

Closing the Gap on Cleft Care for July Craniofacial Awareness and Prevention Month

Christine Thang, MD, FAAP

Cleft lip and cleft palate (CLP) are two of the most common birth conditions in the United States, affecting approximately 1 in 600-700 births [1]. National Cleft and Craniofacial Awareness and Prevention Month in July was established to raise awareness for the infants, children, teens, and adults with craniofacial conditions. As pediatricians, we play an important role in helping children and families with clefts, especially when working together with multidisciplinary team care centers. As a pediatrician who is part of a multidisciplinary craniofacial team, I want to take this opportunity to highlight the care coordinator through members of this team. During medical school and residency training, I admittedly knew very little about the care of pediatric patients with CLP. As an early career physician, I had the opportunity to join a multidisciplinary craniofacial team, and it has become one of my favorite clinical experiences. Here's to closing the gap on cleft care!

The American Cleft Palate–Craniofacial Association (ACPA) describes the goal of cleft/craniofacial teams “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” [2]. Areas of focus for the team usually include audiology, dentistry, genetics, pediatrics, nursing, nutrition, oral surgery, orthodontics, otolaryngology, plastic surgery, psychology, social work, and speech pathology [2,3].

Beginning in the pediatric office, the role of the primary pediatrician often starts with timely diagnoses and referrals. Pediatricians provide ongoing health care maintenance through well child visits, address acute care concerns as they arise (i.e., feeding challenges, ear infections, wound checks), and provide anticipatory guidance. Pediatricians advocate for the patient and serve as a liaison between the family and the craniofacial/cleft team.

Primary surgeries take place with the plastic surgeon. Cleft lips are usually repaired at approximately 10 weeks of age. Cleft palates are repaired later between 9 months and 1 year of age. The benefits of closing the cleft early (i.e., speech development) are balanced with the risks related to earlier repairs (i.e., fistula formation, midface hypoplasia). Close attention is paid to the functionality of the palatal musculature as this informs speech development.

Oral health is important for children with CLP as it impacts cleft-related outcomes. The dentists and orthodontists on craniofacial teams monitor teeth development and facial growth for the planning and timing of cleft-related procedures. When there is an alveolar cleft present, alveolar bone grafting is performed to fill in the gum line. Orthodontic treatments correct debilitating malocclusions. Oral hygiene becomes even more important when considering the various devices placed in the mouth including palate expanders, braces, and retainers.

Since children with CLP often experience eustachian tube dysfunction, recurrent otitis media, and conductive hearing loss, audiologists and otolaryngologists frequently work together on cleft teams. Many children with CLP develop otitis media with effusion at least once during the first year of life, and frequent eustachian tube dysfunction contributes to more frequent ear infections and hearing loss. Given these concurrent issues, tympanostomy tubes or ear tubes are routinely placed at the time of palatal repair. Following their ear tubes, children experience better long-term speech and language outcomes.

The American Academy of Pediatrics (AAP) recommends that children with CLP undergo regular speech assessment by a speech and language specialist. About a quarter of children with CLP have a persistent cleft-related speech difficulty called velopharyngeal insufficiency (VPI) after their palate repair. When pediatricians notice hypernasality in speech among their patients, referral to the plastic surgeon and the speech pathologist is needed since speech therapy alone might not suffice (and palate surgery might be warranted).

Studies exploring wellbeing among youth with CLP have yielded equivocal results, with varying levels of psychological functioning and distress. Some youth struggle with their craniofacial differences and some experience bullying. Hence, psychosocial services are important aspects of cleft team care. Special support is recommended around surgeries including involvement from social workers and child life specialists, and for planning around families' needs including time off from school and work and the care for other siblings. Transition from pediatric to adult care is another challenging stage as patients may "age out" of their pediatric care before their cleft-related care is completed.

Given the association of clefts with some genetic syndromes, geneticists are included on multidisciplinary craniofacial teams. Adolescence is a good time for patients to learn more about the genetics of CLP and, specifically, more about family planning.

The American Academy of Pediatrics (AAP) and the American Cleft Palate–Craniofacial Association (ACPA) offer guidelines and standards for cleft-related and craniofacial care [2,3]. While there is a lot to cover in CLP care for the busy practicing pediatrician, it is rewarding to work alongside a craniofacial team that cares for your mutual patient and family.

References:

- [1] Rahimov F, Jugessur A, Murray JC. Genetics of nonsyndromic orofacial clefts. *Cleft Palate Craniofac J*. 2012;49(1):73–91
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- [3] Lewis, CW, Jacob LS, Lehmann CU, AAP 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. Available at: <https://publications.aap.org/pediatrics/article/139/5/e20170628/38824/The-Primary-Care-Pediatrician-and-the-Care-of>.



Dr. Christine Thang is an Assistant Clinical Professor in the Division of General Pediatrics at the David Geffen School of Medicine at UCLA. She is a faculty pediatrician for the UCLA Pediatric Craniofacial Program.

For any questions or requests for information about cleft and craniofacial care at UCLA Health, please contact email address: UCLACFC@mednet.ucla.edu or visit the UCLA Pediatric Craniofacial Specialty Care Clinic [website](#).