Cleft Lip and Cleft Palate

What are cleft lip and cleft palate?

- Cleft lip and cleft palate are among the most common congenital anomalies. A *cleft* is an opening or a separation.
- *Cleft lip* is a separation in the upper lip. It can be present on one side or both sides of the lip.
- *Cleft palate* is an opening in the roof of the mouth (called the *palate*).
- Cleft lip and cleft palate can occur alone or together.

How common are they?

- Cleft lip and/or cleft palate affects more than 8,000 newborns a year in the United States, with an incidence of 1 case per 600 to 700 births.
- Cleft lip and/or cleft palate can occur alone or in association with known genetic syndromes. More than 300 other known syndromes have been described in children with cleft lip and/or cleft palate. Syndromes may sometimes affect a child's development, ability to learn, or ability to see or hear, or they may sometimes cause other health problems.

What are some common characteristics of children who have cleft lip and/or cleft palate or of the condition as children present with it?

- The cleft, or opening, in the lip or palate is usually identifiable at the time of birth.
- Less commonly, a cleft occurs in the muscles of the soft palate but not in the lining of the mouth, so an opening or a separation is not visible. This cleft is called a *submucosal cleft palate* and is sometimes diagnosed only if a child has complications, such as difficulty with sucking and feeding, nasal regurgitation of breast milk (human milk) or infant formula, recurrent ear infections, and speech disorders.
- Children with cleft lip and/or cleft palate are more likely than other children to have issues in the following areas:
  - **Feeding:** Babies with cleft palates, and occasionally those with isolated cleft lips, often have difficulty feeding from the breast or a normal bottle. Specifically, babies with cleft palates cannot generate adequate suction and typically need a special bottle and nipple to take in enough breast milk or infant formula to gain weight and grow. A variety of cleft feeders are available. Generally, babies born with cleft palates (alone or with a cleft lip) cannot breastfeed but can drink expressed breast milk from a cleft feeder. A certified lactation consultant can help parents obtain and use a breast pump. This condition can also cause nasal regurgitation (breast milk or infant formula that comes out of the nose). Most babies with cleft palates will swallow a great deal of air and require frequent burping. Rarely, special appliances called *obturators* (a prosthetic device that closes the opening of the cleft) are required. To babies who are developmentally ready, age-appropriate solid foods can be offered. This may also be associated with nasal regurgitation that is seldom a problem. Young children who are ready to drink from a cup may do so, but they may be more successful with an open cup, rather than a sippy cup. The cleft or craniofacial team caring for the child can give advice on feeding.
  - **Ear infections and hearing loss:** A cleft palate causes disruption of the normal muscle anatomy of the palate. This disruption interferes with the function of the eustachian tube that connects the middle ear to the back of the throat. Eustachian tube dysfunction can cause fluid to collect in the middle ear, which can interfere with hearing and predispose children to ear infections. Many children with cleft palates have tubes placed into their ears to allow the middle ear fluid to drain more easily.
  - **Dental problems:** Cleft lip and/or cleft palate affects how the teeth erupt and how the upper and lower jaw develop and grow. Children with cleft lip and/or cleft palate are at higher risk for dental decay. Good oral hygiene at home (brushing at least twice daily with fluoride toothpaste, drinking fluoridated water, and avoiding too many sugary foods and drinks) and regular professional dental care are especially important for children with cleft lip and/or cleft palate. Most children with cleft lip and/or cleft palate need orthodontic treatment at least once during both childhood and adolescence.


Baby with cleft lip

Cleft Lip and Cleft Palate *(continued)*

- **Speech problems:** A specific type of speech problem called *velopharyngeal insufficiency* (VPI) occurs more commonly in children with cleft palates (either alone or with a cleft lip), even after the cleft palate has been repaired. When VPI occurs, too much air comes out of the nose when a child makes certain sounds or words; in turn, the child's speech may become difficult to understand. A speech-language therapist with expertise in caring for children with cleft palates is important in the evaluation of children at risk for VPI. All children with cleft palates require regular evaluation by a speech-language therapist as part of their cleft or craniofacial team care. When a child is diagnosed as having VPI, treatment usually involves surgery; speech-language therapy alone is not sufficient.
- **Teasing and bullying:** Young children are curious about peers with facial differences. Involving the child and family in teaching other children about cleft lip and/or cleft palate helps promote understanding and compassion. Older children with facial differences may be subject to teasing or bullying; to the extent that school staff, teachers, and parents/guardians are aware, teasing and bullying should not be tolerated. A strong sense of self-esteem and unconditional love from parents/guardians and caregivers promotes resilience that helps all children thrive.

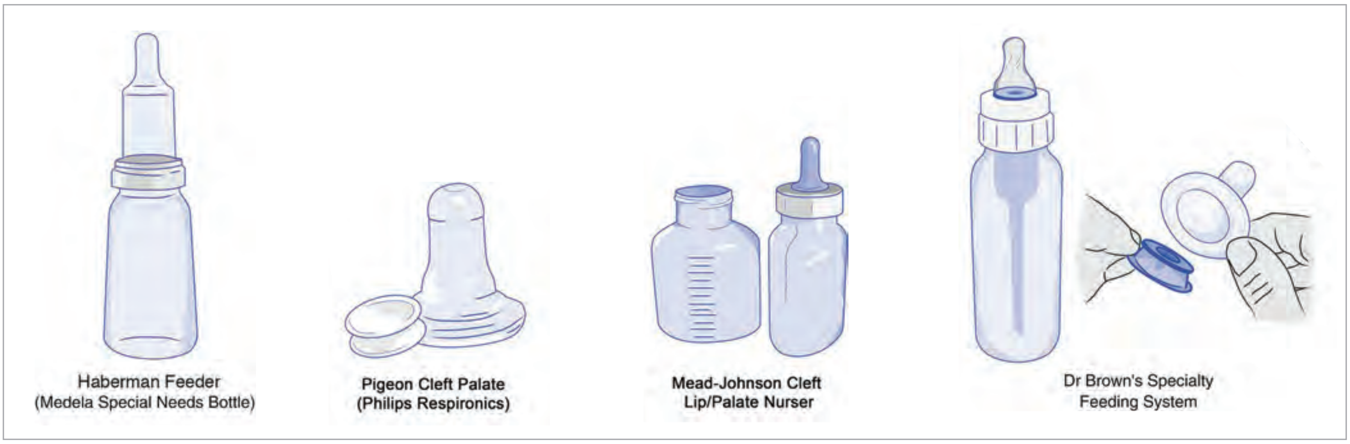
Who might be on the treatment team?

- A treatment team that specializes in the care of children with cleft lip and/or cleft palate should be involved. The treatment team usually includes the child's pediatrician/primary care provider in the medical home, a plastic surgeon, a pediatric dentist, a pediatric otolaryngologist (ie, ears, nose, and throat doctor), an audiologist, a speech-language therapist, and a psychologist or social worker to address family concerns. Other important consultants should include a medical geneticist, an orthodontist, a maxillofacial surgeon, and nurses or occupational therapists who are trained in feeding children with cleft lip and/or cleft palate.
- Most children with cleft lips will have surgery to close the lip between birth and 3 months of age.
- Cleft palate repair usually occurs by 1 year (ie, 12 months) of age.
- For children with cleft palates and a collection of fluid in the middle ear or with recurrent ear infections, ear tubes are often placed during the palate repair surgery.
- Some children with cleft lip and/or cleft palate may require therapy or special education services.
- Children who are younger than 3 years (ie, 36 months) may receive speech-language therapy through local *early intervention* programs. Early intervention is a system of services to support infants and toddlers with disabilities and their families.
- Children 36 months and older may receive therapy services through *special education and related services* provided by their local public school systems.

What adaptations may be needed?

Dietary Considerations

- The Care Plan for an infant with cleft lip and/or cleft palate may include the use of special feeding devices such as the Haberman Feeder or a Mead-Johnson Cleft Lip/Palate Nurser (bottles specialized for feeding children with cleft palates) or, less frequently, an obturator, which is a special device used to close the opening of the cleft.


Haberman Feeder
(Medela Special Needs Bottle)

Pigeon Cleft Palate
(Philips Respironics)

Mead-Johnson Cleft
Lip/Palate Nurser

Dr Brown's Specialty
Feeding System

AAP

Special feeding devices for children with cleft lip and/or cleft palate

Cleft Lip and Cleft Palate *(continued)*

- Children with cleft lip and/or cleft palate should gain weight normally and should have no difficulty swallowing. If a child with cleft lip and/or cleft palate has difficulty gaining weight or swallowing, the child's regular doctor and cleft or craniofacial team should be alerted, because additional specialized evaluation and management may be required.
- For some children with more feeding difficulty, the formula or breast milk may be concentrated or fortified with more calories to help the child get sufficient calories with lower volumes.
- Feeding a child with cleft lip and/or cleft palate should not be rushed but should take no longer than 30 minutes.

Physical Environment and Other Considerations

- Focus on the child as an individual, and point out positive attributes that do not involve physical appearance or speech difficulty.
- Some children with cleft lip and/or cleft palate may require additional surgery, and the child may miss days from child care or school. When the child begins elementary school, it is critical to develop a plan up-front to work in partnership with parents/guardians and teachers to ensure that the child's education is ongoing and that those transitions go smoothly.
- Any child, with or without a cleft lip and/or cleft palate, who has difficulty hearing or seeing in the classroom needs additional evaluation and treatment. When such problems go untreated, learning is more difficult. Hearing problems are more common in children with cleft lip and/or cleft palate, and these children may use hearing aids, may need preferential seating, or may use special devices to help them hear better in the classroom.
- Because of potential hearing problems, be aware of the possible need to repeat directions or use visual cues.
- Children with cleft lip and/or cleft palate may be at risk for teasing by classmates. Be sensitive to this possibility, and promote acceptance activities.
- Most children with cleft lip and/or cleft palate have normal intelligence.
- Work with speech-language therapists to help children pronounce words clearly.

What should be considered an emergency?

There are no special emergencies that children with cleft lip and/or cleft palate face.

What types of training or policies are advised?

Children with cleft lip and/or cleft palate may have problems with choking. Reviewing first-aid training for choking may be helpful for staff. Everyone who cares for children should receive pediatric first-aid training that includes CPR (management of a blocked airway and rescue breathing) with instructional demonstration and return demonstration by participants on a mannequin. *Pediatric First Aid for Caregivers and Teachers* is a course designed to teach these skills. Please see Additional Resources (page 265) for more information.

What are some resources?

- American Academy of Pediatrics: www.aap.org—Lewis CW, Jacob LS, Lehmann CU; American Academy of Pediatrics Section on Oral Health. The primary care pediatrician and the care of children with cleft lip and/or cleft palate. *Pediatrics.* 2017;139(5):e20170628
- American Cleft Palate-Craniofacial Association: www.cleftline.org, 1-800-242-5338
- American Speech-Language-Hearing Association: www.asha.org, 1-800-498-2071
- Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities: "Facts About Cleft Lip and Cleft Palate" (Web page), www.cdc.gov/ncbddd/birthdefects/cleftlip.html
- Children's Craniofacial Association: https://ccakids.org, 1-800-535-3643