



The Primary Care Pediatrician and the Care of Children With Cleft Lip and/or Cleft Palate

Charlotte W. Lewis, MD, MPH, FAAP,^a Lisa S. Jacob, DDS, MS,^b Christoph U. Lehmann, MD, FAAP, FACMI,^c SECTION ON ORAL HEALTH

Orofacial clefts, specifically cleft lip and/or cleft palate (CL/P), are among the most common congenital anomalies. CL/P vary in their location and severity and comprise 3 overarching groups: cleft lip (CL), cleft lip with cleft palate (CLP), and cleft palate alone (CP). CL/P may be associated with one of many syndromes that could further complicate a child's needs. Care of patients with CL/P spans prenatal diagnosis into adulthood. The appropriate timing and order of specific cleft-related care are important factors for optimizing outcomes; however, care should be individualized to meet the specific needs of each patient and family. Children with CL/P should receive their specialty cleft-related care from a multidisciplinary cleft or craniofacial team with sufficient patient and surgical volume to promote successful outcomes. The primary care pediatrician at the child's medical home has an essential role in making a timely diagnosis and referral; providing ongoing health care maintenance, anticipatory guidance, and acute care; and functioning as an advocate for the patient and a liaison between the family and the craniofacial/cleft team. This document provides background on CL/P and multidisciplinary team care, information about typical timing and order of cleft-related care, and recommendations for cleft/craniofacial teams and primary care pediatricians in the care of children with CL/P.

INTRODUCTION

Clefts of the lip and palate (CL/P) are a heterogeneous group of disorders affecting the structure of the face and oral cavity (Fig 1A presents normal structure).¹ These disorders have been divided into 3 general categories with variability in phenotype (Tables 1 and 2): (1) cleft palate alone (CP [Fig 1B]); (2) unilateral or bilateral cleft lip with or without cleft alveolus (CL ± A [Fig 1 C and D, respectively]); and (3) unilateral or bilateral cleft lip and cleft palate (CLP [Fig 1 E and F]).

abstract

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^aDivision of General Pediatrics and Hospital Medicine, Department of Pediatrics, University of Washington School of Medicine and Seattle Children's Hospital, Seattle, Washington; ^bGeorgetown Pediatric Dentistry and Orthodontics, Georgetown, Texas; and Departments of ^cBiomedical Informatics and Pediatrics, Vanderbilt University Medical Center, Nashville, Tennessee

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TABLE 1 Standard Accepted Cleft Classifications and Abbreviations

Cleft Classification	Abbreviation	Exclusion
Cleft lip	CL	Excludes (1) cleft lip and alveolus; (2) cleft lip and palate; and (3) cleft palate alone
Cleft lip with or without cleft alveolus	CL ± A	Excludes (1) cleft lip and palate; and (2) cleft palate alone
Cleft palate alone	CP	Excludes (1) cleft lip; and (2) cleft lip and palate
Cleft lip and palate	CLP	Excludes (1) cleft lip; and (2) cleft palate alone
Cleft lip with or without cleft palate	CL ± P	Excludes cleft palate alone
Cleft palate with or without cleft lip	CP ± CL	Excludes cleft lip and cleft lip and alveolus
Cleft lip and/or cleft palate	CL/P	No exclusion

Modified from Huang AH, Patel KB, Maschhoff CW, et al. Occlusal classification in relation to original cleft width in patients with unilateral cleft lip and palate. *Cleft Palate Craniofac J*. 2015;52(5):574-578.

TABLE 2 Associations and Other Features of CL/P According to Phenotype

Associations and Other Features	Cleft Phenotype	
	Cleft Lip With or Without Cleft Palate (~1 in 600–700 US Births)	CP (~1 in 1000–1500 US Births)
Sex	Male:female ratio 2:1 ²	Male:female ratio 1:2 ²
Racial/ethnic	Most common in American Indian, Alaska Native, Latino, and Asian subjects (1/300–1/500) ³ ; intermediate in white subjects (1/1000); and less common in black subjects (1/2500) ¹	No racial/ethnic association
Syndrome	30% associated with a syndrome ¹	50% associated with a syndrome ¹
Location	CLP is about twice as common as CL ± A. ⁴ Usually, the CL is contiguous with the cleft alveolus and CP. Less commonly, there may be a CL that is separated from the CP by apparently normal alveolar ridge and/or anterior palate	CP may involve the entire secondary palate (posterior to the incisive foramen) or a more posterior portion of the palate. A submucosal cleft palate is a defect in the palatal musculature with intact overlying mucosa, and the effects on feeding, Eustachian tube function, and speech may be similar to those in children with an overt CP
Unilateral vs bilateral and sidedness	Approximately 75% of clefts involving the lip are unilateral. ⁵ Among unilateral CL ± P, those affecting the left side are twice as common as the right side ⁵	CP is usually in the midline

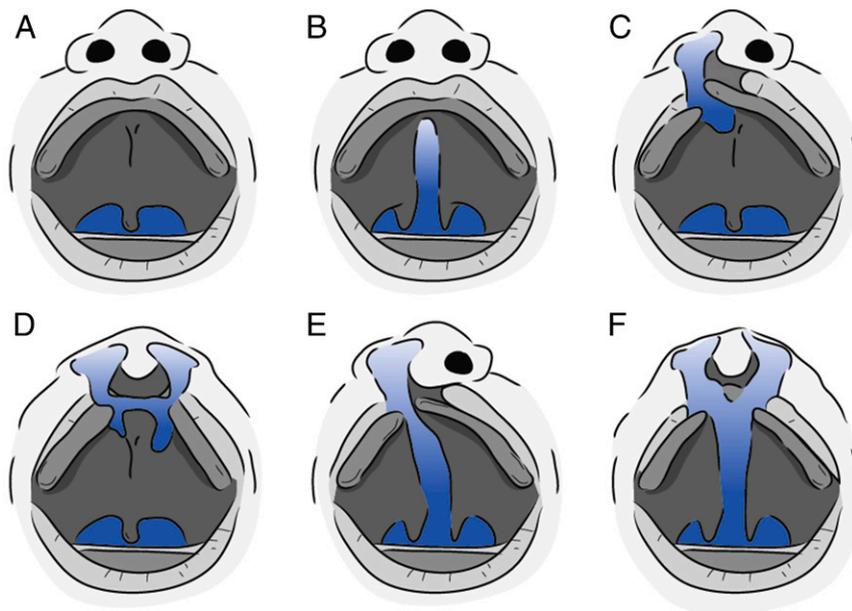


FIGURE 1

Types of CL/P. A, Normal. B, Cleft palate alone. C, Unilateral cleft lip and alveolus. D, Bilateral cleft lip and alveolus. E, Unilateral cleft lip and palate. F, Bilateral cleft lip and palate.

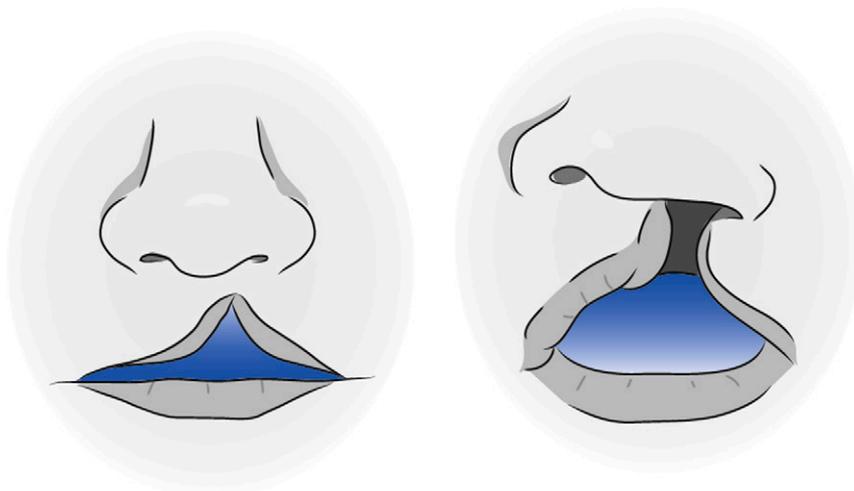
Rarer forms of orofacial clefting, such as oblique facial clefts and median clefts, require specialized craniofacial

team care. The present article focuses on the more common forms of orofacial clefting (specifically CL/P).

From an embryologic perspective, CL/P results from failure of the maxillary first branchial arch to complete fusion with the frontonasal process in early gestation.⁶ Historically, CL, CL ± A, and CL ± P have been considered variants of the same anomaly that only differ in severity,⁷ although this topic remains an area of active research. CP alone is an entity distinct from CL ± P.⁶ Clefts of the lip are subcategorized as complete or incomplete, depending on the degree that the cleft extends through the lip and into the nose (Fig 2).

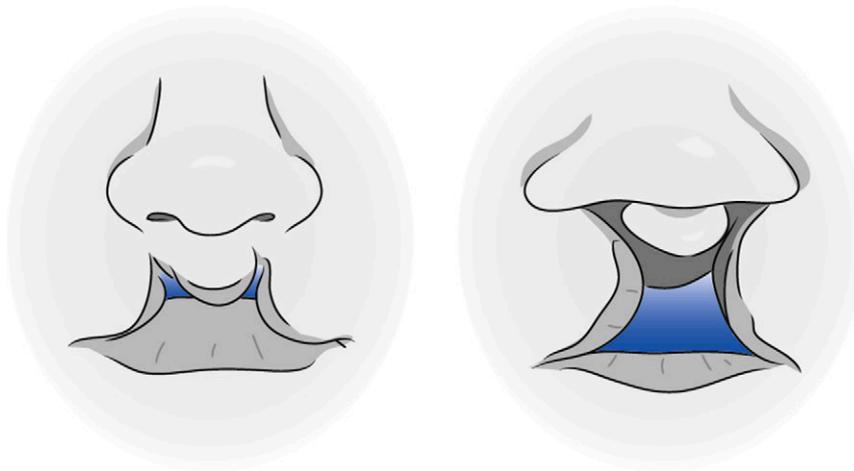
EPIDEMIOLOGY AND ETIOLOGY OF CL/P

CL/P is one of the most frequently observed congenital anomalies, occurring in approximately 1 in 600 to 700 births in the United States (Table 2).⁸ The Centers for



Unilateral incomplete

Unilateral complete



Bilateral incomplete

Bilateral complete

FIGURE 2

Incomplete versus bilateral unilateral cleft lip (bilateral cleft lip may be incomplete or complete or a combination).

Disease Control and Prevention recently estimated that approximately 2650 infants are born with a CP and 4440 infants are born with a CL ± P in the United States annually (Fig 3).⁹ Certain racial groups, including American Indian/Alaska Native, and Asian subjects, have a higher incidence of CL ± P than do white or black subjects.²

Children with CL ± P are at lower risk of an underlying syndrome than children with CP alone. An estimated

30% of children with CL ± P and 50% of children with CP alone have an associated syndrome.¹ At least 275 syndromes with orofacial clefting as a primary feature have been identified; the causes include mutation of a single genetic locus, chromosomal abnormalities, and teratogens.⁵

Nonsyndromic CL/P is a multifactorial condition caused by a combination of genetic and environmental factors. Although additional family members may have CL/P, the pattern of inheritance does

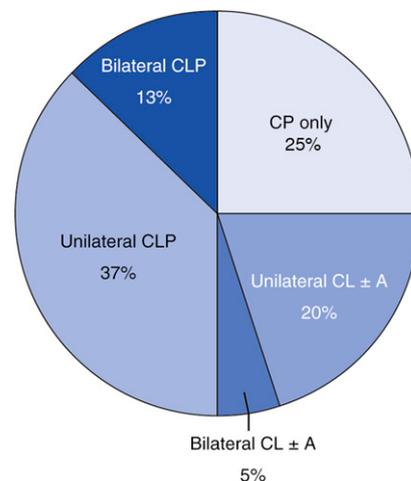


FIGURE 3

Approximate distribution of CL/P in the United States.

not fit typical Mendelian genetics.¹⁰ The recurrence risk of nonsyndromic CL ± P in subsequent siblings and offspring of the proband child is considered to be approximately 3% to 5%. The recurrence risk of nonsyndromic CP is estimated to be 2% to 3% in siblings and offspring.¹⁰⁻¹² The risk of recurrence of either CL ± P or isolated CP is further increased if more than one first-degree relative has a cleft. Specific genetic-environmental interactions are known to increase the risk of nonsyndromic CL/P. For example, although smoking during pregnancy doubles the risk of cleft lip, women with a specific MSX1 allele who smoke have a threefold risk of having a child with CL/P.¹³

Folic acid is important for the prevention of neural tube defects, but there is inconclusive evidence that preconception folic acid supplementation decreases the risk of oral clefting. A recent population-based study from 1999 to 2013 in Norway concluded that there was no statistically significant association between maternal folate use and risk of isolated oral clefts.¹⁴ However, the investigators reported a lower risk for oral clefts that occurred in combination with other malformations, such as heart, limb,

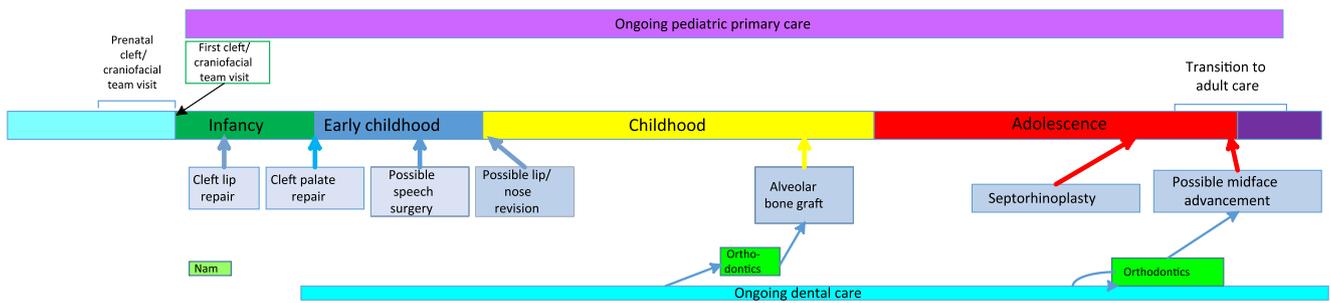


FIGURE 4 Timeline of cleft care, including surgical and orthodontic interventions. Various cleft/craniofacial teams may differ slightly in the timing and sequence of care from this time line, and not all children with CL/P require all of these procedures. Light blue in graphic indicates cleft-related surgery; green indicates orthodontics; and turquoise indicates dental. NAM, nasaloalveolar molding or other pre-orthopedic appliances.

or urinary tract congenital anomalies (adjusted risk ratio: 0.63 [95% confidence interval: 0.45–0.88]).

The American Academy of Pediatrics recommends that all women of childbearing age consume 0.4 mg (400 µg) of folic acid daily to prevent 2 common and serious birth defects (spina bifida and anencephaly) according to the US Public Health Service and the Centers for Disease Control and

Prevention. Preconception folic acid supplementation may also have a protective effect against some types of CL/P.

TEAM CARE

Primary care pediatricians have an important role in helping families of children with CL/P find multidisciplinary team care. Many cleft/craniofacial teams are

affiliated with the American Cleft Palate–Craniofacial Association (ACPA), which provides guidelines and standards for cleft-related and craniofacial care. The ACPA has established 2 categories of teams: cleft teams and craniofacial teams.¹⁵ Cleft teams generally provide care only to children with CL/P; craniofacial teams have a broader level of technical and professional expertise, and they generally provide care for a larger number of patients with CL/P as well as those with more complex craniofacial conditions (eg, craniosynostosis, craniofacial microsomia, oblique facial clefts). Cleft and craniofacial teams are groups of experienced and qualified professionals from medical, surgical, dental, and allied health disciplines working in an interdisciplinary and coordinated system. Coordination of care is necessary because of the complexity of the medical, surgical, dental, and social factors that must be considered in treatment decisions.¹⁶ Primary disciplines represented on the team usually include audiology, dentistry, genetics, pediatrics, nursing, nutrition, oral surgery, orthodontics, otolaryngology, plastic and reconstructive surgery, psychology, social work, and speech pathology. A multidisciplinary team is needed because CL/P outcomes occur in the surgical, speech, hearing, dental, psychosocial, and cognitive domains.

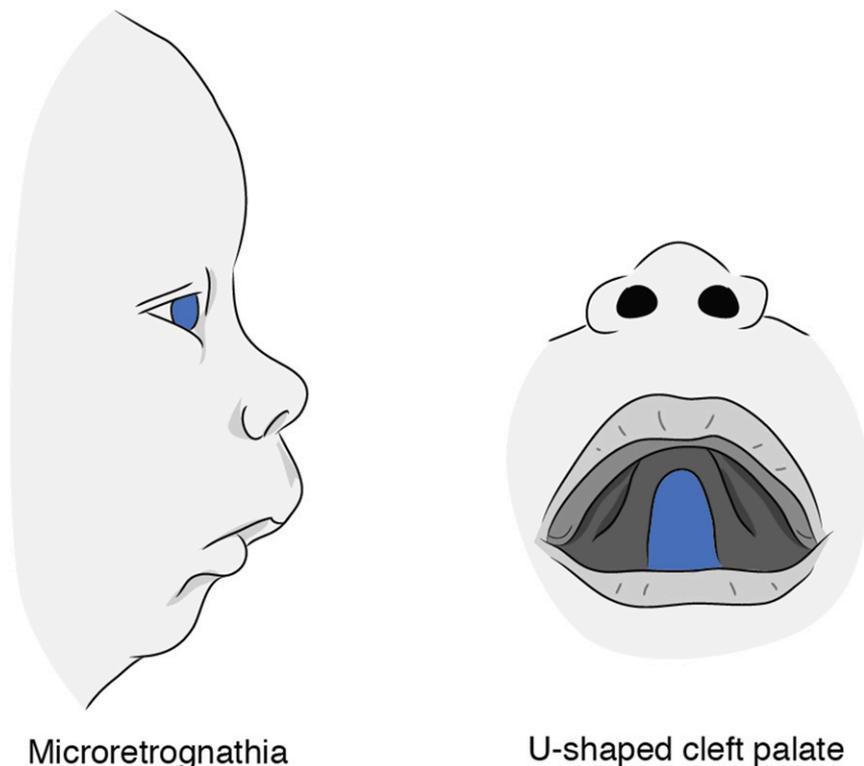


FIGURE 5 Pierre Robin sequence.



Haberman Feeder
(Medela Special Needs Bottle)



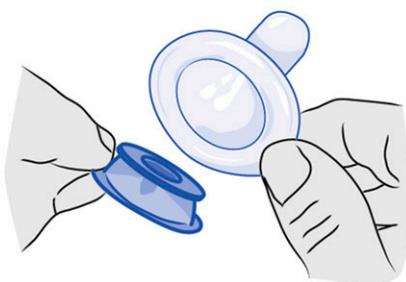
Pigeon Cleft Palate
(Philips Respironics)



Mead-Johnson Cleft Lip/Palate Nurser



Dr Brown's Specialty Feeding System



birth and continues until skeletal maturity has been reached, at which point the final stage of reconstructive surgery can be performed. Proper timing of interventions is critical because of the interaction of facial growth, dental occlusion, and speech. Although reconstructive surgeries are important milestones for children with CL/P, it is important that the ongoing focus remain on the medical and psychosocial issues that these children and their families face. The primary care pediatrician has an essential role in providing longitudinal and holistic attention to the well-being of the child with CL/P and his or her family.

More than 8000 primary CL and CP repair procedures are performed in the United States each year, typically during the first 1.5 years of life. In the United Kingdom, cross-sectional studies indicate that centralization and multidisciplinary cleft care, as well as higher patient volume, predict better long-term functional and aesthetic outcomes in children with CL/P.¹⁷⁻²² Successful cleft-related surgical outcomes are improvements in appearance, speech intelligibility, chewing, sleep, and breathing. Good outcomes from initial procedures may reduce the need for secondary surgeries during patients' childhood, adolescence, and beyond.

The American Academy of Pediatrics recommends that children born with CL/P receive coordinated care through a multidisciplinary cleft or craniofacial team.

ORAL HEALTH AND DENTAL CARE FOR CHILDREN WITH OROFACIAL CLEFTS

Dental care and orthodontic care are particularly important for children with CL/P because oral health plays a significant role in cleft-related outcomes. In addition to being susceptible to typical caries risk factors, children with CL/P face additional potential risk factors for

FIGURE 6
Cleft feeders.

The goal of the cleft/craniofacial team, as articulated by the ACPA, is "to ensure that care is provided in a coordinated, consistent manner with the proper sequencing of evaluations and treatments within the framework of the patient's overall developmental, medical, and

psychological needs."¹⁵ Although this overarching goal is consistent across teams, there is some degree of variability between teams in timing, order, and choice of specific procedure.

Cleft/craniofacial team care usually begins prenatally or shortly after

TABLE 3 Areas for Specific Attention According to Age for Children With CL/P Beyond the Newborn Period³⁶

Stage	Age Range	Recommendation
Younger infant	3–6 mo	<ul style="list-style-type: none"> • CL repair • Regular nutrition, growth, development, psychosocial, sleep, speech and hearing, and oral health evaluation, management and anticipatory guidance
Older infant/toddler	7–23 mo	<ul style="list-style-type: none"> • Reinforce importance of using fluoride toothpaste twice daily, community water fluoridation, and regular professional dental care (at every age) • Fluoride varnish at least twice yearly • Palate repair typically at 9–18 mo. Tympanostomy tubes may be placed for children with CP who have middle ear fluid • Speech evaluation • First dental visit occurs when first tooth erupts or within the first year of life • Regular nutrition, growth, development, psychosocial, sleep, speech and hearing, and oral health evaluation, management, and anticipatory guidance
Early childhood	2–5 y	<ul style="list-style-type: none"> • Reinforce importance of using fluoride toothpaste twice daily, community water fluoridation, and regular professional dental care (at every age) • Fluoride varnish at least twice yearly • Regular team visits • Regular nutrition, growth, development, psychosocial, sleep, speech and hearing, and oral health evaluation, management, and anticipatory guidance • Dental visits every 3–6 mo • Possible lip and/or nose revision
Later childhood	6–11 y	<ul style="list-style-type: none"> • Palate or pharyngeal surgery for speech may be needed in the setting of VPI • Consult orthodontist to determine if palate expansion or braces needed (first phase) • Ongoing facial growth and occlusal assessment • Discuss with surgeon need for alveolar bone graft surgery • Continue speech therapy if needed • Regular dental visits and ongoing oral health anticipatory guidance • Regular nutrition, growth, development, psychosocial, sleep, speech and hearing evaluation
Adolescence	12–18 y	<ul style="list-style-type: none"> • Regular nutrition, growth, development, psychosocial, sleep, speech and hearing, and oral health evaluation, management, and anticipatory guidance • Possible lip revision • Second phase orthodontic treatment • Jaw surgery may be needed • Continue regular dental visits • Possible septorhinoplasty • Genetic counseling
Adulthood	≥19 y	<ul style="list-style-type: none"> • Final surgeries • Transition to adult care

Source: Lisa S. Jacob, DDS.

caries and other oral disease that are specific to their condition and treatment.²³ These risks include the following: (1) enamel hypoplasia, increasing the risk of dental decay in affected teeth; (2) structural anomalies that favor the formation of retention niches for food residues and which impair self-cleansing of the teeth; (3) devices in the mouth (eg, palatal expanders, orthodontic brackets and wires, obturators, retainers), which become colonized with cariogenic bacteria and that can interfere with oral hygiene²⁴; and (4) tight scars after surgeries that restrict space in the oral vestibule, resulting in disturbed occlusion and articulation and making

toothbrushing and flossing more difficult.

There is also overlap between population groups at risk for CL/P and for early childhood caries (ECC). American Indian/Alaska Native individuals are at higher risk for both ECC and CL ± P. Other population groups at higher risk for ECC are children of lower socioeconomic status; relative to the pediatric population as a whole, more children with CL/P are Medicaid insured (E. Wallace, PhD, personal communication, 2016), which is a marker for lower income status.

Parents may voice concerns about their child's teeth to their primary

care pediatrician. Natal teeth, which are teeth present at birth, are more common in children with CL ± P. Furthermore, children born with CL/P are at increased risk for congenital dental anomalies, such as supernumerary teeth, missing teeth, and hypodontia. Primary teeth may erupt ectopically, for example, in the cleft site or into the palate, or dental eruption may be delayed. The appearance of crooked primary teeth, a common finding in children with CL/P, might concern parents. Parents should be reassured that orthodontic treatment is part of cleft-related care and is usually initiated as the permanent teeth begin to erupt. In the presence of an alveolar (gum

TABLE 4 Recommendations for Care of Children With CL/P

Developmental Stage	Recommendation
Prenatal care	All women of childbearing age should consume 0.4 mg (400 µg) of folic acid daily to prevent spina bifida and anencephaly
Newborn care	Children born with CL/P should receive coordinated care through a multidisciplinary cleft or craniofacial team Every effort should be made to visualize the palate during the initial newborn examination to exclude presence of a CP Newborn infants born with CL/P who have persistent feeding problems should receive prompt consultation with or transfer of care to a cleft/craniofacial specialist Newborn infants with CL/P should be seen for early newborn follow-up by their primary care pediatrician and evaluated by a cleft/craniofacial specialist or team as soon as possible after discharge from birth hospitalization, ideally within 1 wk of discharge Infants with a CP need a special feeding device and the support of a feeding therapist, certified lactation consultant, and/or nurse experienced in feeding children with CP. Infants with CL ± A can often breastfeed with attention to position and latch Early initiation of dental care (before age 1 y) is important for children with CL/P because oral health influences craniofacial treatment and outcomes Infants and children, and especially those with CL/P, should have their teeth brushed twice daily using fluoride toothpaste and, where available, drink optimally fluoridated water. Children at high risk for dental caries, including children with CL/P, should receive at least twice-yearly fluoride varnish applications beginning with the first tooth eruption
Early childhood care	Cleft/craniofacial teams must be advocates for children with CL/P who are Medicaid insured or whose family cannot afford out-of-pocket payments so that these children can obtain timely, appropriate, and equitable cleft-related reconstructive surgery, and dental, orthodontic, and prosthodontic care Early assessment and regular monitoring by craniofacial experts in partnership with the primary care pediatrician are needed to ensure the health and safety of infants and young children with Pierre Robin sequence Children with CP need regular audiologic evaluation and otolaryngology assessment as part of cleft/craniofacial team care
Childhood care	Children with CL/P and their families should be offered psychosocial support from specialists such as child life professionals, particularly around times of surgery Children with CP ± CL need regular speech assessment by a speech and language specialist with expertise in detecting and evaluating VPI. Primary care pediatricians should be aware that VPI may require surgical management; in these cases, VPI will not improve with speech therapy alone
Adolescent care	Transitioning the care of a patient with CL/P to adult care requires individualized planning and referrals. When transitioning, patients need a detailed summary of their cleft/craniofacial team care and surgery as well as information about their other special needs

line) cleft, it is particularly important that the primary teeth not be moved with orthodontic treatment because such movement may adversely affect the blood supply of teeth adjacent to the cleft.

Dental and orthodontic care may be provided as part of the cleft/craniofacial team care or, with some teams, patients may be directed to community-based dental and orthodontic providers. Good oral health, ideally resulting from regular home oral hygiene and professional dental care, influences a child's ability to obtain timely and adequate orthodontic treatment, which is an essential component of the reconstructive process and required precursor to surgery for children with CL/P. In this way, access to dental and orthodontic care is critical to promoting optimal outcomes in children with CL/P.

Throughout childhood and adolescence, dental and orthodontic

involvement in cleft care is needed for monitoring facial growth and dental eruption to assist in the planning and timing of surgical procedures. This approach is particularly important for the alveolar bone graft (ie, the graft to fill in the alveolar cleft), which needs to be timed to coincide with the eruption of certain permanent teeth (usually at 8–10 years of age) to maximize the chance for graft success. Orthodontic treatment is also necessary as a framework for reconstructive surgery as well as to correct debilitating occlusal abnormalities. Without appropriate orthodontic care, reconstructive and midface advancement (ie, jaw) surgeries may be compromised, and outcomes can potentially be jeopardized. The end result may be unstable and/or malpositioned oral structures; premature tooth loss; functional deficiencies in chewing, swallowing, airway, and speech; and poor esthetic results.²⁵ The

important interrelationship and interdependence between dental and orthodontic care and reconstructive surgery for children with CL/P from early in life into young adulthood are shown in Fig 4.

Access to orthodontic care for children with CL/P who are uninsured or publicly insured or who live in rural areas can be problematic. In a 2004 Washington state survey, very few orthodontists (approximately 2%) accepted Medicaid, and those who did were located at academic medical centers in large urban areas. Similar circumstances occur in other states as well. Nationwide, 37% of all children,²⁶ but 50% of children with CL/P, are insured through Medicaid (E. Wallace, PhD, personal communication, 2016). This discrepancy results in a potential mismatch between the percentage of orthodontists accepting Medicaid and the percentage of Medicaid-insured children with CL/P who require orthodontic treatment as part of



FIGURE 7
Children with CP ± CL are at risk for midface hypoplasia, which produces a class III skeletal malocclusion in which the lower teeth are forward from the upper teeth.

their cleft care. It serves to highlight concerns regarding differential access to orthodontic care and the risk of disparities in cleft-related outcomes. Likewise, dental implants and other prosthodontic treatment needed for some patients with CL/P are costly and may not be readily available except to those with financial means.

Cleft/craniofacial teams play an important role in advocating for children with CL/P who are Medicaid insured, or whose families cannot afford out-of-pocket payments, so that these children can obtain timely, appropriate, and equitable cleft-related reconstructive surgery and dental, orthodontic, and prosthodontic care.

ROLE OF THE PRIMARY CARE PEDIATRICIAN IN CARING FOR CHILDREN BORN WITH CL/P

Prenatal

With widespread availability of prenatal ultrasonography, many

(although not all) parents know in advance that their newborn infant will have a CL. Because of technologic limitations in antenatal diagnosis of a CP, prenatal diagnosis is usually limited to CL ± A and unknown posterior palate status.²⁷ Once there has been a prenatal diagnosis of a CL ± P, there may be any number of options for further maternal–fetal medicine and/or genetic consultation, depending on local practice and resources. Such referrals are usually facilitated by the woman’s obstetrician or family physician. Prenatal consultation with a cleft/craniofacial team, which is different from genetic counseling, is increasingly common and often involves parents meeting various members of the cleft/craniofacial team and learning about the care of children born with CLP.

Before/During the Birth Hospitalization

Most infants born with CL ± P do not have an underlying syndrome and do well in the newborn period as long as they have access to appropriate feeding equipment and support. When pediatricians are aware that parents are expecting an infant with a CL ± P, they can advise parents on which hospitals have more experience and resources available to support feeding in infants with CL/P. Local or regional cleft/craniofacial team staff are usually available by telephone to assist primary care pediatricians in identifying appropriate resources. Infants born at term with CL ± P as their only prenatally identified anomaly do not have a higher rate of birth-related problems or complications, and they do not typically need delivery in a high-risk obstetric unit or special accommodations in the delivery room. Most of these infants are able to room in with their mothers.

Psychosocial Needs

Regardless of whether the diagnosis of the CL/P was made prenatally, parents and other family members

need support to adjust to having an infant who may have a facial difference, who will need more surgery than the typical child, and who may have special feeding and other needs. Parents often grieve the “loss” of the perfect infant. Anger and guilt (eg, a mother worries that she did something during the pregnancy to cause the cleft), as well as fear for the child’s future social acceptance, are common reactions.¹⁶ Consultation with a craniofacial specialist, if possible, and provision of psychosocial support can be beneficial during the birth hospitalization.

Physical Examination

As with any newborn infant, the initial physical examination is intended to confirm that the infant is healthy and has no additional findings on physical examination which would suggest the need for specialty referral (such as genetics consultation) or imaging studies. Infants born with CP typically are not identified until after birth. Infants are sometimes discharged from the hospital with an undiagnosed CP only to return to the primary care provider’s office with feeding difficulties and poor weight gain.²⁸ A recent report from the United Kingdom described that 16% of cases of CP were undetected on the first examination.²⁹

The American Academy of Pediatrics recommends that every effort be made to visualize the palate during the initial newborn examination in the birth hospital to exclude the presence of a CP.

Furthermore, identification of cleft-related conditions is an important component of the initial physical examination of a newborn infant with CL/P. An important example is the Pierre Robin sequence, which includes microretrognathia (small, recessed jaw), glossoptosis (posteriorly displaced tongue), breathing

difficulties attributable to airway compromise from the posteriorly positioned tongue (loud snoring, snorting, and/or desaturation), and a U-shaped cleft palate (Fig 5). Infants with Pierre Robin sequence frequently require nutritional support, prone positioning, or more invasive treatment of upper airway obstruction. Infants with suspected Pierre Robin sequence should be evaluated by a craniofacial specialist, ideally during the birth hospitalization or very shortly thereafter. Although some neonates with Pierre Robin sequence have immediate airway problems, other newborn infants with Pierre Robin sequence may look deceptively well in the first week of life and then proceed to develop serious airway, feeding, and weight gain problems a short time later. It is important that the pediatrician anticipate these potential problems and ensure that infants with Pierre Robin sequence are seen by a craniofacial specialist as soon after birth as possible.

Early assessment and regular monitoring by craniofacial experts in partnership with the primary care pediatrician are needed to ensure the health and safety of infants and young children with Pierre Robin sequence.

Feeding

In general, infants who have a CP ± CL need a special feeding device³⁰ (Fig 6) because they cannot generate adequate negative intraoral pressure to suck or transfer milk effectively.³¹ These infants need support from a feeding therapist or other health care provider experienced in feeding infants with CP ± CL. In many community hospitals, the certified lactation consultant is the person with the most experience helping mothers to feed infants with CL/P and the individual most familiar with feeding devices used with infants with CL/P.

It is rare that infants with CP ± CL can breastfeed sufficiently to support

normal weight gain.¹⁶ A mother who wants to provide her milk to her infant with CL/P should be seen by a certified lactation consultant for evaluation, feeding support, and assistance with procuring and using a breast pump. Pumping and feeding expressed milk provides the benefits of human milk, including protection against ear infections, for which infants with CP ± CL are at higher risk. However, there are other benefits of breastfeeding that parents look forward to, and grieving the loss of exclusive breastfeeding is not uncommon among parents who have an infant with a CP ± CL.

The situation is different for infants born with CL or CL ± A. Infants born with CL ± A and no CP may be able to form an adequate seal to generate adequate intraoral negative pressure to suck and transfer milk effectively. Infants with CL ± A can often successfully breastfeed. A certified lactation consultant can help mother and infant with position and latch to optimize breastfeeding.

Although not specific to infants with CL/P, many mothers desire to breastfeed and will therefore benefit from the involvement of a certified lactation consultant. In general, infants with a cleft palate either as cleft lip with cleft palate or cleft palate alone (CP ± CL) need a special feeding device and the support of a feeding therapist, certified lactation consultant, and/or nurse experienced in feeding children with CP. Infants with CL ± A can often breastfeed with attention to position and latch.

It is unusual for infants with CL/P to demonstrate evidence of dysphagia (eg, coughing, choking, difficulty swallowing, desaturation with oral feedings), and such signs should prompt additional evaluation for another cause of the feeding problems. Furthermore, if an infant's feeding problems persist beyond 3 days during the birth hospitalization, contacting the nearest craniofacial

specialist or cleft/craniofacial center for consultation, expedited team visit, or inpatient transfer may be needed.

The American Academy of Pediatrics recommends that persistent feeding problems in the newborn period in infants born with CL/P prompt consultation with or transfer of care to a cleft/craniofacial specialist.

Hearing

Similar to all neonates, infants born with CL/P should have newborn hearing screening before discharge; however, newborn infants with CP ± CL sometimes do not pass the hearing screen because they already have middle ear effusion present at birth. Regular audiologic evaluations and otolaryngology assessments are a part of cleft/craniofacial team care.

Postdischarge

After discharge from the birth hospital, newborn infants with CL/P should have an early primary care evaluation to assess weight, jaundice, feeding, newborn health, and maternal/family well-being. A child born with CL/P should be seen by a multidisciplinary cleft/craniofacial team, ideally within 1 week of birth or discharge from the birth hospital.

The American Academy of Pediatrics recommends that newborn infants with CL/P be seen for early newborn follow-up by their primary care pediatrician and evaluated by a cleft/craniofacial specialist or team as soon as possible after discharge from the birth hospitalization, ideally within 1 week of discharge.

CONSIDERATIONS DURING THE FIRST YEAR

Growth and Development

As with every infant, the first year of life for a child born with CL/P means frequent visits to the pediatrician for well- and sick-child visits. Developmental delay or

findings suggestive of an underlying syndrome may manifest during the first year of life or later, prompting the need for referral to early intervention services and/or further genetic evaluation. Infants born with CL/P should have similar weight gain and growth compared with infants born without CL/P.³⁰ If this scenario is not the case, the infant may need closer attention from the primary care pediatrician and the cleft/craniofacial team. Craniofacial surgeons are particularly attentive to weight gain in infants with CL/P and may postpone surgery if an infant is not adequately nourished.

Timing and Goals of Cleft Lip and Palate Repair

For children born with CL ± P, the primary CL repair (cheiloplasty) usually occurs between 2 and 6 months of age. However, it is not unusual to delay cheiloplasty in children with other more pressing medical issues, such as needing surgery for congenital heart disease. For a child born with a wide CL, the cleft surgeon may recommend taping or nasoalveolar molding or other procedures to physically bring the cleft edges closer together before cheiloplasty. The goals of the primary cheiloplasty are to reconstruct the muscles of the oral sphincter, add symmetry to and lengthen the upper lip, and improve symmetry and function of the nasal airway.

Repair of the CP or palatoplasty closes the connection between the nasal and oral cavities and reconstructs the palatal musculature to enable normal speech development. Because palatoplasty is important for development of normal speech in children who have CP ± CL, the age at which this surgery is performed is an important consideration. For infants with CP ± CL, primary palate repair typically occurs between approximately 9 and 18 months of age, although some teams perform a combined CL

and CP repair at approximately 7 months of age. Earlier palatoplasty is not recommended because it has been associated with later midface hypoplasia.³¹

Hearing and Otitis Media With Effusion

It is estimated that more than 90% of children with CP ± CL develop otitis media with effusion at least once before 1 year of age. Because of the high prevalence of Eustachian tube dysfunction among children born with CP, many cleft/craniofacial centers will place tympanostomy tubes, often at the same time as palatoplasty, if middle ear fluid is present. Eustachian tube dysfunction also contributes to more frequent acute otitis media and mild to moderate conductive hearing loss among children with CP ± CL. A 2014 systematic review identified that children with CP ± CL and otitis media with effusion who receive tympanostomy tubes have better long-term speech and language outcomes.³²

Children with CP need regular audiologic evaluation and otolaryngology assessment as part of cleft/craniofacial team care.

Oral Health and Dental Care

Pediatricians play an important role in promoting oral health through provision of anticipatory guidance, dental referral, and fluoride varnish application. The American Academy of Pediatrics recommends that all children, regardless of whether they have CL/P, visit a dentist by 1 year of age.³³ Furthermore, the American Academy of Pediatrics recommends that children begin having their teeth cleaned twice daily using a rice grain size amount of fluoride toothpaste at the first tooth eruption.³⁴ At 3 years of age, the amount of fluoride toothpaste should be increased to a pea-sized amount. In addition to using fluoride toothpaste, children (including those with CL/P) should

drink optimally fluoridated water, where available, and receive at least twice-yearly fluoride varnish applications beginning with the first tooth eruption.³⁵

The American Academy of Pediatrics recommends that all children be seen by a dentist by 1 year of age. Early initiation of dental care is particularly important for children with CL/P because oral health influences craniofacial treatment and outcomes.

Infants and children, and especially those with CL/P, should have their teeth brushed twice daily using fluoride toothpaste and, where available, drink optimally fluoridated water. It is recommended that children at high risk for dental caries, including children with CL/P, receive at least twice-yearly fluoride varnish applications beginning with the first tooth eruption.

CONSIDERATIONS IN CHILDHOOD

Well-Being

In much the same way that other children do, children with CL/P need attention paid by their primary care pediatrician to nutrition, growth, development, school performance and learning, family dynamics, sleep hygiene, psychosocial function, and speech, hearing, and oral health. Some children with CL/P have developmental delay or learning problems, struggle with being “different,” or experience bullying, all areas to which pediatricians bring important insight and expertise.

Children born with CL/P often undergo multiple reconstructive surgeries during childhood (Tables 3 and 4). The time period surrounding surgeries can be frightening and stressful for both children and their families, necessitating special support (eg, involvement of child

life specialists, tour and orientation to the operating and recovery rooms) and planning (eg, time off from school and work, care of other siblings).

The American Academy of Pediatrics recommends that children with CL/P and their families be offered psychosocial support and involvement of specialists such as child life professionals, particularly around times of surgery.

Speech

Between 10% and 25% of children with CP ± CL will have a persistent cleft-related speech difficulty called velopharyngeal insufficiency (VPI) after their palate repair.³⁷ The incidence may vary depending on surgical technique and timing of palatoplasty. VPI occurs when the soft palate does not adequately close against the posterior pharyngeal wall to effectively prevent nasal air escape when talking. In English, the consonants /m/ as in “mint,” /n/ as in “nut,” and /ŋ/ as in “walking” are the only sounds that should be nasal. Complete closure of the soft palate to the posterior pharyngeal wall is necessary to make pressure consonant sounds, which are those that require pressure buildup in the mouth (ie, /b/ as in “boy,” /d/ as in “daddy,” /s/ as in “snake”). When VPI occurs, there is nasal air escape when making these pressure sounds, leading the child’s speech to sound weak, hypernasal, or muffled.

Because VPI is a structural problem, it generally requires surgical management to correct. Children with CP ± CL are also at risk for difficulty learning how to correctly use their palate. This functional difference is not the same as VPI; thus, considering the differential diagnosis is imperative to effective treatment. Children with CP ± CL

should therefore be evaluated regularly by a speech and language pathologist with expertise in detecting and evaluating VPI and other speech issues common in children with a CP. On cleft/craniofacial teams, these evaluations generally begin before the palate is repaired to educate parents about VPI. Cleft/craniofacial teams should advocate for access to high-quality, community-based speech therapy when it is not available directly through the cleft/craniofacial team.

The American Academy of Pediatrics recommends that children with CP ± CL undergo regular speech assessment by a speech and language specialist with expertise in detecting and evaluating VPI. Primary care pediatricians should be aware that VPI may require surgical management, in which case it will not improve with speech therapy alone.

CONSIDERATIONS IN ADOLESCENCE

Treatment Goals

During adolescence, the goals of cleft-related surgical and orthodontic care include improving the child’s occlusion and tooth positioning, nasal airway patency, and facial skeletal relationships. Almost all children with CL/P require orthodontic treatment to ensure a functional occlusion and long-term oral health and hygiene. Children with CL/P are at risk for a deviated nasal septum. A septorhinoplasty is usually performed during the teenage years. Midface hypoplasia, a relatively common finding in children with CP ± CL, produces a discrepancy in positioning of the upper and lower jaw, with the mandible being forward from the maxilla, referred to as a class III skeletal malocclusion (ie, involving the jaws, not just the teeth) (Fig 7). Orthodontic treatment alone

may not adequately address the class III malocclusion, and children with midface hypoplasia could need midface advancement after skeletal growth is completed.

Psychosocial Considerations

As children enter adolescence, they may rebel against time-consuming visits to the cleft/craniofacial team or surgeries that interfere with other activities. It is important that children be allowed to gradually assume a larger role in shared decision-making regarding cleft-related care. Adolescence is also a good time for patients to learn more about the genetics of CL/P and, specifically, more about their own chance of having children with CL/P; genetic counseling can be beneficial in facilitating this process.

The Importance of Preventive Health Maintenance

Adolescence is also a time of testing rules and of seeking independence, which may mean straying from healthy habits such as regular toothbrushing and flossing and initiating unhealthy behaviors such as smoking and eating junk food. Unfortunately, these bad habits coincide with a risk for worsening dental caries and the onset of gingivitis and periodontal disease that begins with hormonal changes in the preteen and teenage years. Implications for children with CL/P are considerable because poor oral health may affect a patient’s candidacy for orthodontics, or a teenager’s oral health may significantly worsen during orthodontic treatment if oral hygiene is not fastidiously maintained, and this behavior, in turn, may affect future oral health and cleft-related outcomes. Likewise, obesity, which is increasingly common in children and teenagers, may worsen obstructive sleep apnea of anatomic etiology, leading to adverse health and school performance issues. Incorporating motivational interviewing into visits with the cleft/craniofacial team and

primary pediatric care physician may be helpful in promoting healthier choices and lifestyles.

TRANSITIONING TO ADULT CARE

For children with CL/P, transitioning from pediatric to adult care can be as challenging as it is for other children with special health care needs. In some cases, it may be even more challenging for patients with CL/P because they may “age out” of their pediatric cleft/craniofacial team or children’s hospital before their cleft-related care is completed, leading to disruptions in care. Aging out is more likely for male subjects, who reach skeletal maturity at an older age (possibly into their third decade) than female subjects. Furthermore, patients with CL/P may have ongoing cleft-related special needs that continue into adulthood. Outside of the pediatric age span, various subspecialty medical/surgical/dental and allied health providers represented on cleft/craniofacial teams must now be accessed separately (eg, audiology, plastic surgery, otolaryngology, orthodontics), without the benefit of ongoing cleft/craniofacial team care coordination and expertise. Dental, orthodontic, and prosthodontic care may be more difficult for young adults to access because of limitations in community dentists’ expertise, affordability, and/or insurance coverage. Primary care pediatricians can help patients and families anticipate and plan for the transition to adult care.

Transitioning the care of a patient with CL/P to adult care requires individualized planning and referrals. When transitioning, patients need a detailed summary of their cleft/craniofacial team care and surgery, as well as information about their other special needs.

LIST OF RESOURCES AND RELIABLE WEB SITES

1. Centers for Disease Control and Prevention: Birth Defects—Facts about Cleft Lip and Palate. Available at: <http://www.cdc.gov/ncbddd/birthdefects/cleftlip.html>
2. Cleft Palate Foundation (an excellent source of information for families). Available at: <http://www.cleftline.org/>
3. Seattle Children’s Hospital: Cleft Lip and Palate. Available at: <http://www.seattlechildrens.org/medical-conditions/chromosomal-genetic-conditions/cleft-lip-palate/>
4. American Speech-Language-Hearing Association—Cleft Lip and Palate. Available at: <http://www.asha.org/public/speech/disorders/CleftLip/>
5. Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Anomalies. American Cleft Palate-Craniofacial Association. Revised Edition. November 2009. Available at: http://www.acpa-cpf.org/uploads/site/Parameters_Rev_2009.pdf

AUTHORS

Charlotte W. Lewis, MD, MPH, FAAP
Lisa S. Jacob, DDS, MS
Christoph U. Lehmann, MD, FAAP, FACMI

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ABBREVIATIONS

ACPA: American Cleft Palate–Craniofacial Association
CL: cleft lip
CL/P: cleft lip and/or cleft palate
CLP: cleft lip and cleft palate
CP: cleft palate alone
CL ± A: cleft lip with or without cleft alveolus
CP ± CL: cleft lip with cleft palate or cleft palate alone
ECC: early childhood caries
VPI: velopharyngeal insufficiency

Address correspondence to Charlotte W. Lewis, MD, MPH. E-mail: cwlewis@uw.edu

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An error occurred in the American Academy of Pediatrics Clinical Report “The Primary Care Pediatrician and the Care of Children With Cleft Lip and/or Cleft Palate” (*Pediatrics*. 2017;139(5)e20170628; <http://pediatrics.aappublications.org/content/139/5/e20170628>). Reference 2 was incorrect; it should be as follows: Mossey PA, Little J. Epidemiology of oral clefts: an international perspective. In: Wyszynski DF, ed. *Cleft Lip and Palate: From Origin to Treatment*. New York, NY: Oxford University Press; 2002:127–158.

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