air passing through the nose), our speech team helps children maximize their speech potential. If we think surgery may help their speech, it would occur between ages 3 to 8. If speech is progressing normally, we bring the family to our clinic prior to kindergarten (ages 5 to 6) for a group assessment. At this time, we may recommend another surgery to the lip or nose.

Kindergarten to middle school – Alveolar bone grafting: We see the child once per year until the time of alveolar bone grafting (bone is implanted to fill the cleft at the gumline). This surgery may occur between ages 7 to 11 when adult teeth begin to come into the cleft. Healthy bone in this area helps ensure the adult teeth are positioned properly. We typically borrow this bone from the hip bone. In some cases, we may use specially processed, packaged bone from donors.

Middle school through high school – Orthodontics: After alveolar bone grafting is complete, the orthodontist plays an important role in helping move teeth into straight positions and develop a complete smile.

As teens make friends and move from one school grade to the next, we offer assistance from a school-aged psychologist and social worker, who can assess if any learning, behavioral or social needs exist.



A school-aged patient with a history of cleft lip and palate who is getting ready to have bone grafting.

High school and beyond – Possible jaw and nose surgery: Facial bones typically stop growing at ages 15 to 16 for a girl and ages 17 to 19 for a boy. We continue using orthodontics and check the degree of the underbite. If we decide jaw surgery is needed, the surgeon and orthodontist work together to plan the surgery. They typically take a 3D CT scan of the jaw and use this to virtually plan the surgery. This ensures teeth align as well as possible to create the best bite and improve appearance.



A teenager with bilateral cleft lip and palate following jaw, nose surgery and dental restoration.

Following jaw surgery, nose surgery (rhinoplasty) is typically the final procedure in the “prenatal to prom” timeline. The surgeon discusses how the procedure (cleft rhinoplasty) can help improve the nose look and function.

Pierre-Robin sequence babies
(Cleft palate but no cleft lip and a small jaw)

When babies are born with a cleft palate, a very small chin and difficulty breathing or eating, our specialists may be able to help. Our team will usually take a 3D CT scan to look at the jaw bones. Surgery to lengthen the lower jaw bone (mandibular distraction) can push the tongue forward. This improves breathing and the “suck, swallow, breathe” reflex for oral feeding.



An infant with Pierre Robin Sequence who underwent mandible lengthening to improve breathing and feeding.