



The Team's goal is to provide coordination and facilitation of care and is not a substitute for the patient's local care providers or primary care physician.

The cleft clinic is held every month and most patients are seen one time per year or more often if needed and will see all or selected team members depending on the diagnosis or specific needs.



For Patients and Families:

North East Heights Cleft Clinic - (505) 272-2290 or (505) 272-2302

For Physicians:

UNM Physician Access Line - (505) 272-2000 or (888) 866-7257 (UNM-PALS)































Important Phone Numbers

| Audiology | | (505)272-3535 | | | | |
|--|------------------------------|----------------|--|--|--|--|
| Lara Alessandrelli- Audiologist | lalessandrelli@salud.unm.edu | (505) 272-3535 | | | | |
| Child life | | (505)272-2671 | | | | |
| Cleft & Craniofacial team/nurse | (505) 272-2302 | | | | | |
| Financial assistance | (505)272-2521 | | | | | |
| Genetics | | (505) 272-6631 | | | | |
| Joanna Milisa with Genetics | <u>jmilisa@salud.unm.edu</u> | (505) 272-6631 | | | | |
| Lactation support services | | (505)272-0480 | | | | |
| Medical interpreter services | | (505)272-5399 | | | | |
| Medical records | | (505)272-2141 | | | | |
| Orthodontic services | | | | | | |
| Lisa King, DDS <u>ir</u> | nfo@lisakingortho.com | (505) 299-7678 | | | | |
| Dana M Casaus, DDS, MS | drcasaus@gmail.com | (505) 288-9378 | | | | |
| Parking services | | (505)272-4074 | | | | |
| Patient advocate | | (505)272-0943 | | | | |
| Security | | (505)272-2160 | | | | |
| Speech Pathology | (505) 272-2455 | | | | | |
| University of New Mexico Hospital information desk | | (505) 272-2111 | | | | |





















What is a cleft lip and palate?

A cleft lip and palate or cleft palate alone are very common birth defects, which are seen when the baby is born. A cleft is an opening in the lip or the roof of the mouth (palate).

What causes cleft lip and palate?

The exact cause of clefting is often unknown. There are many possible causes including environmental, genetic, or related to a syndrome. A syndrome is a set of features or traits that occur together. The features can be physical, developmental, or behavioral. An isolated cleft palate is associated with a syndrome in about 50% of patients and with cleft lip and/or palate in about 15%. Most children with clefts do not have a syndrome or any other genetic problems.

How common are clefts?

- 1 in 1000 Caucasian babies born in the United States has a cleft lip with or without cleft palate which are twice as common in boys as in girls.
- Cleft lip with or without cleft palate are more common in Asians (2.1/1000) and Native Americans (3.6/1000).
- 1 in 2000 cleft patients has cleft palate only which is twice as common in girls as in boys.

What are the types of clefts?

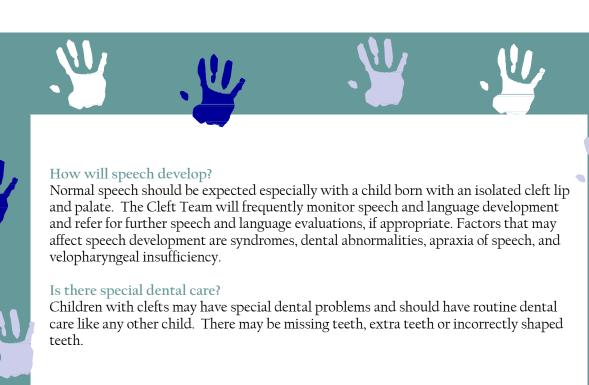
A cleft can be of the lip, the palate, or both. Below are the different types of clefts we see in our clinic.

Submucous Cleft Palate

A submucous cleft is present when the uvula is split or "bifid" and the muscles and bone are not formed underneath the tissue (mucosa) of the palate. A notch in the palate bone can often be felt and a clear line in the middle of the palate can be seen. About 50% of children with submucous cleft palate will not need surgery to achieve normal speech but speech therapy will be needed. The other half of the children will have velopharyngeal insufficiency and need surgery to fix the muscles.

Cleft Lip

Unilateral cleft lip involves only one side of the lip and bilateral involves both sides of the lip. In bilateral cleft lip, the center portion of the lip may protrude and may require treatment prior to surgical repair.





What will my child look like after surgery?

Before surgery:



During healing:





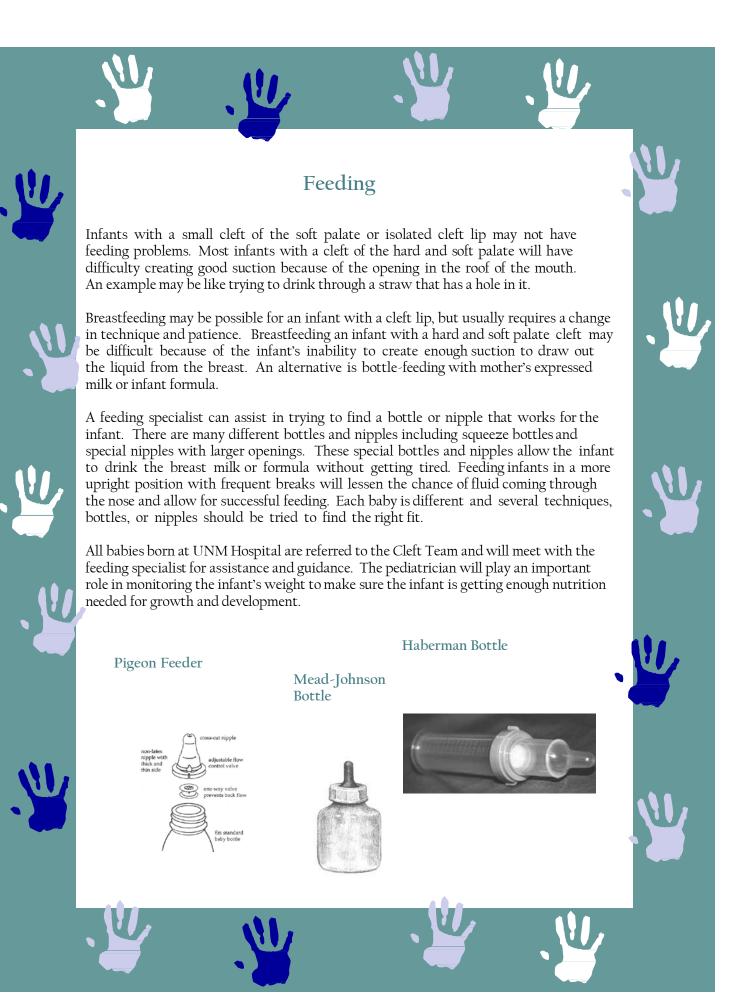














Soon After Birth:

Some babies with severe clefts of the lip can benefit from lip taping or pre-surgical orthopedics or naso-alveolar molding (NAM). This technique can be used to slowly mold the tissues of the nose and lip into a better position prior to surgery and takes several months. This may delay the repair of the lip until 5 or 6 months of age.

Lip repair:

The usual timing of the lip repair is around 3 months of age, if the baby is healthy, feeding, and growing well. There are several types of lip repair surgeries and the surgery will be tailored to the baby's specific needs.

Reasons for delay of surgery:

- 1. No speech development due to developmental delays or syndromes.
- 2. Poor general health.
- 3. Poor weight gain.
- 4. Breathing difficulty due to a small mandible (lower jaw) or other anatomical problems.

Ears:

Children with clefts of the palate almost always develop fluid in the middle ear, behind the eardrum. Some of the palate muscles normally open small tubes connecting the throat to the middle ear (Eustachian tubes) to allow air in to the middle ear. Since the palate muscles are not connected in the center with a cleft, these ear muscles cannot function and fluid collects in the middle ears causing a conductive hearing loss "similar to hearing under water". Surgery is needed to drain out the fluid and place small tubes (pressure equalization tubes) in the eardrums to keep the ears ventilated and return the hearing to normal. Some children will need multiple sets of ear tubes throughout childhood.

Secondary Surgery:

Not all procedures are successful the first time. Revision surgery is sometimes needed to improve the appearance of the lip repair or if your child has hypernasal speech or a fistula a secondary palate surgery may be necessary.









| Age Range | Intervention |
|-------------------------|---|
| Prenatal | Refer to cleft team Genetic counseling offered Consider psychosocial issues |
| Neonatal (0-1 month) | Provide feeding instructions, monitor growth Hearing screening |
| 1-4 months | Monitor feeding and growth Repair cleft lip and nasal deformity |
| 5-12 months | Monitor cleft lip healing |
| 13-24 months | First dental evaluation |
| 4-5 years | Consider lip/nose revision |
| 6-11 years | Assess for need for an alveolar bone graft Monitor school and psychosocial needs |
| 12-21 years | Consider genetic counseling for the child Consider nose surgery (rhinoplasty) Monitor school and psychosocial needs |











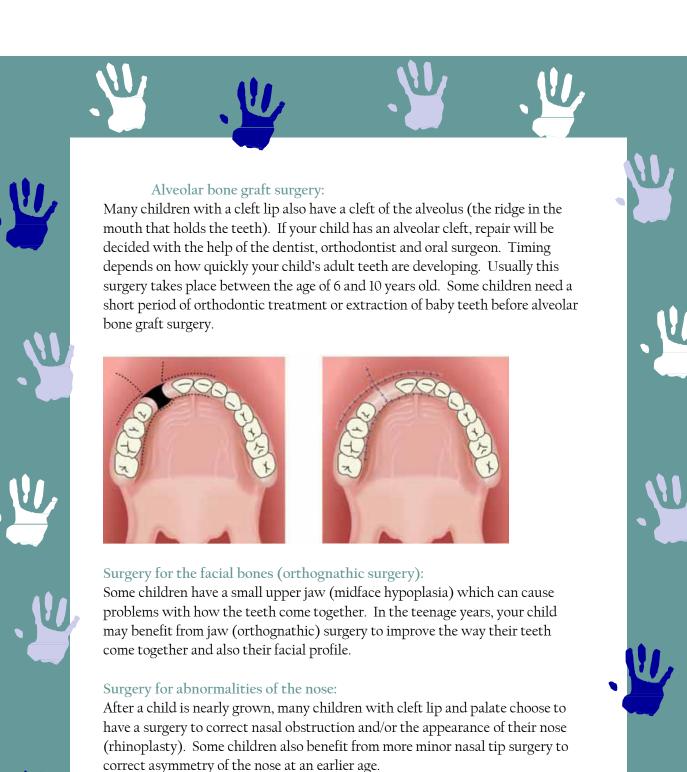














Naso-Alveolar Molding (NAM)

Naso-alveolar molding is a procedure for children with extremely deforming, difficult to repair bilateral cleft lip. In conjunction with our experienced prosthodontist, this may be recommended for selected patients. It involves several months of appliances attached to the baby's palate and nose to remodel the soft tissues and bones of the face before cleft lip repair. In these patients, it can decrease tension on the wound, lead to better scar formation, and provide a less deformed nose for improved appearance and function.



Mandibular Distraction Osteogenesis

This is a procedure that makes the upper airway larger by forming new bone in the jaw. A surgical cut in the jaw is made on each side and a device that moves the bone apart is placed to help form new bone over a one and a half to two week period. This procedure may be helpful for infants with Robin Sequence in which the small mandible does not allow enough room for the tongue in the mouth causing problems breathing. Without this procedure, these infants may need a tracheostomy to improve breathing. If the mandible is successfully enlarged, we may be able to avoid tracheostomy and improve quality of life.

Clinical and Pediatric Psychology

Patients and their families may be assessed for psychosocial and/or emotional difficulty due to the patient's medical condition. Issues that are addressed include: parent grief, marital difficulty, 0-3 years of age services for the patients that need a jump start with speech, physical therapy, occupational therapy, and feeding issues. For older children, the effects of teasing and rude remarks made by peers in school are addressed with both the parent and student. Individual and family therapy is provided for patients that demonstrate signs and symptoms of depression and anxiety. Testing for developmental and learning disabilities is performed, if needed.





















With proper care, children born with a cleft lip and/or palate can have healthy teeth. This requires proper cleaning, good nutrition, and fluoride treatment. Cleaning with a small, soft-bristled toothbrush should begin as soon as teeth appear. Oral hygiene instructions and preventative counseling can be provided by a pediatric dentist or a general dentist. Many dentists recommend that the first dental visit be scheduled at about one year of age. The treatment recommended depends upon many factors. Some children require only preventative care while others will need fillings or other treatments.

Orthodontic Evaluation

The first orthodontic evaluation may be scheduled even before the child has any teeth. The purpose of this visit is to assess facial growth, particularly the growth of the jaws. Later as teeth begin to erupt, the orthodontist will make plans for the child's short and long-term dental needs. For example, if a child's upper teeth do not fit together (occlude) properly with the lower teeth, the orthodontist may suggest early treatment to correct the relationship of the upper jaw to the lower jaw. It is not unusual for this initial treatment to be followed by a long rest period when the orthodontist monitors facial growth and tooth development. With the eruption of the permanent teeth, the final phase of orthodontics completes alignment of the teeth.

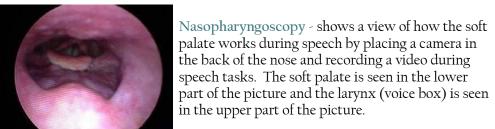
Genetic Counseling

A consult with the genetics counselor may include diagnosis or confirmation of a specific genetic condition, discussion of medical management recommendations, calculation and discussion of genetic risk for future children, and interpretation of available genetic tests. Parents of children with an isolated birth defect, such as cleft lip and/or palate are given information on the chance the birth defect will happen again in another pregnancy. Parents of children with multiple birth defects are offered genetic consultation to try to identify a diagnosis. Parents of children with a known syndrome are offered genetic counseling to review the inheritance, recurrence risks, genetic testing, and reproductive options. Children or young adults with any of these conditions are offered genetic evaluation and/or counseling appropriate to their age and development.

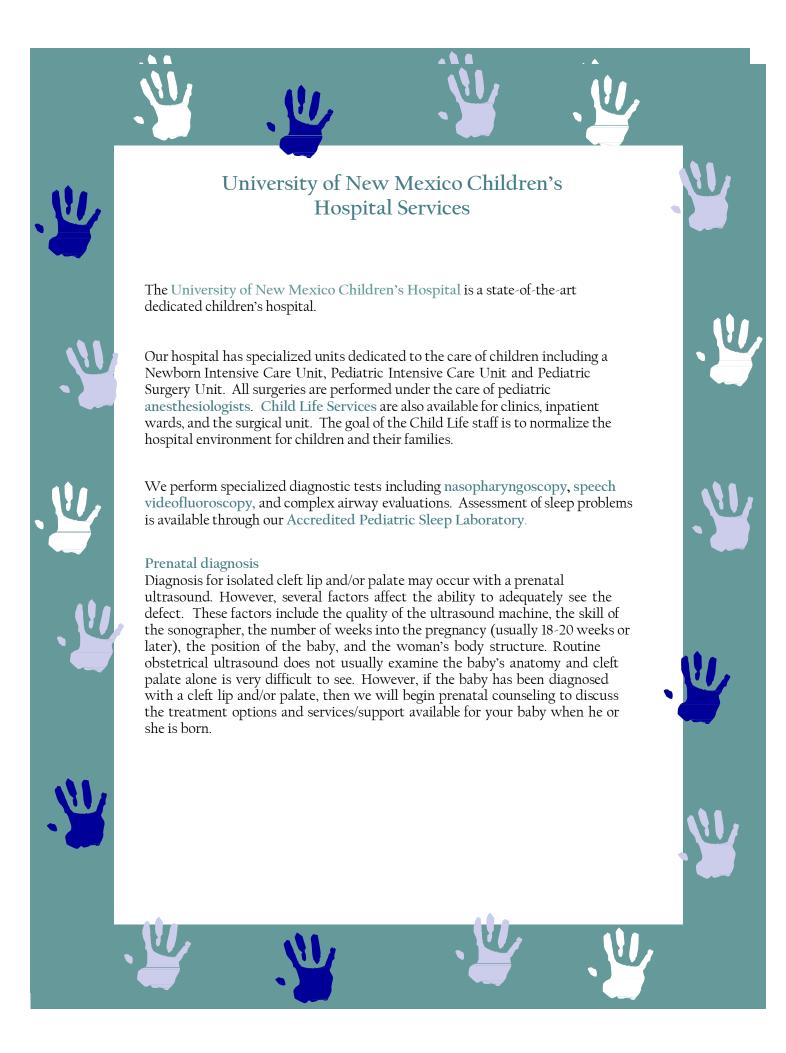
Specialized Services Developmental Care The Developmental Care Specialist provides prenatal consults for those whose unborn babies have been identified with a cleft. Each baby that is born with a cleft at UNM, or transferred to our hospital, is followed in the Newborn Nursery (NBN), Intermediate Care Nursery (ICN) or Newborn Intensive Care Unit (NBICU) to help the family establish and support feeding. All of the appropriate referrals to the necessary medical services are made. Service coordination is provided to assure follow-up for weight monitoring, home health care nurse follow-up, primary care physician contact, community Family-Infant- Toddler (FIT) programs, and Children's Medical Services. Velopharyngeal Insufficiency Surgery Specialized surgery to correct velopharyngeal insufficiency for children with and without cleft palate is offered. We perform surgery tailored to each patient, such as palatal lengthening, sphincter pharyngoplasty, or posterior pharyngeal flaps. The surgery is selected based on the individual's velopharyngeal anatomy. We assess palatal movement with nasopharyngoscopy and/or speech videofluoroscopy to determine the specific problem and choose the most appropriate procedure based on

the findings. Occasionally, non-surgical therapy using a prosthesis (palatal lift or speech bulb) is recommended.











University of New Mexico Children's Hospital

2211 Lomas Blvd. NE, Albuquerque, NM 87131



Directions:

From I-25 (just south of I-40), take the Lomas exit Go east, toward the mountains
Take a left on Yale Blvd
Go right at the traffic circle
Park in parking structure or across the street in patient parking

Map:











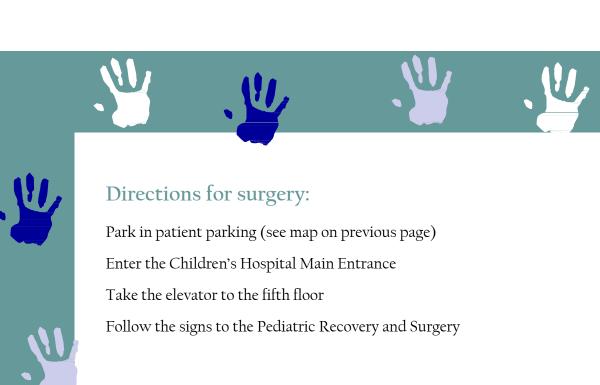




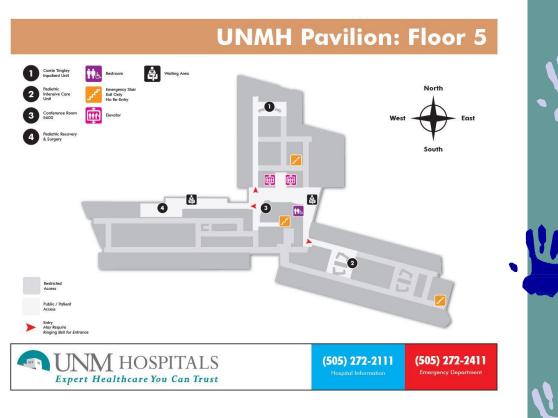








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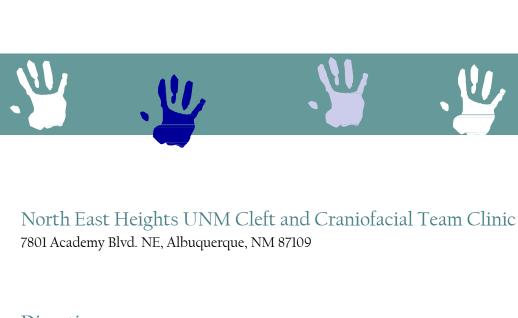












Directions:

From I-25 (north of I-40)

Take the San Mateo exit and head east (towards the mountains)

Take a left in a few blocks at Academy Road

Take Academy road for several blocks, past the golf course on the right.

Take a left into the Northeast Heights Clinic parking lot, just after Cubero Dr.

If you get to Wyoming, you have gone too far.

Map:









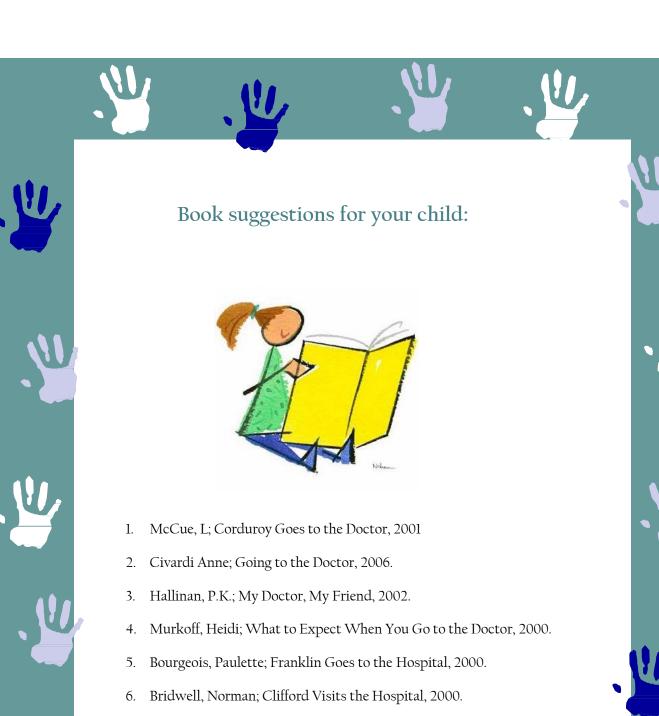












- 7. Civardi, Anne; Going to the Hospital, 2006.
- 8. Karim, Roberta; This is a Hospital, Not a Zoo!, 2002
- 9. Rey, H.; Curious George Goes to the Hospital, 1966.
- 10. Rogers, Fred; Going to the Hospital. 1997.









Glossary of Medical Terms Auditory brain stem response (ABR): A type of hearing test, that does not require the patient to tell you they are hearing, which is very useful in children. Alar cartilage: The cartilage that forms the tip of the nose and nostrils. Alveolar bone graft: A surgery to repair a cleft in the alveolus and gums. Bone is generally taken from the hip to put under the gums to support the adult teeth or potentially a dental implant. Alveolar ridge: The bony ridge of the jaws (maxilla and mandible) that contains the Anaplastologist: An individual who provides custom made prostheses to replace missing body parts. Apraxia: A speech disorder in which a child has trouble saying what he/she wants

correctly and consistently.

Articulation: The formation of speech sounds.

Articulation Disorder: Difficulty with formation of speech sounds.

Audiogram: A test of hearing levels.

Audiologist: A medical professional who can diagnose and treat hearing loss.

Bilateral: Both sides, right and left.

Columella: The midline portion of the lower nose that divides the nostrils.

Conductive Hearing Loss: Hearing loss that occurs when there is a problem conducting sound through the external ear canal, ear drum and middle ear. This is frequently caused by fluid accumulation in the middle ear in children with cleft palate.

Congenital: A problem present at the time of birth.

Dental Arch: The normal curve formed by the teeth.

Eardrum: Tympanic membrane

Eustachian tube: The passageway or tube that connects the middle ear to the back of the nose that allows the middle ear to ventilate.

Expander or palate expander: An orthodontic device to expand the palatal arch.

Fistula: A hole that may remain after palate surgery

Furlow palatoplasty: A type of surgical repair of the palate that lengthens the palate, named after the well-known surgeon who first described it.

Genetics: The science of heredity, how traits pass on to children.

Hard Palate: The bony part of the palate, also the front of the roof of mouth.

Hypernasality: Air or sound escaping from the nose during speech.

Hyponasality: Decrease in normal air flow through the nose during certain speech

sounds. Nasal obstruction is the common cause.

Language disorder: Difficulty communicating due to problems with understanding or expressing language.

Malocclusion: Abnormal relationship of the upper and lower teeth.

Mandible: The lower jaw.

Maxilla: The upper jaw. The alveolar ridge, teeth and palate are part of it. Maxillary advancement: A common orthognathic surgery to advance an underdeveloped upper jaw (maxilla) to normalize dental occlusion and the facial profile.













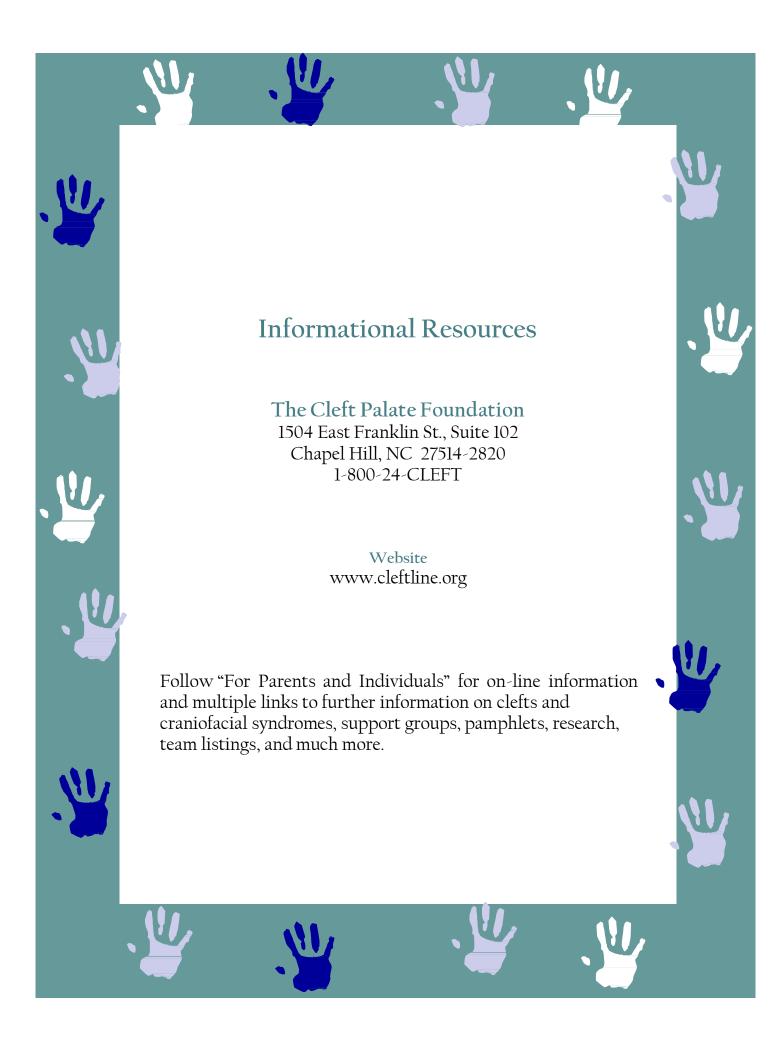












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