JOHNS HOPKINS ALL CHILDREN'S HOSPITAL

Cleft Lip and Palate Clinical Pathway

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All Children's Hospital

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Updated: January 23, 2026

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This pathway is intended as a guide for physicians, physician assistants, nurse practitioners and other healthcare providers. It should be adapted to the care of specific patient based on the patient's individualized circumstances.

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Rationale:

This Clinical Pathway was developed by a consensus group of Johns Hopkins All Children's Hospital (JHACH) physicians, advanced practice providers, nurses, and dieticians to standardize the management of children hospitalized for cleft lip and/or palate. It addresses the following clinical questions or problems:

1. Newborn evaluation for patients with oral-facial clefts
2. When to consider admission for further evaluation in the setting of dehydration, nutrition concerns, and feeding difficulties.
3. When—and whom—should clinicians consult when there is concern for a new diagnosis of an oral-facial cleft?

Background:

Cleft lip and/or palate (CL/P) are among the most common congenital craniofacial anomalies, resulting from failure of fusion of embryologic facial processes during early gestation.[1] A cleft lip occurs due to incomplete fusion of the medial nasal and maxillary processes, typically between weeks 4 and 7 of gestation. A cleft palate (CP) results from incomplete fusion of the palatal shelves between weeks 7 and 10.[2] These anomalies can occur in isolation or as part of a syndrome. Around 40-50% of patients with isolated CP have an associated syndromic diagnosis, in contrast to cleft lip and palate which typically occurs as an isolated condition.[3] The global prevalence of CL/P is approximately 1 in 700 live births, with variations by geographic region, sex, and ethnicity.[4] Cleft lip with or without CP is more common in males, while isolated CP is more common in females. Morbidity includes feeding difficulties, recurrent otitis media, conductive hearing loss, speech and resonance disorders, dental anomalies, and psychosocial impacts. Without surgical intervention and multidisciplinary care, affected individuals may experience impaired growth, delayed speech development, and social stigma. Mortality is rare in high-resource settings due to the availability of surgical repair and supportive care. In low-resource settings, untreated clefts can contribute to malnutrition, infection, and increased infant mortality.[5]

Diagnosis:

Diagnosis is confirmed at birth by a health care provider, with early Plastic Surgery consultation recommended to evaluate and verify the cleft phenotype. Patients with cleft lip are often identified prenatally on fetal anatomy ultrasound, and expectant parents are typically referred to a cleft craniofacial surgeon for prenatal consultation, comprehensive care counseling and early care planning. Following delivery and completion of routine newborn care, early Plastic Surgery consultation is recommended to confirm the cleft lip and/or palate diagnosis and provide care

recommendations**.** Plastic Surgery consultation after birth is important to confirm infant phenotype and time sensitive care needs. Refer to Appendix B for illustrative examples of cleft lip and palate types.

Testing/Workup:
Initial diagnosis is clinical at birth but may be delayed in cases of isolated CP.
Identifying the CP at birth often missed resulting in unsuccessful feeding with non-adapted bottle or breastfeeding, not providing appropriate interventions have negative consequences such as infants experiencing malnutrition that could have been prevented.[10]

Once cleft palate and or cleft lip identified and or suspect, Plastic/Craniofacial Surgery should be consulted to confirm diagnosis, recommendations regarding acute management and long-term follow-up, evaluate for possible associated craniofacial abnormalities and to establish a relationship with the caregivers.

Radiology studies:
If additional imaging or workup is indicated, it should be under the direction of Plastic Surgery.

Clinical Management:

Multidisciplinary Care:
Patients affected by cleft lip and/or palate require coordinated care from infancy through adulthood.[6] Plastic/Craniofacial Surgery should evaluate all patients to rule out additional craniofacial diagnoses that may be present and to establish care. Early evaluation by Speech-Language Pathology (SLP) helps address feeding challenges. Growth and development should be followed closely by the Pediatrician. Audiology services are consulted for hearing assessment. Otolaryngology (ENT) is recommended for airway evaluation and consultation regarding hearing deficits. Genetics consultation may be indicated depending on associated findings, especially in patients with a new cleft diagnosis and/or concomitant craniofacial or other anomalies. Gastrointestinal (GI) and Nutrition consultation should be considered for persistent feeding difficulties, weight gain difficulties, reflux concerns and/or specialty formula management/ fortification.

Feeding and Nutrition:
Infants with cleft lip and palate, CP, and complete cleft lip, are at risk for feeding difficulties as the infant cannot generate intraoral suction to extract milk.[8]

Lack of suction results in increased infant exertion when feeding from conventional bottle or breast feeding and puts the infant at risk for poor weight gain.[9] Due to CP anatomy, infants will need a specialty cleft feeding device until they are well-healed from their future cleft surgeries, anticipated mid-to-late infancy pending clinical progress. Refer to Appendix D for examples of specialty cleft feeding devices.

Patients will need to be followed closely on an outpatient basis due to risk of weight gain difficulties in infancy. Weekly pediatrician weight checks and close SLP feeding follow-up are recommended until the infant weighs at least 10 pounds and demonstrates appropriate progression on the infant growth chart.

For patients who do not demonstrate adequate oral intake and/or appropriate weight gain, hospital admission is recommended to evaluate for dehydration and assess weight trends. If admitted for weight gain concerns, the patient will need daily naked, no diaper, weights on an electronic infant scale at the same time every morning prior to infant feeding to monitor weight trends and infant standardized scores (z-score). An SLP evaluation is recommended to assess the most appropriate cleft feeding device, bottle nipple positioning, and patient positioning to support optimal feeding in infants with cleft. SLP will provide a feeding handout for nursing and a parent/caregiver reference and often provide daily inpatient feeding therapy until feeding goals are met.[10]

Patients are recommended to attempt all feeds by mouth unless there are clinical contraindications; recommend oral feeds are completed in less than 30 minutes. Oral feeds that take longer than 30 minutes increase caloric expenditure and place the patient at risk for weight loss. In these cases, enteral tube feeding should be considered to complete feeding volumes until oral feeding goals are met.

A Nutrition consultation is recommended for infants with cleft lip and/or palate. Monitor the need for expressed breast milk fortification and/or increased formula fortification to compensate for increased caloric expenditure associated with routine cleft feeding due to cleft anatomy.

Patients with concern for consistent poor weight gain, consistent poor feeding and or dehydration, should be evaluated for admission to the Pediatrics team, newborns to the NICU if approved by NICU team, with possible involvement of GI, pending patient presentation, weight trends and oral feeding history.

Surgical Timing:
Surgical repair typically begins within the first few months of life, depending on the extent of involvement. Lip repair is generally performed around 3 months, and palate repair is between 9 and 12 months.[6] Adequate nutrition and positive weight gain trends are essential prerequisites for timely surgery.

Airway Assessment:
If airway concerns are present, ENT should be consulted in addition to Plastic/Craniofacial Surgery. As a first-line measure in the inpatient hospital setting, position the infant in the prone or side-lying position with continuous pulse oximetry and cardiorespiratory monitoring. Document any desaturation events and refer to the designated airway management pathway in your area for escalation guidance.

Documentation Reminders:

- Record time required to complete oral feeds each feed:
    - nutritional volume consumed by mouth, feeding tolerance
    - perform feedings per SLP recommendations (infant positioning, bottle type, formula type, amount, duration)
- Obtain and document naked weights daily at the same time; monitor diapers for intake/ output monitoring.
- Document oxygen desaturations and repositioning events if airway concerns exist.

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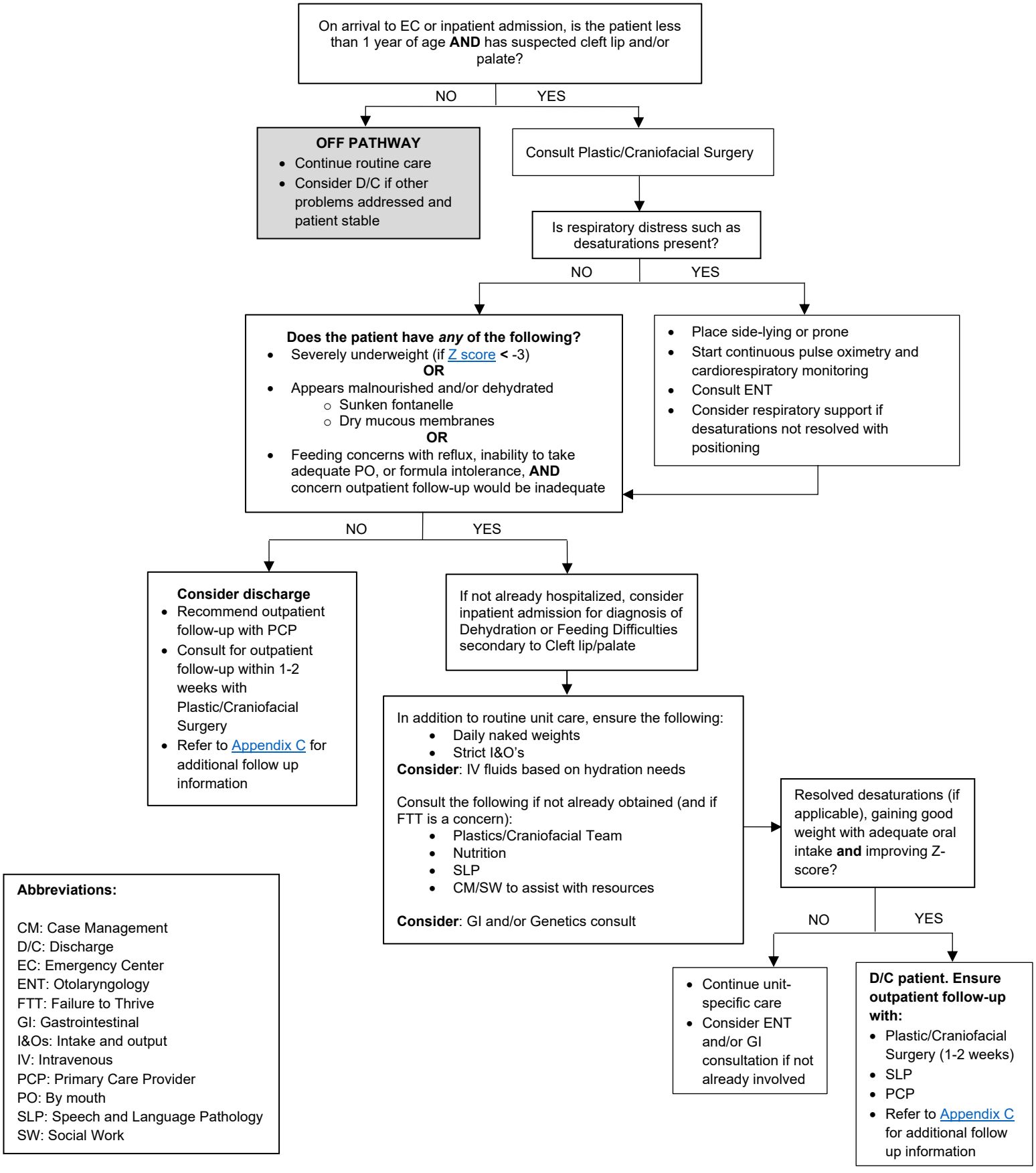

Abbreviations:

CM: Case Management
D/C: Discharge
EC: Emergency Center
ENT: Otolaryngology
FTT: Failure to Thrive
GI: Gastrointestinal
I&Os: Intake and output
IV: Intravenous
PCP: Primary Care Provider
PO: By mouth
SLP: Speech and Language Pathology
SW: Social Work

Discharge:

Patients may be discharged when feeding and weight concerns are resolved or improving and any respiratory concerns are appropriately managed. They must have follow-up appointments scheduled with Plastic/Craniofacial Surgery, SLP, and Pediatrician within 1-2 weeks of discharge.

Discharge readiness includes:

- Resolution of dehydration, if applicable
- Resolved cardiorespiratory/airway, events if applicable
- Adequate oral intake and feed completion within 30 minutes using specialty feeding devices
- Demonstrated improvement in weight trajectory

Outcome Measures:

Inpatient Measures:

- Length of stay
- Target 24-hours PO intake
- Weight gain/improvement in Z-score
- Readmission rate
- Follow-up appointments confirmed (Plastic Surgery, SLP)

Outpatient Measures:

- Weight gain/improvement in Z-score
- Weekly weight check appointments with PCP

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10. Kotlarek KJ, Benson M, Williams J. Current practice patterns and training pathways for feeding infants with cleft palate. *Cleft Palate Craniofac J*. 2024;61(6):1018-1026.

Clinical Pathway Team

Cleft Lip and Palate Clinical Pathway

Johns Hopkins All Children's Hospital

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Date Approved by Institute Clinical Practice Council, if applicable: N/A

Date Approved by JHACH Clinical Pathways Development Committee: January 6, 2026

Date Approved by JHACH Clinical Practice Council: January 21, 2026

Date Content Last Revised: January 23, 2026

Date Available on Webpage: January 23, 2026

Disclaimer

Clinical Pathways are intended to assist physicians, physician assistants, nurse practitioners, and other health care providers in clinical decision-making by describing a range of generally acceptable approaches for the diagnosis, management, or prevention of specific diseases or conditions. The physician must make the ultimate judgment regarding the care of a particular patient in light of the patient's individual circumstances.

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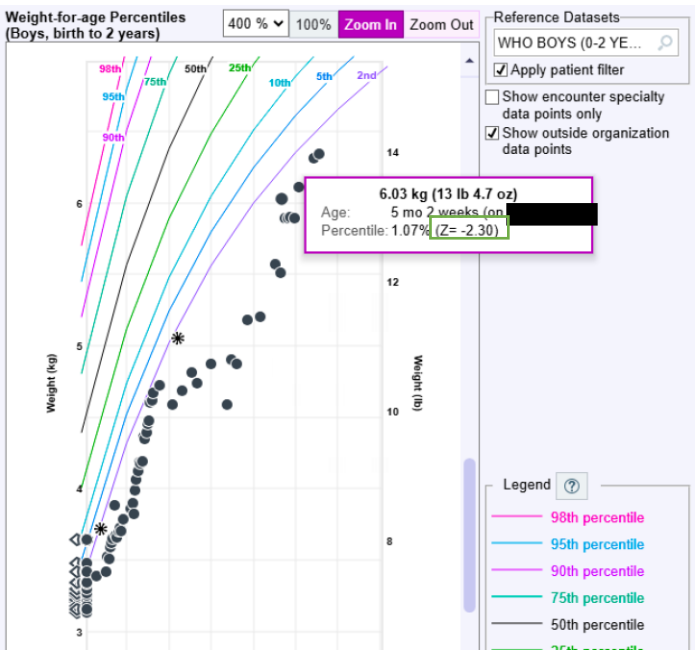
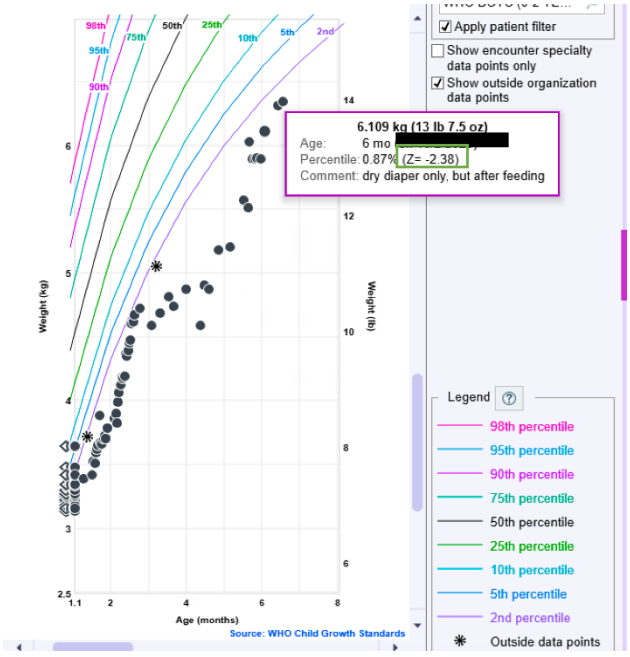
Appendix A: Infant Z-scores

Z-scores are the most accurate way to assess infant growth because they are standardized deviations from the mean based on normative infant growth data. These two growth curves demonstrate that although a child gained weight over 2 weeks (from 6.03 to 6.1 kg), the Z-score indicates this weight gain is inadequate.



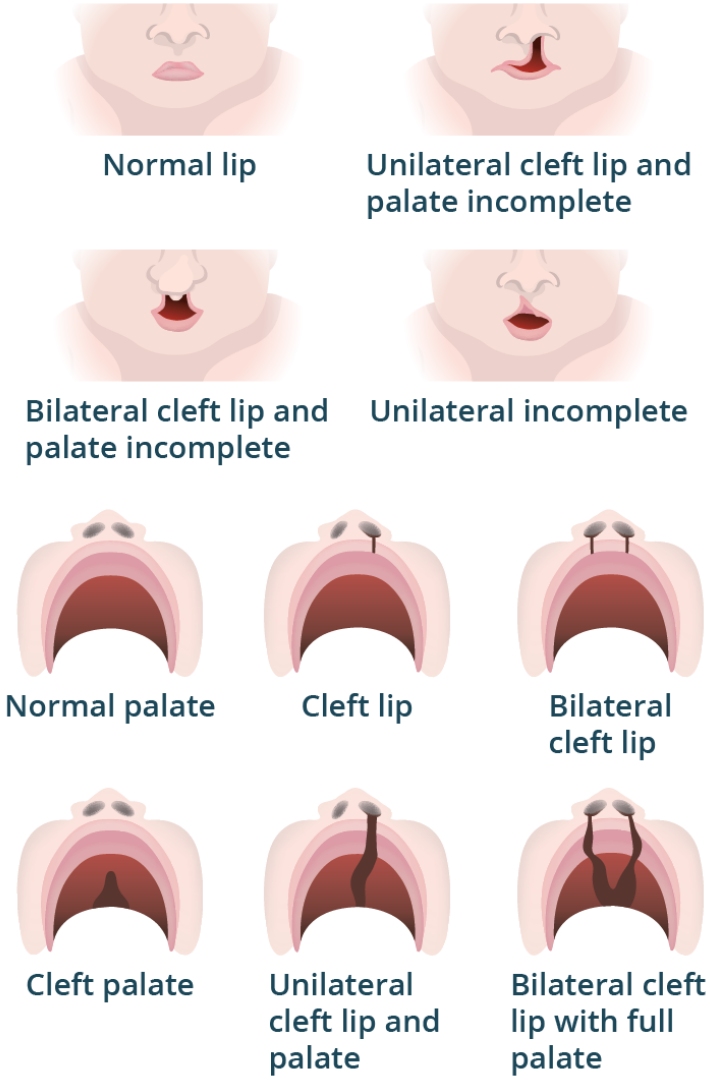


For more information on Z-score calculation, refer to reference below:

Reference:

UpToDate. Calculator: Body mass index (BMI) percentiles and Z-scores, males 2 to 20 years (CDC) – patient education. Wolters Kluwer. Accessed December 9, 2025. https://www.uptodate.com/contents/calculator-body-mass-index-bmi-percentiles-and-z-scores-males-2-to-20-years-cdc-patient-education

Appendix B: Cleft Lip and Palate Types



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Cleft lip and cleft palate. *Healthdirect*. Updated October 2023. Accessed December 9, 2025. https://www.healthdirect.gov.au/cleft-lip-and-cleft-palate

Appendix C: Team Care for Patients with Cleft Lip and Palate

Children born with cleft lip and/or cleft palate typically require individualized treatment into adulthood. These patients should be followed by an American Cleft Palate-Craniofacial Association (ACPA) approved cleft and craniofacial team. These multidisciplinary teams are typically comprised of a plastic/craniofacial surgeon, team pediatrician, ENT, orthodontist, speech and language pathologist, audiologist, psychologist, and other providers specialized in the care of patients with facial clefts. The optimal time for the first evaluation of an infant with a cleft or craniofacial condition is within the first few weeks of life and, whenever possible, within the first few days.

The ACPA approves teams that meet the Standards for Approval of Cleft Palate and Craniofacial Teams, based on the Parameters of Care. ACPA Approved Teams are listed on their website and are available for the public to reference when choosing a provider for cleft and craniofacial healthcare needs.[6]

https://acpacares.org/about-care-teams/

For more information about the Johns Hopkins All Children's Hospital Cleft and Craniofacial Team, visit https://www.hopkinsmedicine.org/all-childrens-hospital/services/cleft-and-craniofacial-program.

Appendix D: Infant Feeding with Cleft Lip and Palate

- Orofacial clefts can create anatomical challenges in creating adequate suction for bottle and breastfeeding in infancy.
- This leads to increased feeding times and efforts causing increased calorie expenditure.
- Underlying anatomical variances may further complicate feeding in addition to gastroesophageal reflux and formula intolerance.
- A multidisciplinary approach is needed for treatment of infants with facial clefts, involving the pediatrician, speech and language pathologist, and plastic/craniofacial surgeon for close weight monitoring. Formula and/or breast milk may need to be modified or fortified to enhance kilocalories per feed.
- If challenges persist, Gastroenterology and/or Nutrition may need to be consulted to assist with overcoming feeding barriers.
- Feeding times should be kept brief – less than 30 minutes to avoid negative caloric expenditure, and families are encouraged to attempt feeding often, typically every 2-3 hours. This should be directed by the Speech-Language Pathology (SLP) team.

Specialized bottles are typically employed by SLP to assist with feeding. These are designed to overcome the cleft-related feeding barriers and can be used throughout infancy.

Figure 1: Dr. Brown's Specialized Bottle

Figure 2: Pigeon Nipple

Reference:

Chee-Williams JL, Kotlarek K. A tutorial for feeding infants with orofacial clefting: general guidelines and patient-specific intervention. Perspect ASHA Spec Interest Groups. 2025;10(3):802-813. doi:10.1044/2024_PERSP-24-00179

https://www.drbrownsmedical.com/products/specialty-feeding/
https://www.pigeonstore.com/collections/cleft-lip