



Comprehensive Cleft Care Recommended Timeline

This document provides guidelines for family education and clinical management of patients with cleft lip and/or palate, along with a recommended timeline. The goals of this document are as follows: 1) to summarize recommended aspects of clinical care for affected patients; 2) to support partners with “target” times for education initiatives, assessments, and treatments; and 3) to spark a conversation about best practices for global patient populations. Please note that NOT ALL assessments and treatments are covered by Smile Train Grant Programs.

It is understood that socioeconomic conditions can affect the implementation of this timeline. Therefore, cleft teams are challenged to creatively adjust the timeline to achieve the best outcomes for their patients. For more information or contributions, contact your local Smile Train Manager or partner@smiletrain.org.

Prenatal period – birth:

- **Family Education:** Family education should begin at the time of prenatal diagnosis or soon after birth. It should cover types and causes of clefts, and aspects of ongoing care for the child.
- **Genetic Counseling:** If available, genetic counseling should be provided to explain the recurrence risks and other related issues, especially if the cleft is part of a syndrome.
- **Nutrition & Feeding:** Caregivers should be given information about potential challenges with feeding caused by the cleft. Upon birth, nutrition should be assessed and feeding modifications should be determined, especially for children with cleft palate.
- **Hearing:** A screening should be done soon after birth, especially for children with cleft palate. If patient fails newborn hearing screen, they should undergo complete hearing evaluation including auditory brainstem response testing (ABR).

0 – 9 months:

- **Nutrition & Feeding:** Caregivers should be instructed on effective feeding techniques depending on the child’s cleft. They should also learn how to monitor the child’s feeding and weight gain in order to ensure that the child will be healthy and ready for cleft surgery.
- **Oral Hygiene:** Caregivers should be instructed that it is mandatory to wipe the child’s gums after every meal and before bed with special attention to the cleft area. Once the teeth start to erupt, caregivers must brush the child’s teeth and continue to wipe the gums after every meal and before bed with special attention to the cleft area. They can use disposable wipes, wet cotton or gauze, or a clean finger brush, whatever is most convenient.

- **Presurgical Infant Orthopedics (PSIO):** A child with a complete cleft of the primary palate (lip and alveolus) should be seen by a team pediatric/general dentist, orthodontist, and/or surgeon in order to determine if PSIO would be beneficial prior to cleft lip surgery. (PSIO can help decrease the size of the cleft and improve the aesthetic outcome of the lip repair.) If recommended, PSIO should begin between 2 – 6 weeks of age and continue until the time of primary surgery.
- **Primary Lip Nose Surgery:** Surgical repair of the lip should be done between 3 – 6 months of age, preferably waiting until 6 months to ensure safety. Lip scar massage should begin 3 weeks after surgery. If affected by the cleft, the nose should be corrected at time of primary lip repair.

6 months – 3 years:

- **Oral Hygiene:** Caregivers should be instructed to avoid giving the child a bottle with milk, juice or sugar water at bedtime because this can cause dental caries (cavities) quickly.
- **Dental Care:** The child should be seen by a pediatric dentist immediately after the first tooth erupts or by the time of the child’s first birthday, whichever comes first.
- **Speech and Language Development:** Caregivers should be educated about early speech and language development and stimulation techniques. If the caregivers are concerned about language development, which is most likely in children with syndromes, a language evaluation and therapy should be considered.
- **Hearing and ENT Services:** Hearing should be monitored, particularly for children with cleft palate. This is because children with cleft palate are at increased risk for middle ear effusion (fluid in their ears), which can lead to conductive hearing loss. Insertion of pressure equalizing tubes in the child’s eardrum at time of palate surgery should be considered to improve hearing. While some children’s hearing and ENT issues are resolved by 3 years, many must be continually monitored and treated.
- **Primary Palate Surgery:** Repair of the palate should be done between 9 – 18 months. Simultaneous surgical repair of the hard and soft palate is usually recommended, but exceptions may be necessary for larger clefts. Special feeding and nutrition instructions should be provided after cleft palate surgery.

3 – 5 years:

- **Speech/Resonance Assessment:** This assessment should be done between the ages 3 – 4 years. It should include a perceptual evaluation of resonance, an assessment of airflow and the presence of nasal emission, and a test of speech sound production to identify speech placement errors. This assessment is necessary to determine if there is velopharyngeal dysfunction (VPD), which requires surgery, or speech placement errors, which require speech therapy.
- **VPD Instrumental Assessment (ENT Service):** If there is evidence of velopharyngeal dysfunction (VPD), such as hypernasality (sound in the nose) and/or audible nasal emission during speech, then instrumental tests should be considered, if available. Nasopharyngoscopy and videofluoroscopy show the size and location of the velopharyngeal opening, which is most useful in surgical planning. Nasometry provides objective data that is useful for outcome studies.

- **VPD Surgery:** VPD surgery should be done between the ages of 3 – 5 years, to take advantage of this critical period of normal speech development. If there is a short palate and/or sagittal orientation of the levator muscles, a Furlow Z-plasty should be considered. If there is a lateral gap (on one or both sides of midline), a sphincter pharyngoplasty should be considered. If there is a large and/or a midline opening, a pharyngeal flap should be considered.
- **Postoperative Speech/Resonance Assessment:** A postoperative speech/resonance assessment should be done 3 – 6 months following the VPD surgery. If there is residual VPD or evidence of significant sleep apnea, a surgical port revision should be considered. Nasopharyngoscopy should be done to determine the source of the velopharyngeal leak or obstruction.
- **Speech Therapy:** Speech therapy is most effective after correction of VPD. If there will be a delay in the surgical correction of VPD due to medical or other issues, speech therapy to correct placement errors can be initiated. In this case, speech therapy will be most effective with the use of a nose plug so that there is oral airflow.
- **VPD Prosthetic Management:** If there is upper airway obstruction or other issues that delay VPD surgery, a palatal lift should be considered until the child is ready for surgical management.
- **Fistula Management:** If the child has a palatal fistula (opening) that is affecting speech or causing leakage of foods and liquids through the nose, the fistula should be repaired, preferably at the time of alveolar bone graft. Earlier repair can be done for large fistulas in younger children. A palatal obturator can be considered before the repair, or if the repair cannot be done.

6 – 12 years:

- **Orthodontic Care:** For a child with a complete cleft of the primary palate, an X-ray should be done between the ages of 6 – 7 years, to determine the need for an alveolar bone graft (ABG) and the appropriate timing. Orthodontics may be needed 6 – 9 months prior to the ABG in order to reposition the upper teeth, particularly those that are adjacent to the cleft. A fixed or removable maxillary expander device may also be needed prior to the ABG surgery.
- **Alveolar Bone Graft (ABG):** ABG surgery should be done for children with a cleft of the primary palate if there is insufficient bone for eruption and maintenance of the lateral incisor (if present) and canine around the cleft. Depending on the eruption pattern of the patient, ABG is usually done between the ages of 7 – 9 years, before these teeth erupt. The bone is usually harvested from the iliac crest (hip) and placed within the cleft and under the base of the nose. If a maxillary expansion was performed prior to ABG, either a fixed appliance or a retainer should be worn until ABG healing is complete. Radiographs should be delayed until 4 – 6 months after surgery.

15 – 20 years:

- **Orthodontic Care:** Additional orthodontic care may be necessary after permanent dentition is complete. In addition, orthodontic treatment, starting around 15 years of age, is usually required to prepare the adolescent for orthognathic surgery.
- **Orthognathic Surgery:** Once facial growth is completed (usually 15 – 16 years old in girls and 18 – 19 years old in boys), a Le Fort I maxillary advancement may be needed to correct maxillary (upper jaw) alignment with the mandible (lower jaw). On occasion, the mandible may require surgical alignment simultaneously.

- **Speech/Resonance Assessment:** Speech and resonance should be reassessed following jaw surgery, particularly if there has been a noticeable change in speech and resonance. If there is hypernasality or audible nasal emission after surgery, VPD surgery should be considered, and ENT assessments performed. If the patient has abnormal articulation placement, speech therapy should be considered.
- **Lip/Nose Revision Surgery:** If necessary, the lip and/or nose should be revised after facial growth is complete in order to improve airflow as well as symmetry and aesthetics of the face.

Ongoing

- **Psychosocial Support:** Social and emotional counseling should be offered to children affected by cleft and their families throughout the timeline of comprehensive cleft care.
- **Oral Hygiene & Dental Care:** Children and their caregivers should be educated about the importance of maintaining good oral hygiene through regular brushing and flossing, and dental appointments every 6 months. This is necessary for the child's general health and for the child to be eligible for orthodontics and surgery, if/when needed.
- **Regular Cleft Team Appointments:** Interdisciplinary team clinic appointments should be offered to all children and their families. An annual team visit is recommended until the child is 8 – 9 years of age and has undergone ABG (if necessary). From age 10+ years, at least biannual team visits are recommended until the child has completed all care, including orthognathic surgery.

