The University of New Mexico
Cleft and Craniofacial Clinic

505-272-2290
505-272-2302
The UNM Cleft and Craniofacial Team

The UNM Cleft and Craniofacial Team is an interdisciplinary team for the assessment, diagnosis, education, and treatment of children with cleft lip and/or palate, submucous cleft palate, velopharyngeal incompetence/insufficiency, and all related problems. We assess patients with a variety of craniofacial abnormalities and disorders, such as, 22q11.2 deletion syndrome, microtia and hemifacial microsomia, Robin sequence, Stickler syndrome, and other disorders. We have a fully staffed team and work with and refer to multiple other specialties within UNM Children’s Hospital as appropriate.

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.

Contact and Referral Information:

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)
Team Members

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Kathie Esquibel-Baca, MS, CCC-SLP, Developmental Care
Joshua McDowell, MS, CCC-SLP
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Sharon Hoff, RN- Oral/Maxillofacial Surgery
Megan Korovlev, RN- Pediatric ENT Surgery
Important Phone Numbers

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Child life  (505)272-2671
Cleft & Craniofacial team/nurse Sheree Shaw, RN  (505) 272-2302
Financial assistance  (505)272-2521
Genetics  (505) 272-6631
Joanna Milisa with Genetics  jmilisa@salud.unm.edu  (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  info@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
Common Questions

**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.

**Cleft Palate**
There are two types of cleft palate: a hard palate cleft (hole in the hard, bony, or front part of the palate) and a soft palate cleft (hole in the soft, muscular, or back part of the palate). Clefts can be “incomplete” involving only a part of the palate or “complete” involving the entire palate.

**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.
How will speech develop?
Normal speech should be expected especially with a child born with an isolated cleft lip and palate. The Cleft Team will frequently monitor speech and language development and refer for further speech and language evaluations, if appropriate. Factors that may affect speech development are syndromes, dental abnormalities, apraxia of speech, and velopharyngeal insufficiency.

Is there special dental care?
Children with clefts may have special dental problems and should have routine dental care like any other child. There may be missing teeth, extra teeth or incorrectly shaped teeth.

Will my child have hearing problems?
Children with cleft palate are more susceptible to hearing loss due to fluid behind the ear drum and middle ear disease. Hearing screening is recommended routinely for early detection and treatment of hearing loss and middle ear problems. Even a mild degree of hearing loss can have a negative effect on speech and language development as well as learning.

What will my child look like after surgery?

Before surgery:

During healing:
Feeding

Infants with a small cleft of the soft palate or isolated cleft lip may not have feeding problems. Most infants with a cleft of the hard and soft palate will have difficulty creating good suction because of the opening in the roof of the mouth. An example may be like trying to drink through a straw that has a hole in it.

Breastfeeding may be possible for an infant with a cleft lip, but usually requires a change in technique and patience. Breastfeeding an infant with a hard and soft palate cleft may be difficult because of the infant’s inability to create enough suction to draw out the liquid from the breast. An alternative is bottle-feeding with mother’s expressed milk or infant formula.

A feeding specialist can assist in trying to find a bottle or nipple that works for the infant. There are many different bottles and nipples including squeeze bottles and special nipples with larger openings. These special bottles and nipples allow the infant to drink the breast milk or formula without getting tired. Feeding infants in a more upright position with frequent breaks will lessen the chance of fluid coming through the nose and allow for successful feeding. Each baby is different and several techniques, bottles, or nipples should be tried to find the right fit.

All babies born at UNM Hospital are referred to the Cleft Team and will meet with the feeding specialist for assistance and guidance. The pediatrician will play an important role in monitoring the infant’s weight to make sure the infant is getting enough nutrition needed for growth and development.
Timing for Cleft Lip and Palate Surgery

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.

Palate repair:
Repair of the palate is usually between 8 and 14 months of age. The baby must be healthy, feeding well, and gaining weight. The palate should be repaired around the time speech is forming. If the child is not developing speech, the surgery may be delayed.

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.
# Time Line for Cleft Palate:

<table>
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<tr>
<th>Age Range</th>
<th>Intervention</th>
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<tr>
<td>Prenatal</td>
<td>Refer to cleft team&lt;br&gt;Offer genetic counseling&lt;br&gt;Consider psychosocial issues</td>
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<tr>
<td>Neonatal (0-1 month)</td>
<td>Provide feeding instructions, monitor growth&lt;br&gt;Hearing screening</td>
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<tr>
<td>1-8 months</td>
<td>Monitor feeding and growth&lt;br&gt;Monitor ears and hearing&lt;br&gt;Consider placing ear tubes</td>
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<tr>
<td>8-15 months</td>
<td>Repair cleft palate&lt;br&gt;Consider placing or replacing ear tubes&lt;br&gt;First dental care</td>
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<tr>
<td>16-24 months</td>
<td>Assess speech and language development&lt;br&gt;Monitor ears and hearing</td>
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<tr>
<td>2-5 years</td>
<td>Assess and treat any speech and language problems&lt;br&gt;Monitor ears and hearing&lt;br&gt;Assess development and psychosocial needs&lt;br&gt;Consider need for revision palate surgery</td>
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<tr>
<td>5-11 years</td>
<td>Orthodontic evaluation and treatment&lt;br&gt;Monitor school and psychosocial needs</td>
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<tr>
<td>12-21 years</td>
<td>Consider genetic counseling for the child&lt;br&gt;Consider jaw (orthognathic) surgery</td>
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Alveolar bone graft surgery:
Many children with a cleft lip also have a cleft of the alveolus (the ridge in the mouth that holds the teeth). If your child has an alveolar cleft, repair will be decided with the help of the dentist, orthodontist and oral surgeon. Timing depends on how quickly your child's adult teeth are developing. Usually this surgery takes place between the age of 6 and 10 years old. Some children need a short period of orthodontic treatment or extraction of baby teeth before alveolar bone graft surgery.

Surgery for the facial bones (orthognathic surgery):
Some children have a small upper jaw (midface hypoplasia) which can cause problems with how the teeth come together. In the teenage years, your child may benefit from jaw (orthognathic) surgery to improve the way their teeth come together and also their facial profile.

Surgery for abnormalities of the nose:
After a child is nearly grown, many children with cleft lip and palate choose to have a surgery to correct nasal obstruction and/or the appearance of their nose (rhinoplasty). Some children also benefit from more minor nasal tip surgery to correct asymmetry of the nose at an earlier age.
Specialized Services

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.
Specialized Services

Dental Evaluation
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.

Speech Videofluoroscopy - shows the motion of the palate with speech using contrast in the nose and a special technology which creates a movie from continuous x-rays.

Nasopharyngoscopy - shows a view of how the soft palate works during speech by placing a camera in the back of the nose and recording a video during speech tasks. The soft palate is seen in the lower part of the picture and the larynx (voice box) is seen in the upper part of the picture.
The University of New Mexico Children’s Hospital is a state-of-the-art dedicated children’s hospital.

Our hospital has specialized units dedicated to the care of children including a Newborn Intensive Care Unit, Pediatric Intensive Care Unit and Pediatric Surgery Unit. All surgeries are performed under the care of pediatric anesthesiologists. Child Life Services are also available for clinics, inpatient wards, and the surgical unit. The goal of the Child Life staff is to normalize the hospital environment for children and their families.

We perform specialized diagnostic tests including nasopharyngoscopy, speech videofluoroscopy, and complex airway evaluations. Assessment of sleep problems is available through our Accredited Pediatric Sleep Laboratory.

Prenatal diagnosis
Diagnosis for isolated cleft lip and/or palate may occur with a prenatal ultrasound. However, several factors affect the ability to adequately see the defect. These factors include the quality of the ultrasound machine, the skill of the sonographer, the number of weeks into the pregnancy (usually 18-20 weeks or later), the position of the baby, and the woman’s body structure. Routine obstetrical ultrasound does not usually examine the baby’s anatomy and cleft palate alone is very difficult to see. However, if the baby has been diagnosed with a cleft lip and/or palate, then we will begin prenatal counseling to discuss the treatment options and services/support available for your baby when he or she is born.
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:
Directions for surgery:

Park in patient parking (see map on previous page)
Enter the Children’s Hospital Main Entrance
Take the elevator to the fifth floor
Follow the signs to the Pediatric Recovery and Surgery
North East Heights UNM Cleft and Craniofacial Team Clinic
7801 Academy Blvd. NE, Albuquerque, NM 87109

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:
Book suggestions for your child:

1. McCue, L; Corduroy Goes to the Doctor, 2001
2. Civardi Anne; Going to the Doctor, 2006.
5. Bourgeois, Paulette; Franklin Goes to the Hospital, 2000.
6. Bridwell, Norman; Clifford Visits the Hospital, 2000.
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 teeth.

**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.
**Middle ear:** The space behind the ear drum that should contain air and small ear bones that transfer sound to the inner ear.

**Middle ear effusion:** A collection of fluid in the middle ear which may cause temporary hearing loss.

**Myringotomy:** A small incision made in the ear drum to drain fluid from the middle ear.

**Nasal emission or escape:** Abnormal flow of air through the nose during speech.

**Nasal septum:** The midline wall that divides the two sides of the nose.

**Naso-alveolar molding (NAM):** A technique that can be used to slowly mold the tissues of the nose and lip into a better position prior to lip repair surgery.

**Nasopharyngoscopy:** A procedure performed with a small tube attached to a camera which is inserted in the nose to examine the anatomy of the throat during speech.

**Obturator:** A retainer-like device sometimes worn to block a fistula or cleft to aid in feeding and speech.

**Occlusion:** The relationship of the upper and lower teeth.

**Oral-maxillofacial surgery:** A surgical specialty of dentistry that manages dental and skeletal problems.

**Orthodontics:** A specialty of dentistry that studies and treats malocclusion. “Braces” placed on the teeth to straighten them into better occlusion.

**Orthognathic surgery:** An operation to properly align the teeth by repositioning the upper and lower jaw which is performed after facial growth is complete.

**Otitis media:** Inflammation of the middle ear that may cause a collection of fluid.

**Otolaryngologist:** A surgical specialty of diagnosis and treatment of disorders of the head and neck.

**Palatal lift:** A prosthetic device to lift the palate.

**Palate:** The roof of the mouth containing the hard and soft portions.

**Pharyngeal flap:** A surgical procedure that attaches a portion of tissue from the back of the throat to the soft palate to decrease hypernasality.

**Palatoplasty:** Repair of the palate.

**Philtral columns:** The ridges of skin beneath the nostril, between the columella and the upper lip.

**Premaxilla:** The portion of the upper jaw, which contains the four front teeth which often protrudes with bilateral cleft lip.

**Pressure Equalization Tubes (PE Tubes):** Tiny hollow tube made of plastic or metal inserted into the eardrum for ventilation of the middle ear.

**Prolabium:** The central part of the upper lip below the columella and between the philtral columns which protrudes with a bilateral cleft lip.

**Prosthesis:** An artificial extension that replaces a missing body part.

**Prosthodontist:** A specialist of dentistry who provides custom-made appliances for the mouth.

**Resonance:** Vibration of air in the mouth and nose during speech.

**Soft palate:** The back portion of the roof of the mouth containing muscles.

**Speech bulb:** A removable prosthesis to help close off the palate during speech. This is an alternative to surgery for select patients with velopharyngeal insufficiency.

**Speech-Language Pathologist:** A person licensed to diagnose and treat speech, language and communication disorders.
**Speech videofluoroscopy:** A continuous x-ray of the soft palate and throat during speech used to examine the speech mechanism.

**Sphincter pharyngoplasty:** A surgical procedure that rearranges muscle and tissue from behind the tonsils to the back of the nose to decrease hypernasality.

**Submucous cleft:** A cleft in the palate muscles with intact mucosa that can lead to hypernasal speech.

**Uvula:** The small “bell” at the back of the soft palate that contains muscle.

**Velopharyngeal closure:** The closure between the nose and mouth, which directs air out through the mouth during speech. Closure requires muscles in the soft palate to close with structures in the back of the throat.

**Velopharyngeal incompetence:** Inability to achieve velopharyngeal closure even when the soft palate structures appear normal.

**Velopharyngeal insufficiency (VPI):** A problem with the structure or function of the palate or throat resulting in poor velopharyngeal closure and hypernasal speech.

**Velum:** The Latin name for the soft palate.

**Vermillion:** The red portion of the lips.
Informational Resources

The Cleft Palate Foundation
1504 East Franklin St., Suite 102
Chapel Hill, NC 27514-2820
1-800-24-CLEFT

Website
www.cleftline.org

Follow “For Parents and Individuals” for on-line information and multiple links to further information on clefts and craniofacial syndromes, support groups, pamphlets, research, team listings, and much more.