Cleft Lip & Palate in New Mexico

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Information for Parents and Providers

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Member American Society of Plastic Surgeons and American Cleft Palate Association

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INTRODUCTION

Cleft lip and palate is one of the most common developmental conditions affecting newborn babies. The exact cause is unknown. Most cases occur sporadically with no family history or other anomalies. The goal of treatment is to provide the child with as normal an appearance, speech and life as possible. To accomplish this, numerous specialists are involved at different stages of life from birth to infancy, and into childhood, adolescence and adulthood.

INCIDENCE OF CLEFT LIP AND PALATE IN NEW MEXICO

Cleft lip and palate occurs in approximately 2.6 per 1,000 births in New Mexico, one of the highest in the country. The higher incidence in our state may be due to ethnic and genetic factors. The highest incidence of clefts is found in Native Americans and Hispanics. Based on epidemiological studies, there are approximately 40 to 50 children born with cleft per year.

Of all clefts

- 25% will have associated syndromes
- 20% will be high risk
- 25% will involve cleft lip only
- 50% will involve cleft lip and palate
- 25% will involve cleft palate only

DIAGNOSIS AND CLASSIFICATION

When a baby is born with a cleft, it is important to establish a precise diagnosis. Children will appear to have missing tissue or often be mistaken to have a midline defect. Closer inspection will reveal the nature of the cleft. Tissue is misplaced, but not necessarily missing.

Questions to ask:

- Is the defect unilateral or bilateral?
- Does it involve the lip alone, palate alone, or both lip and palate?
- Is the defect complete or incomplete?
- Are there any associated syndromes?

GENETICS AND RISK OF CLEFT LIP & PALATE

- If this is your first child with cleft,
  -The overall risk for another sibling or offspring = 4%
- If more than one immediate family member is affected,
  -The overall risk for another sibling or offspring = 10-16%

EMBRYOLOGY

Clefts occur during the first stages of embryological development as the face is forming by the fusion of various elements. Failure of fusion is the cause of clefts of both the lip and palate.

PRIORITIES in CLEFT MANAGEMENT

At birth:

- Coping
- Adapting
- Feeding
- Preparing for surgery

After birth:

- Appearance
- Speech
- Hearing
- Dental

> The goal of treatment is to provide optimal results in terms of appearance, speech, hearing and dental outcomes.

FEEDING

Initially, feeding may be difficult due to the inability to achieve suction and maintain intra-oral negative pressure since there is an open connection between the oral and nasal cavities.

FAMILY COUNSELING

It is imperative that a member of our team meet with the parents as soon as the baby is born to assist in feeding, often in the delivery room or during hospitalization. During consultation we review various aspects of clefts and show before-and-after pictures in preparation for the first surgery.

ULTRASOUND DIAGNOSIS

Many mothers are now finding out about their baby's cleft while still pregnant. With newer techniques in ultrasound, the details of the face can be determined. As soon as an ultrasound diagnosis is made a meeting is held with the expectant mother and family to provide support and give information. Knowing what to expect can be very helpful.

TYPES OF CLEFTS

Clefts can be unilateral or bilateral, involve the lip alone, lip and palate or just the palate. All share common features of failure of fusion of lip or palatal elements.

CLEFT PALATE AND VARIATIONS:

The typical cleft is a defect in the hard and soft palates. It may begin at the gum line and extend to the back of the palate, causing a split or gap. The muscles controlling the movement of the palate, know as the levators, are disrupted and abnormally placed, allowing air and food to escape into the nose. Cleft palate is repaired at 9 months.

Submucous Cleft Palate - A condition in which the uvula is split and it appears that the palate is intact, when, in fact the muscles and underlying structures are clefted. Repair is often indicated if there is risk of abnormal speech development. Many times these cases are diagnosed late when the child is 6 to 7 years old. Any child with hypernasal speech should undergo evaluation by a trained cleft specialist.

Robin Sequence - A condition in which babies are born with an excessively short mandible or jaw, along with a very wide cleft of the palate, often called a "U-shaped" cleft. These babies sometimes require respiratory and feeding support shortly after birth. As the child grows, the mandible tends to grow as well. Cleft palate repair may be delayed until 10 to 14 months.

22q11 deletion syndrome with or without cleft palate - this is an increasingly diagnosed spectrum of conditions also known as Velocardiofacial Syndrome, Stickler's Syndrome, DiGeorge Syndrome and others – all are characterized by hypernasal speech. Therapy and sometimes surgery can be helpful

UNILATERAL CLEFT LIP (WITH OR WITHOUT CLEFT PALATE)

In the unilateral cleft lip, the defect involves only one side, extending from the gum, through the lip and into the nose. In some cases, a small band is present at the base of the nose, sometimes called an "incomplete" cleft lip. The muscles of the mouth and lips are split and do not form a sphincter so when the baby cries, the lip actually opens up. In addition, there is a gap in the bone of the maxilla through the gum and gingiva. This is addressed when your child is 6-8 years old. The columella of the nose is smaller and the entire nose can appear displaced or crooked including a deviated septum. These nasal deformities are corrected when the child is older. Lip repair is usually done at 3 months of age.

BILATERAL CLEFT LIP (WITH OR WITHOUT CLEFT PALATE)

The bilateral defect is the most severe form of clefting. In this deformity, there are two gaps extending from the gum to the nose. The central part of the lip, called the prolabium, has nothing to hold it back so it tends to protrude. After repair, the prolabium will mold back into a more normal place. The orbicularis muscle of the mouth is widely split and will be realigned in the midline at the time of repair. The nasal deformity is greater with a small columella and displaced nostrils. Bilateral cleft lip repair is usually done at 4 months of age

SURGERY

The two most important surgeries will take place in the first year of life. These operations are to correct the lip and palate. Timing and technique are critical.

REPAIR CLEFT LIP - AGE 3-5 MONTHS

The lip is repaired when the baby is 2½ to 3 months old for unilateral and 4 to 5 months for bilateral cleft lips. Performing surgery at this age insures that the immune system, airway, respiratory system and blood counts are strong enough to tolerate surgery and anesthesia.

The goals of surgical correction are to create a pleasing harmonious lip and eliminate the stigmata of cleft lip deformity, avoid secondary deformities and additional surgeries. This is done by using the triangular flap repair developed by Tennison and Randall. The technique involves reconstituting lip height, realignment of the orbicularis muscle, recreating the Cupid's Bow of the lip by aligning the white roll, creating a vermillion tubercle, releasing and realigning the nostril while maintaining an adequate labial sulcus. Sometime minor revisions are necessary at a later time.

Surgery takes 3 hours and includes closure of the most anterior portion of the hard palate with vomer flaps. An otologist usually inserts PE tubes in the ears at this time. Baby stays in the hospital with the mother 2 nights, sutures are removed in 7 days in the operating room.

REPAIR CLEFT PALATE - AGE 9 MONTHS

Studies have shown that 9 months is the ideal time for cleft palate repair in terms of better speech results and fewer complications. This is done before meaningful speech patterns develop and healing is complete by the time the baby begins to form words. At this stage, the entire palate is closed. Vomer flaps are used to close the anterior palate at the time of the lip repair.

The goal of palate surgery is to restore normal anatomy in order to achieve as normal speech as possible and to eliminate the stigmata of cleft palate hypernasal speech. The main defect associated with the cleft palate is an open communication between the nasal and oral cavities. Mucosal deficiency is present and the palate is shortened with the muscles of the soft palate displaced. They are split, retracted and have an abnormal insertion onto the posterior margin of the palate rather than in the midline. Repair consists of realignment of speech muscles, especially the levator veli palatini. Most commonly used technique is the V to Y lengthening and retropositioning with mucoperiosteal flaps. (Veau-Wardill-Kilner). This is done by mobilizing flaps from the sides. This lengthens the palate, closing the gap while repositioning the muscles.

ALVEOLAR BONE GRAFT - AGE 6-8 YEARS

One of the most important procedures for a child with a cleft is the alveolar bone graft. This operation is performed by an Oral & Maxillofacial Surgeon optimally between the ages of 6 and 8 years old in order obtain maximal results. The bone is harvested from the hip through a small incision and leaves no deficit. The bone graft is placed in the gap of the gum (or aveolus) as a place for the adult teeth to grow. Without this procedure, the adult teeth have no where to erupt, and can often be permanently lost.

ANESTHESIA, HOSPITALIZATION AND RECOVERY

Babies and children with clefts are managed by an experienced team of pediatric specialists. All surgery is done at Presbyterian Hospital. The anesthesiology staff at Presbyterian Hospital includes fellowship-trained specialists using state-of-the-art techniques especially designed for infants and children. For most surgeries, the baby or child will remain hospitalized for one to two nights, until feeding has returned to normal. Infants will be fitted with soft restraints on the arms, they will be fed with a special feeding bottle called a Zip-n-Squeeze. For lip repairs, sutures are removed the following week by placing the baby under light anesthesia. All palate repairs are done with dissolving sutures, and no suture removal is required. A small pack is placed in the palate, which will fall out on its own. After surgery the baby will be admitted with IV fluids, antibiotics, and small doses of narcotics for pain. When the baby can feed fully, he or she will be switched to oral medications. Pain after surgery is well controlled in this way, but many babies will be fussy and irritable. Drainage and low grade fever is normal after surgery. Most bottle feeding can be resumed after one week. You will be given detailed instructions on wound care, diet and follow-up. Recovery and healing generally takes 3 weeks.

SECONDARY SURGERY AND MAJOR REVISIONS

Poorly performed surgery done elsewhere by other surgeons resulting in severe deformities or speech abnormalities can have a devastating impact on the patient and family. Sadly, we see too many such cases. Major revisions may be required at any age, especially if there exists a significant problem with either the appearance of the lip or problems with speech or palate function. Minor revisions or corrections are sometimes necessary for the lip, palate and nose.

DENTAL AND FACIAL SKELETON ABNORMALITIES

Children with clefts exhibit a wide variety of facial skeleton and dental abnormalities from malocclusion to gross maxillary deficiency. These defects consist of hypoplastic maxilla on the cleft side and malalignment of the dento-alveolar arches. With a bilateral cleft, the defects are more severe and the premaxilla is often grossly deficient in bone. Dental abnormalities include supernumerary teeth, dystrophic teeth, congenitally missing teeth and malocclusion in nearly all patients. Ectopic tooth buds may be present as infants. The most common orthodontic deformity involves a crossbite usually occurring on the side of the cleft. Surgical treatment with alveolar bone graft is performed by an Oral & Maxillofacial surgeon between ages 6-8 years to allow permanent teeth to grow. A maxillary expander is sometimes placed prior to bone graft. When the permanent teeth erupt, orthodontic braces are then applied to realign the teeth. If maxillary retrusion or severe malocclusion occur, further orthognathic surgery may be required at age 15-18 years.

NASAL ABNORMALITIES

One of the most visible cleft abnormality is the nose. The nasal abnormality consists of deficient and displaced cartilage structures, deviated nasal septum and tip abnormalities. Partial correction is obtained at the initial lip repair. Further corrections may be done at age 4 to 6 years, with the final correction occurring at age 16 to 18 years in the form of a complete reconstructive rhinoplasty. After full skeletal maturity in the teenage years, the final operation to be performed is a complete rhinoplasty and septoplasty to reshape the nose.

HEARING ISSUES

Virtually all patients with a cleft involving the palate (with or without cleft lip) will develop middle ear effusions due to abnormal drainage of the Eustachian tube. If untreated, this can lead to chronic ear infections and permanent hearing loss. Therefore, all patients with clefts are evaluated early by an Otologist (an ENT who specializes in hearing) for the need for ventilation tubes (PE tubes or BMT). The majority will demonstrate fluid build up and require tubes to be placed at the time of lip and/or palate surgery. With this aggressive approach, most children can expect normal hearing.

SPEECH THERAPY

After the repair of the cleft palate, the child will gradually begin to speak, first with a few words and then with sentences. This is the critical time for speech development. A speech therapist will monitor for any signs of language, speech and hearing problems. If there is any question of speech problems, the child may be referred for further testing including videofluoroscopy and nasendoscopy. Speech results are better with early recognition of surgically correctable problems. The most common problems we see are language delay and velopharyngeal insufficiency, or VPI. VPI is a result of abnormal healing or scarring of the palate, and may need a second operation to correct. It is vital that a Speech Therapist trained in cleft palate monitor the child.

CLEFT PALATE CENTER CLINIC AND TEAM

The New Mexico Cleft Palate Center is certified and approved by the American Cleft Palate Association. We have established a system in which children are seen at our individual private offices. Here we can spend the required time to perform a personal and through evaluation of your child. Although the NM Department of Health CMS also runs outreach clinics, they have limited resources to deal with the complex issues facing cleft children. We therefore recommend that you register with Dr. Cuadros and his team. We will then make the appropriate referrals and follow-ups.

INDEPENDENT PRIVATE VOLUNTEER MISSION IN GALLUP AND SHIPROCK

The Gallup Cleft Palate Clinic is now being run through the New Mexico Cleft Palate Center with the assistance of local providers and volunteers in cooperation with Gallup Indian Medical Center, Northern Navajo Medical Center, Rehoboth-McKinley Christian Hospital, NM DOH Children's Medical Services, Indian Children's Program, and Growing in Beauty. Please call our office 1-505-243-7670 to register for Gallup or Shiprock clinics.

INSURANCE AND PAYMENT ISSUES

Dr. Cuadros and the members of the cleft palate team are committed to taking care of all children with clefts regardless of payment source. Dr. Cuadros is contracted with all major insurance carriers, HMO's, Salud programs, CMS and Medicaid. In the management of clefts, there should be no barriers to offering these children the best care possible. Additional support for lodging, transportation and feeding supplies are available.

DR. CUADROS - CREDENTIALS AND EXPERIENCE

Dr. Cuadros has been in practice in New Mexico since 1988. He is a graduate of Columbia University and trained at Harvard Medical School. He is a member of the American Society of Plastic Surgeons and American Cleft Palate Association. He is a consultant for Healing the Children and a member of Operation Smile. He has been a provider for CMS Cleft Palate Clinics for 20 years and has extensive experience in surgical management of Cleft Lip and Palate. Dr. Cuadros has dedicated his life to helping these children and families and improving their standard of care in New Mexico.

Dr. Cuadros and his team are contracted to accept ALL forms of insurance and pay sources including Medicaid, Salud, Pres Salud, Molina Salud, Lovelace Salud, Presbyterian Health Plan, Lovelace Health Plan, Cigna, United Health Plan, Aetna, Tricare, and others. No child is turned away. Free consultation and evaluation services are available.

CLEFT AND CRANIOFACIAL SERVICES AT PRESBYTERIAN HOSPITAL

Presbyterian Hospital has advanced and sophisticated specialists available to treat patients with cleft and craniofacial anomalies, including Pediatric Neurosurgery, Oral and Maxillofacial Surgery, ENT, Otology, and Pediatric Dentistry. Presbyterian services include advanced pediatric care such as Perinatology, Cardiology, Gastroenterology, Pulmonary, and Pediatric and Neonatal Intensive Care Units.

Our team currently performs over 100 primary cleft lip & palate surgeries per year and over 300 total surgeries for cleft and craniofacial , including plastic, ENT and dental – by far, the most in the state.

Our data indicates that outcomes at our institution are at or even above national standards for cleft care set forth by the American Cleft Palate Association. Several innovative and state-of-the-art techniques are used at Presbyterian including videoscopic monitoring during surgery, a unique lateral digital palate study, distraction osteogenesis and the use of purified platelet-rich plasma.

OTHER REFERRALS

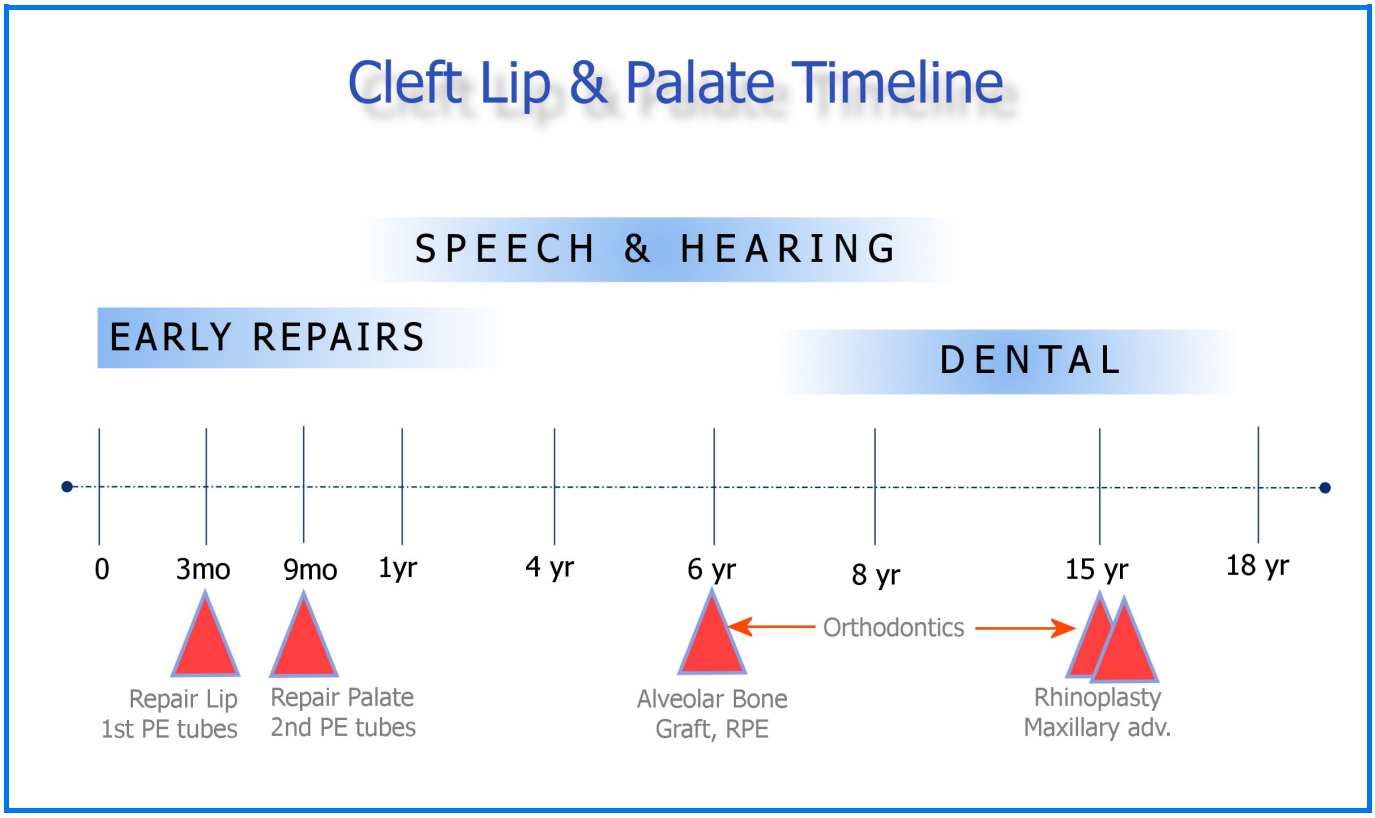
In addition, we work closely with other providers and clinics throughout the state and country including University of New Mexico Hospital, New Mexico State University, Indian Children's Program, and Children's Medical Services. We also work with the Craniofacial Center in Dallas, Texas for more advanced and complex craniofacial problems.

"It must be remembered that true excellence in cleft lip and palate treatment is dependent on a dedicated multi-disciplinary approach in which the surgeon's performance over time is primary in determining the success or failure of the overall treatment. Experience and objective analysis are paramount in determining which procedures, sequencing, or timing protocol gives improved results"

Kenneth E. Salyer , MD - Dallas, Texas.
Journal of Craniofacial Surgery: Volume 12(1) pp 2-5, January 2001
Special Editorial - Excellence in Cleft Lip and Palate Treatment

CLEFT LIP AND PALATE: CHRONOLOGY OF PROCEDURES and TREATMENTS

PROCEDURE/TREATMENT	AGE	Cleft lip	Cleft lip & Palate	Cleft Palate
ALWAYS REQUIRED				
Repair cleft lip	3 months	x	x	
Repair cleft palate	9 months		x	x
Bone graft alveolus	9 years		x	
Dental care	2 - 18 years	x	x	
Orthodontia	10 years	x	x	
PE tubes	3 mo - 10 years		x	x
Audiology	birth -18 years	x	x	x
FREQUENTLY REQUIRED				
Speech therapy	2 - 12 years		x	x
Open nasal revision	4 - 8 years	x	x	
Rhinoplasty/septoplasty	16 years	x	x	
Le Forte maxillary osteotomy	15 years		x	
RARELY REQUIRED				
Pharyngeal flap	4 - 12 years		x	x
Revision cleft lip	any	x	x	
Closure palatal fistula	any		x	x
Nasendoscopy	4 - 12 years		x	x
Videofluoroscopic speech study	4 - 12 years		x	x
OTHER CONSULTATIONS AND EVALUATIONS				
Genetics/dysmorphology	any	x	x	x
Feeding counseling	birth - 1 year		x	x
Nutrition	all	x	x	x
Psychology evaluation	all	x	x	x
Developmental assessment	birth - 12 years	x	x	x
Xrays, MRI, CT scans	all		x	x
Prosthodontics	age 12		x	x



The three phases of cleft care are:

1. Early Repairs (Birth to 1 yr) - includes feeding and preparation for surgeries
2. Speech & Hearing (age 1- 8) - includes speech therapy
3. Dental (age 6-16) - includes orthodontics

In the first year of life, there will be two major operations:

- ▲ Age 3-5 months - Repair of cleft lip (including AHP), first set of PE tubes
- ▲ Age 9 months - Repair of cleft palate, second set PE tubes

After that, may need 1-3 additional procedures depending on type and severity of cleft:

- ▲ Age 6-8 years - Alveolar bone graft
- ▲ Age 15-18 - Maxillary advancement
- ▲ Age 15-16 - Rhinoplasty

SPECIALISTS INVOLVED IN CLEFT CARE:

at some time in the care of cleft children, some or all of these may be involved

Anesthesiologist
Audiologist
Dental Hygienist
Developmental Specialist
Dietician
Dysmorphologist
Feeding Specialist
Endocrinology
Genetics Counselor
Insurance Case Manager
Lactation Specialist
Neonatologist
Nutritionist
Neurosurgeon
Nurses
Obstetrician
Operating Room Nurses
Ophthalmologist
Oral & Maxillofacial surgeon
Orthodontist
Otolaryngologist
Otologist
Parent Volunteer
Pediatric Surgeon
Pediatric Intensivist
Pediatrician
Pedodontist (Dentistry)
Perinatologist
Plastic Surgeon
Psychologist
Radiologist
Social Worker
Speech Therapist

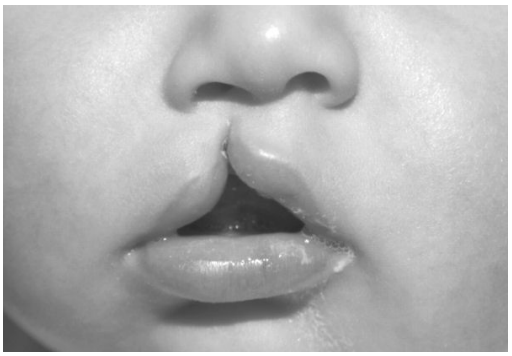
OTHER ANOMALIES AND ASSOCIATED CONDITIONS

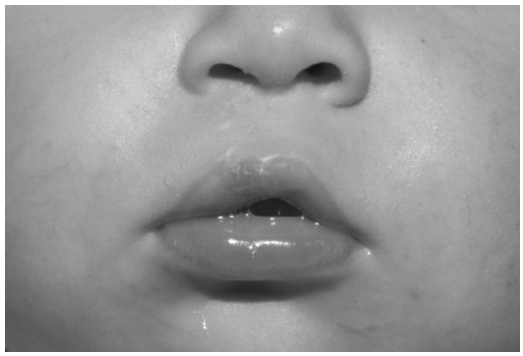
In addition to cleft lip &palate, the following conditions have been seen and treated:
(some of these may or may not involve clefts)

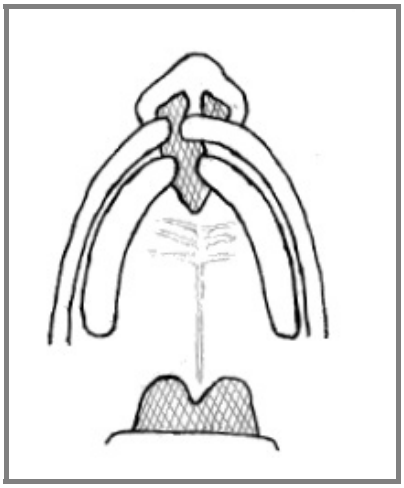
Aarskog Syndrome
Amniotic Band Syndrome
Apert Syndrome
Beckwith Wiedman Syndrome
Binder Syndrome
Charge Association
Craniosynostosis
Crouzon Syndrome
DiGeorge Syndrome
Ear Tags
EEC Syndrome
Encephalocele
Fetal Alcohol Syndrome
Fronto-Nasal Dysplasia
Goldenhar Syndrome
Goltz Syndrome
Hemifacial Microsomia
Holoprosencephaly
Lateral Orofacial Cleft
Lemli Smith Optiz Syndrome
Microtia
Nasopharyngeal Teratoma
Recombinant 8 Syndrome
Robin Sequence
Robinow's Syndrome
Romberg's Disease
Schprintzen Syndrome
Stickler's Syndrome
Syndactyly
Tessier Cleft
Torticollis
Trisomy 21 (Downs Syndrome)
VATER Syndrome
Velocardiofacial Syndrome

CLEFT CLASSIFICATION and RESULTS

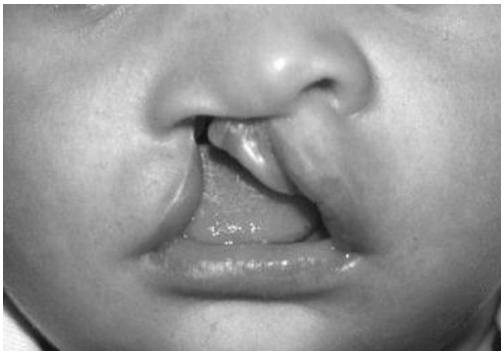
examples shown are cases done by Dr. Cuadros at Presbyterian Hospital

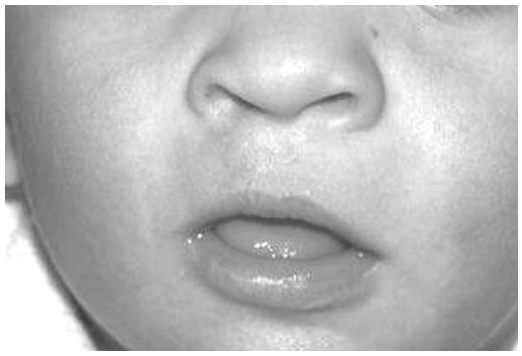


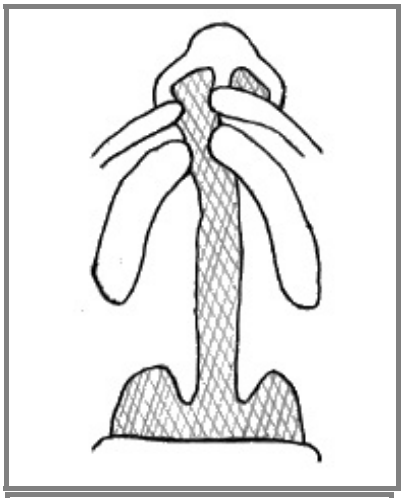




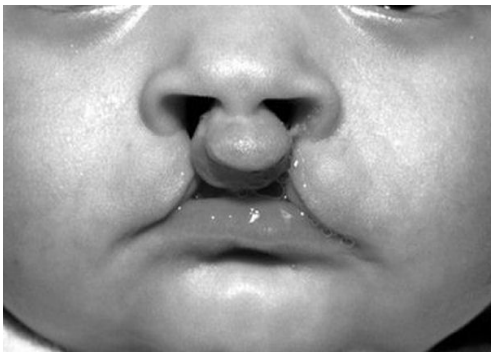
Unilateral Cleft Lip (incomplete)

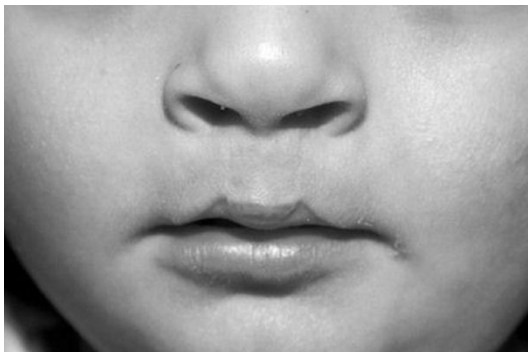


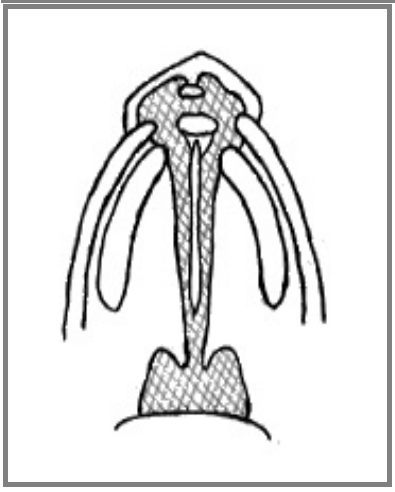




Unilateral Cleft Lip & Cleft Palate (complete)



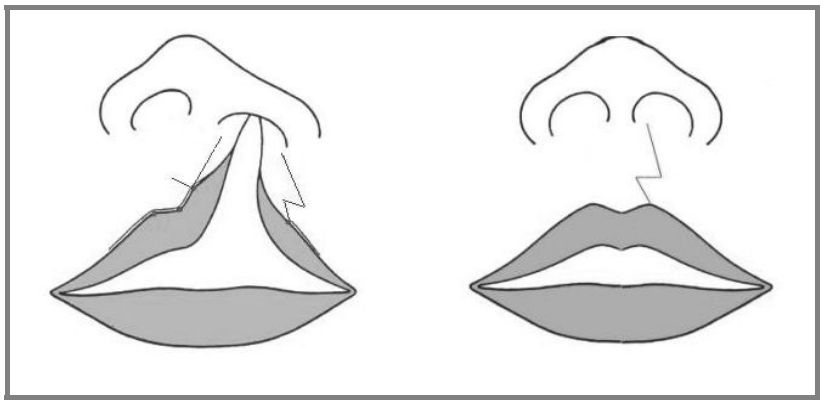




Bilateral Cleft Lip & Cleft Palate

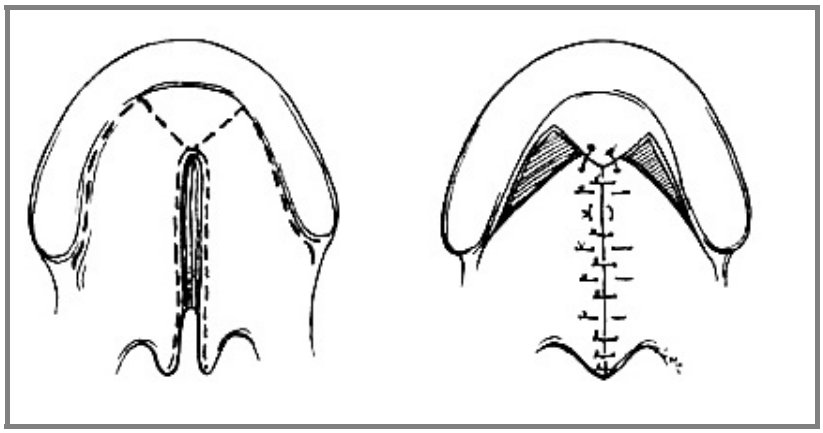
SURGICAL REPAIR OF CLEFT LIP AND PALATE

Repair Cleft Lip - Age 3 months



The Tennison-Randall triangular flap repair is used in virtually all cases. This involves repairing the three layers of the lip: the inner, the muscle and the outer skin. Nose correction is also done. Outer sutures are removed at 7 days.

Repair Cleft Palate - Age 9 months



The technique is called "V to Y push-back" and mobilizes intra-oral flaps to create palatal flaps for closure and length. Again three layers are closed: inner, muscle and outer. A uvula is created. All sutures are dissolving.

FEEDING AN INFANT WITH A CLEFT

Initially, feeding may be difficult due to the inability to maintain intra-oral negative pressure due to the open connection between the oral and nasal cavities. Breast feeding may not be possible when the palate is involved. Some mothers are successful but may need to supplement with breast pumping or formula. Feeding the baby may take a period of trial and error. Most mothers are successful with a soft nipple cross cut at the end or side attached to a Mead-Johnson squeeze bottle. Other products include Pigeon Nipple, NUK nipple, Haberman feeder. These feeders allow the baby to gum the nipple and drip or squeeze milk or formula. Infant should be fed in the slightly upright position, also called the "football hold." Air swallowing can be prevented with more frequent and slower feedings. Remember to burp your baby often. Monitor weight and feeding closely. A feeding specialist can be very helpful. All babies have different abilities, likes and dislikes. The urge to feed is strong, and the best technique is quickly determined. Sometimes it requires patience, time and determination but eventually all babies will learn to feed. Babies need time to learn and to strengthen the muscles of the mouth, tongue and throat. Be creative and resourceful.

Breastfeeding

Breastfeeding an infant with a cleft palate is usually not possible if any part of the palate is affected. If the cleft only involves the lip, then breast feeding may be attempted but will require a more upright positioning so that mother's breast tissue fills the gap in the lip or gum. Nursing at the breast is best limited to 10 minutes, and supplemental bottles are needed if breastfeeding alone does not supply enough food for adequate satisfaction and growth. For most mothers of infants with cleft palate, breast pumping should begin at birth using a high quality electric breast pump and continue each time after the infant eats. A lactation consultant is a breastfeeding mother's best resource for correct positioning and pumping technique. Discuss your feeding plan with this specialist before discharge from the hospital. Weight gain must be followed closely.

Bottle Feeding

Small, frequent feedings are usual in the first weeks of life for an infant with a cleft palate. Give yourself and your baby time to learn how to eat, and expect longer feeding times. Try to limit feedings to 30 minutes with an additional 10 minutes for burping and changing. Hold your baby upright or slightly tilted back (in your arm with a fat pillow under your elbow) to limit the amount of liquid that enters the nasal passage. Some infants totally ignore drainage into the nose, and you should not be alarmed to see a trickle come out. If there is a great amount of liquid in the nose, tilt the baby forward. Your baby will swallow any extra milk in the back of the throat and the extra milk in the front of the mouth and nose will drain by gravity. You may use a bulb suction to help, but the positioning is most important to prevent any extra liquid from sliding to the back of the throat.

Mead Johnson Cleft Palate Nurser

Special feeding bottles and nipples work by allowing the milk to come out of the nipple with little or no suction needed. Some cleft palate bottles need compression, or squeezing, along with an enlarged opening cut into the nipple to help the infant get enough flow of milk. Hold your baby up in a semi-upright seated position with the head and shoulders in one hand and the bottle in your other hand. If you are more comfortable with the baby in the crook of your elbow, place a blanket or pillow under that elbow to hold the baby more upright. Tickle the baby's lower lip or corner of the mouth with the nipple and place it over the tongue when the mouth pops open. You may need to pull the lower jaw down gently to get the baby's tongue down and out of the way. When the nipple is placed in the mouth, allow your baby to suck and breathe a few times before beginning compression of the Mead Johnson Cleft Palate Nurser bottle.

Begin with gentle compression and slowly increase the pressure while watching your infant's face. If the baby takes more than 40 minutes to eat, or if there is leakage from the nipple ring, it may improve feeding efficiency to increase the crosscut about 1/16th of an inch. Any time the nipple opening is enlarged, take care to squeeze less hard until you know how much the flow of formula has increased. There is little you can do to control the amount of air swallowed during feedings. Your baby will need to burp frequently, but don't interrupt the feeding too much. For very young infants, all you will have to do to is straighten up the baby by pushing gently up at the back of the waist and lifting the front of the

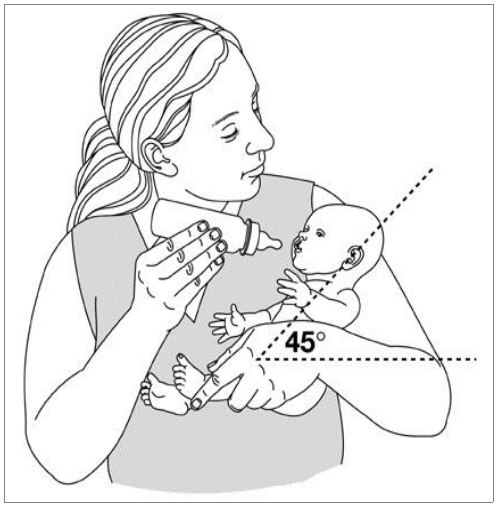
chest with the other hand. Any commercial nipple can be used with the compressible bottle if the tip of the nipple is cut in a 1/8 to 1/4 inch "X" (see diagram).

Pigeon Cleft Palate Nipple

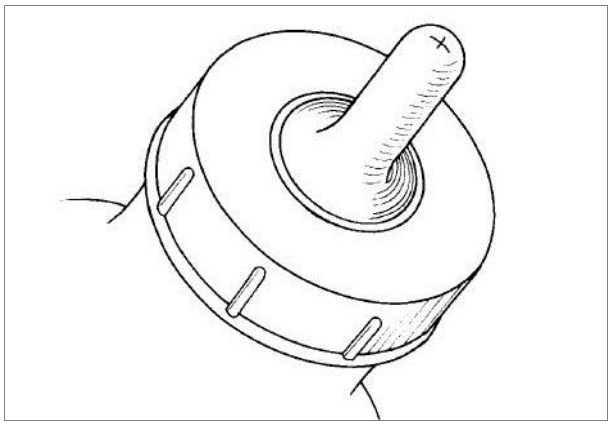
There is a Y cut in the tip of the nipple. Roll the tip with a clean cloth to loosen the opening. Notice the V in the base of the nipple. This is the air vent, and must be positioned on the top of the nipple under the infant's nose for the nipple to work properly. If the nipple collapses or leaks from that hole, remove the nipple from the cap and massage that area to unclog the vent. You may need to poke a toothpick through the vent to clear it. If the bottle system is purchased, follow package directions for assembly. If only the nipple or valve is purchased, the nipple ring from the Enfamil bottle may be used, but not all nipple rings will fit the valve. Put the valve in the base of the nipple, flat side toward the tip. Make sure the nipple lies flat inside the ring and the valve is level with the rim of the nipple. Put the nipple in baby's mouth normally. The infant's tongue will activate the flow. If the nipple collapses, you can unscrew the cap and re-tighten it.

Haberman Feeder (Medela Special Needs Feeder)

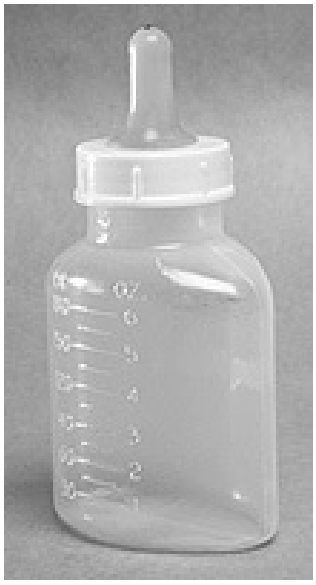
Assemble the bottle and fill with breast milk or formula according to package directions. Line up the shortest line on the compressible reservoir with the baby's nose and tickle the lower lip. Insert the nipple when the mouth opens. Position the nipple on the center of the tongue with the tip turned under the intact part of the palate. The infant will begin to suck. Rotate the nipple until the longest line and greatest flow is under the baby's nose. If your infant cannot tolerate the flow, rotate the bottle back to a slower rate of flow. You may compress the reservoir every second or third suck, or put gently continuous pressure on the section so that more milk will come out of the nipple when the baby compresses the nipple between the palate and tongue.



Holding the baby at 45 degrees can assist the flow of formula or breast milk. It is normal for some food to come out the nose until the baby learns how to direct the food.



Cross-cut nipples, used with compressible bottles, offer the advantage of controlling the flow of liquid when feeding. Also, because the container must be compressed, you have more control of how much milk your baby is getting. The infant aids the feeding process by gumming the nipple after the lip and the bottle make contact.



Mead-Johnson Bottle

Pigeon Nipple with one-way valve

Nuk nipple No 2

Haberman Feeder

GLOSSARY OF CLEFT TERMS

Abbe Flap
An operation that takes some of the lower lip tissue and transfers it to the repaired upper lip to give a fuller upper lip area.

Alveolar Ridge
The bony part of the upper and lower jaws that contain the teeth.

Anomaly
Deviation or departure from the norm.

Anterior hard palate (AHP)
The roof of the mouth, behind the gum line, usually repaired at the first surgery.

Audiologist
A medical professional who diagnoses and treats hearing problems.

Alveolar Bone Graft
Bone borrowed from one part of the body (e.g., the hip, rib or skull) is then transferred to the alveolus or gum area where it is needed for permanent teeth eruption. Best if done at ages 6 to 8 years.

Bilateral Cleft Lip and/or Palate
Affecting the left and right sides.

Cheiloplasty
A scientific term to describe surgery to close a cleft lip. Usually called simply lip repair or revision.

Cleft Lip
A defect in the upper lip due to failure of fusion of the tissue.

Cleft Palate
A defect in the palate involving the hard palate and/or the soft palate, which may also extend to the alveolar ridge or gum line.

Columella
The vertical column portion of the nose dividing the two nostrils.

Complete Cleft
A cleft that extends through the entire oral structure.

Congenital
A condition that is recognized at birth or thought to have been present since birth.

Eustachian Tubes
The tubes that connects the middle ear to the back of the throat, and allow drainage of fluid from the middle ear. These are blocked in cases of cleft palate. Repair of the palate usually improves function.

Expander or Palate Expander
An orthodontic device placed to expand the dental arch before surgery.

Fistula
A hole or remaining opening in the hard palate, can be small or large.

Gavage Feeding
Sending nutrients directly into the stomach by means of a tube. The tube is introduced through either the mouth or nose. Used in the NICU after birth if the baby not feeding well.

Haberman Feeder (aka Medela Special Needs Nurser)
A specialized feeder designed for babies with cleft palate and other special feeding problems.

Hypernasality
Speech that sounds very nasal as if air were escaping from the nose. Usually due to a short palate.

Hyponasality
Speech that sounds as if the nose was plugged. Usually due to nasal obstruction.

Hypoplasia
Incomplete or arrested development. For instance, maxillary hypoplasia is the medical term for an underdeveloped upper jaw.

LeFort I Maxillary Osteotomy (Maxillofacial Advancement)
An orthognathic (jaw) surgery where the maxilla is moved forward to achieve a normal facial profile. performed at age 16 to 18 years old to correct retrusion and maxillary hypoplasia (an underdeveloped upper jaw).

Malocclusion
Any deviation from a physiologically acceptable relationship of the upper and lower teeth with each other.

Mandible
The lower jaw.
Maxilla
The upper jaw, which contains the upper teeth, the palate, the maxillary sinuses, the floor of the nose, and part of the orbital rim.
Mead-Johnson
A cleft palate nurser. This is an extremely pliable plastic bottle with a soft, cross-cut nipple.
Midline Cleft
A unusual cleft that occurs in the midline of the face. Midline clefts are most often occurring as part of another syndrome.
Mixed Dentition
Having some baby teeth and some permanent teeth, usually between the ages of 4 to 7 years old. This is often the optimal time for the alveolar bone graft.
Myringotomy (also known as PE tubes or Ventilation tubes)
A surgical procedure during which a small incision is made in the eardrum to allow the release of pressure caused by excess fluid by placing small plastic tubes. .
Myringotomy Tubes
Tiny rubber or titanium tubes inserted at the myringotomy incision site to aid in the drainage of fluid through the eustachian tubes.
Nasal Septum
The dividing wall that runs down the middle of the nose.
Naso-gastric tube (NG tube)
A pliable plastic tube passed through the nose into the stomach. Used for feeding or giving medications. Also called a gavage tube.
Nasendoscopy
A test in which a fiber optic tube with a small camera is inserted through the nose and/or the mouth allowing doctors to view the nasal and throat surfaces during speech.
NICU
Neonatal intensive care unit, where babies go if they have trouble feeding or breathing after birth
Orbicularis Oris
The circular muscle that goes around the mouth allowing one to pucker. It is separated in all cases of cleft lips. Repair of the cleft involves restoring the orbicularis muscle
Obturator
A type of retainer to close a hole in the palate made of plastic. An obturator is sometimes worn over the cleft of the hard palate to aid in feeding and speech development.
Occlusion
The way the teeth come together. Occlusion may be normal or abnormal (malocclusion) and classified as follows: Class I When the teeth meet in a normal fashion. Class II When the mandibular teeth are behind the normal relationship with the maxillary teeth. Class III When the lower dental arch is in front of the upper dental arch, sometimes called an underbite.
Orthodontics
Braces on the teeth to help alignment
Orthognathic Surgery
The surgical correction of jaw deformities. The word orthognathics means straight jaws.
Osteotomy
The incision, sectioning, or cutting of a bone, for the purpose of repositioning it.
Otitis Media
A build-up of fluid in the middle ear caused when the fluid cannot naturally drain through the eustachian tubes. If untreated, it can lead to hearing loss.
Otolaryngologist
An ear, nose and throat (ENT) physician.
Otologist
An otolaryngologist who specializes in hearing.
Palate
The roof of the mouth, made up of the hard and soft palates.
Palatoplasty
The surgical closure of the cleft palate.

Partial or Incomplete Cleft
A cleft that extends partially through the lip or palate but not all the way through, as in a complete cleft.

Pharyngeal Flap
This is a surgical procedure designed to minimize hypernasality by creating a "bridge" from a flap of skin between the soft palate and the back of the throat. performed to achieve normal closure during speech.

Philtrum
The middle of the upper lip located above the vermillion and bordered on either side by soft ridges, or Philtrum lines (the "Cupid's Bow").

Premaxilla
The middle section of the upper gum containing the four upper front teeth. This section usually protrudes in a bilateral cleft.

Prognathic
When the lower jaw is significantly larger than the upper jaw, therefore in front of it.

Prolabium and Premaxilla
The center part of the upper lip and gum protruding in the case of a bilateral cleft lip deformity.

Prosthodontist
A dentist who specializes in providing prosthetic appliances for oral structures.

Rhinoplasty
Nasal reshaping or reconstruction.

Speech Pathology
The study of speech or language disorders and their diagnosis and correction.

Submucous Cleft
A cleft affecting the muscles that attach in the middle of the soft palate, but not affecting the covering tissue or skin. Submucous clefts are sometimes overlooked as they are not visibly apparent except for a possible tiny cleft of the uvula.

Tympanic Membrane
The eardrum.

Tympanogram
A graphic representation of the air pressure in the ear canal. A tympanogram is used to determine if there is fluid in the eardrum. It can also detect perforations.

Unilateral Cleft
A cleft that occurs on only the right or left side.

Uvula
The dangling punching bag-like structure hanging from the palate in the back of the mouth.

Velopharyngeal Incompetence (VPI)
The leakage of air through the soft palate during speech, causing nasal sounds.

Velum
Latin term for the soft palate.

Vermillion
The darker pink tissue that makes up the lip.

Videofluoroscopy
An videotaped x-ray image to aid in the study of a palatal motion during speech.

Zygoma
The malar or cheek bone.

RESOURCES for PARENTS and HEALTH CARE PROVIDERS
for referrals and information call Dr. Cuadros at any time
505-243-7670 or toll-free in New Mexico 1-888-217-6120

LOCAL RESOURCES:

Dr. Luis Cuadros, MD, FACS, Plastic Surgery and Sue Saiz, RN, Plastic Surgery Nurse
1-505-243-7670, or toll free in New Mexico 1-888-217-6120. Our office is available at any time to discuss issues regarding cleft management. We will arrange for consultation, provide feeding information and supplies.
8232 Louisiana NE, Suite A, Albuquerque, NM 87113
http://www.cuadrosmd.com/cleftlippalate.shtml
info@cuadrosmd.com

Susanne R. Hays, MS, RN, CRRN. Pediatric Rehab Nurse and Feeding specialist is able to consult by phone or home visit for all feeding issues in newborns and babies with clefts.
1-505-294-8338

Dr. Karl Horn, MD - ENT, Hearing Specialist
Ear Associates, 415 Cedar Street SE, # 2, Albuquerque, NM 87106
(505) 224-7610

Oral and Maxillofacial Surgery of New Mexico - oral surgeons dedicated to treating patients with facial cleft and deformities. These surgeons perform bone grafts, tooth extractions and other complicated procedures of the facial skeleton.
Lionel Candelaria DDS, John Mitchell DDS, and Robert Urquhart DDS
6800A Montgomery NE, Albuquerque, NM 87109
505- 881-1130
http://www.omsanewmexico.com/

Children's Medical Services (CMS), New Mexico Department of Health
Funding for children not eligible for Medicaid or Salud programs is available through CMS.
Toll Free 1-877-890-4692

SmileFest

SPEECH THERAPISTS/ SPEECH AND LANGUAGE PATHOLOGY - specialized speech services for children with cleft palates is available through these two highly trained speech therapists:

Gwendolyn Fletcher Doty, M.S., CCC-SLP, Speech-Language Pathology
"Everyone Has Something to Say"
2403 San Mateo, Suite P-15, Albuquerque, NM 87110
Phone: 505-550-9211
gfletcher.slp@gmail.com
www.gfdotyslp.com

Beth DeLozier, MS CCC SLP, Speech-Language Pathology
"Alegria Speech and Language"
11005 Spain Northeast Suite 15, Albuquerque, NM 87111
cell 550-1849, office 314-5865
betholad@yahoo.com

INSTITUTIONAL AND ORGANIZATIONAL RESOURCES

CleftLine: Managed by the Cleft Palate Foundation. 1-800-24-CLEFT .
Call this number 24 hours/ 7 days to obtain information on clefts.
http://www.cleftline.org/

WideSmiles: organization begun by a parent who has adopted three children with cleft palates.
PO Box 5153, Stockton, CA 95205-0153
http://www.widesmiles.org

American Cleft Palate-Craniofacial Association/Cleft Palate Foundation
1504 East Franklin Street, Suite 102, Chapel Hill, NC 27514-2820 USA
(919) 933-9044. info@cleftline.org http://www.acpa-cpf.org/

Children's Craniofacial Association
13140 Coit Road, Suite 517, Dallas, TX 75240
Toll-Free: 800.535.3643, Phone: 214.570.9099, Fax: 214.570.8811
http://www.ccakids.com

The Cleft Advocate -providing educational opportunities, on- and off-line support networks, social interaction and advocacy guidelines, cleftAdvocate gives families the tools they need to obtain the absolute best medical care from their craniofacial team and the best service from their insurer, while encouraging children, teens and adults with cleft lip and/or palate and other craniofacial anomalies to reach their highest level of self-esteem.
http://www.cleftadvocate.org

PRODUCTS

Pigeon Nipples. PIGEON has developed the nursing bottle which enables a baby to suck in the same manner as they would from a mother's nipple by studying the shape, size, elasticity and structure of the nipple. We carry these nipples in our office.
http://www.galtak.com/nipples.htm

Haberman Feeders
Specialized feeders designed for babies with cleft palate.
http://www.medela.com/NewFiles/specialtyfdg.html

Mead Johnson Cleft Palate Nurser (Enfamil Cleft Lip/Palate Nurser) - home delivery
http://store.enfamil.com/
http://store.enfamil.com/bottles_and_nursers.html

DONATIONS TO THE CLEFT PALATE EDUCATION FUND

A charitable fund has been established through the New Mexico Medical Foundation to help with education resources for patients, parents and providers. The fund provides educational materials and learning experiences to improve the care of children in New Mexico.
Please make out checks to New Mexico Medical Foundation and send to:

New Mexico Medical Foundation
c/o NMMS Cleft Palate Education Fund
ATTN: Sally Blackstad, Specialty Society Coordinator
7770 Jefferson NE, Suite 400
Albuquerque, NM 87109

Or, you can contact the office of Dr. Luis Cuadros — 505-243-7670.

New Mexico Cleft Palate Center

An independent, multi-disciplinary team
following the standards set forth by the American Cleft Palate Association

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The New Mexico Cleft Palate Center is composed of experienced practitioners devoted to the care of children born with clefts and other craniofacial deformities. Children of all ages from birth to adult are seen, regardless of insurance or pay source. Patients, parents, pediatricians, primary care practitioners, social workers, case managers, speech pathologists, teachers and other specialists can call at any time for information. Our goal is to insure the best possible treatment for children affected by clefts and other deformities by ascribing to the highest standards of practice available. With over 20 years of experience in treating clefts, our goal is to meet national standards to achieve the best possible outcomes in terms of speech, hearing, dental and appearance.

Our team includes specialists from Plastic Surgery, Oral & Maxillofacial Surgery, Pediatrics, Orthodontics, Dentistry, Speech Pathology, ENT, Audiology, Psychology, Feeding and Nutrition.

All insurances and health plans including medicaid, Salud, and CMS are accepted. Even if there is no coverage, children are seen at no charge. If your child has a cleft or other congenital facial deformity, please call to schedule an appointment.

Specialized services include:
CLEFT PALATE RAPID RESPONSE TEAM: Providing early intervention, in-utero counseling, feeding supplies for mothers and newborns. Available 24 hours a day,7 days a week. Call our office as soon as a child is born or diagnosed with a cleft.

CLEFT PALATE SPEECH STUDY CENTER: Providing diagnostic evaluations for children with cleft palate including speech, hearing, and nasendoscopy. A detailed evaluation and report will then determine the need for further treatment.

COORDINATED CLEFT CARE: Through our center, we provide referrals and appointments to our various specialists. We keep a detailed database file of each patient indicating progress and stage of treatment. Patients from all over New Mexico are seen.

To schedule an appointment and evaluation, please call
The New Mexico Cleft Palate Center
Dr. Luis Cuadros
tel 505-243-7670
toll free in NM1-888-217-6120
info@NMcleft.org
or visit www.NMcleft.org

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