



# Cleft Palate FOUNDATION

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2008 Reprint

# Foreword

Anticipating the birth of a child is an exciting event. Generally, it is also a time of mixed feelings. Excitement, anticipation, and joy alternate with feelings of concern and apprehension. The child who is awaited so eagerly usually is visualized as a physically perfect infant.

The birth of a baby with cleft lip and/or cleft palate is a shock to most families. Many parents have never seen, or even heard about, an individual with a cleft. Consequently, parents have many questions about what can be done to help their baby immediately and in the future. The purpose of this booklet is to provide some of these answers and thus help to lessen parental concerns. The information has been prepared for the Cleft Palate Foundation by health care professionals who are members of the American Cleft Palate-Craniofacial Association, and by lay persons who are members of parent-patient support groups. The authors have known many families who have experienced the birth of a child with a cleft, and much of the information in this booklet is based on their interactions with parents. This experience is shared in the hope that it will provide guidance and support to other parents. Parents often say that their concerns are lessened once they develop an understanding of cleft lip and cleft palate.

The information in this booklet, along with that given to you by your own health care providers, will help you understand how best to care for your baby. Information will be presented in the general order in which parents may need to cope with various situations. Parents should realize that this information will be very general. Every child is an individual, and each requires care and treatment specifically designed for his/her particular needs. Some of what you read may not be appropriate for your baby. Likewise, your doctors may recommend a procedure or a plan of treatment that may not be discussed in this booklet. It is impossible to mention all treatment options; therefore, our purpose is to give you an overview of cleft lip and palate. You should discuss the details of your baby's care with your own doctors. Technical terms are defined as they are mentioned. A glossary at the end of the booklet defines certain words you will be reading and probably hearing during discussions with your baby's doctors. Words in the glossary are bolded when they first appear in this booklet.

# Background Information

## Nature of Cleft Lip and Cleft Palate

If you are like most parents, you may be hearing about clefts for the first time, so some explanation may be helpful. In simple terms, a cleft is a separation of the parts of the lip or roof of the mouth which usually come together during the early weeks in the development of an unborn child. A cleft lip is a separation of the two sides of the lip and often includes the bones of the maxilla (upper jaw) and the upper gum (alveolar ridge). It looks as though there is a split in the lip and upper gum.

**Figure 1: The Normal Lip and Nose**

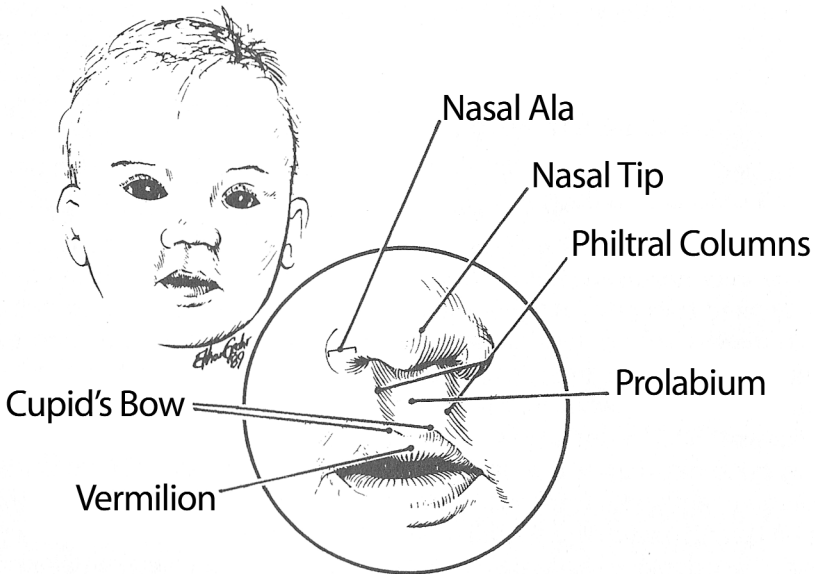
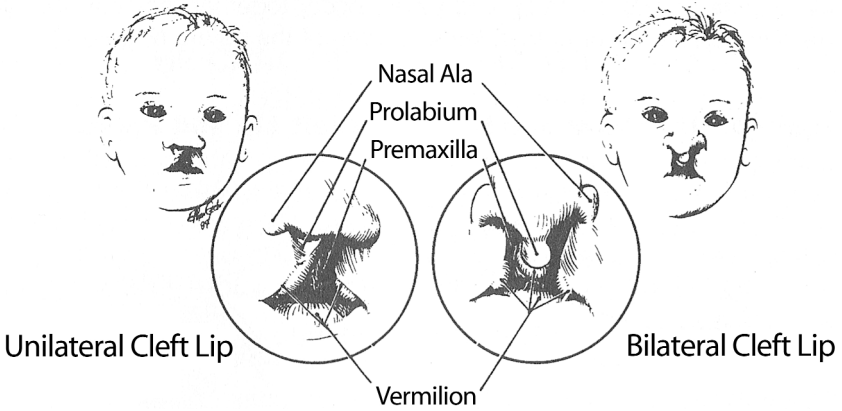


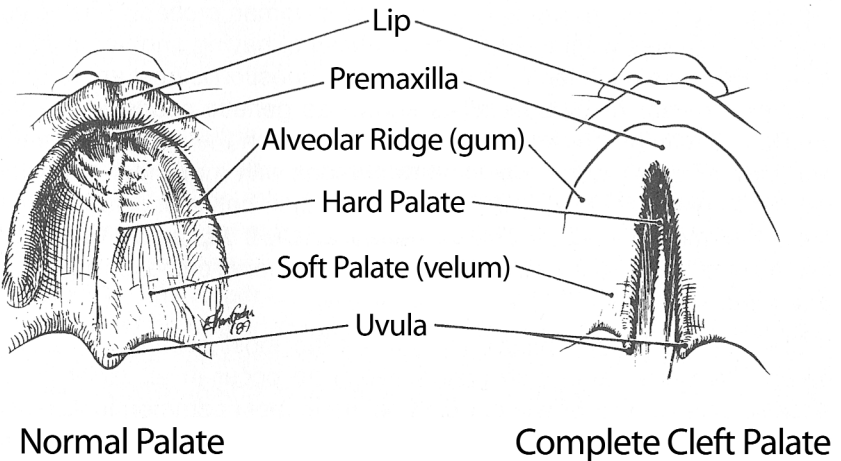
Figure 1 illustrates a normal lip and labels the parts of the lip and the base of the nose. A cleft lip can range from a slight notch in the vermilion (red portion of the lips) to a complete separation of the lip extending into and distorting the tip and side (ala) of the nose. When there is a cleft lip, frequently the alveolar ridge (upper gum) is also separated. As seen in Figure 2, clefts of the lip may occur on one or both sides, with varying degrees of severity. If the cleft occurs on one side, it is called a unilateral cleft lip (Figure 2 left). If the cleft occurs on both sides of the lip, it is called a bilateral cleft lip (Figure 2 right).

**Figure 2: The Cleft Lip and Nose**



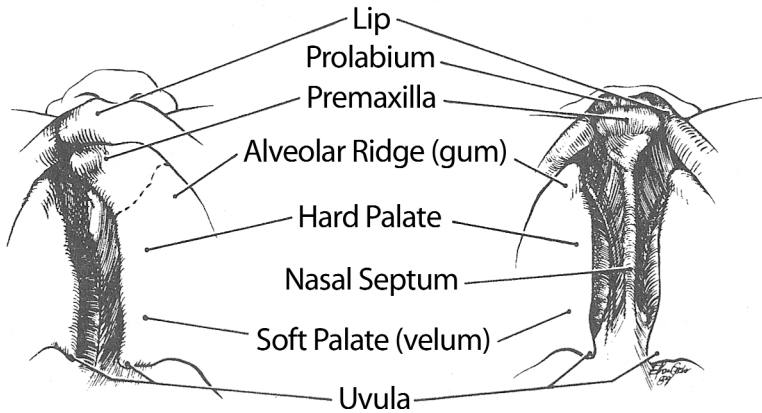
The **palate** is the roof of the mouth. The front part contains bone and is hard (hard palate); the back part does not contain bone and is soft (soft palate). Figure 3 (left) illustrates a normal palate and labels parts of the palate that you may hear discussed. A cleft palate (Figure 3 right) is an opening in the roof of the mouth. A cleft palate does not mean that the palate is “missing” although it may sometimes look that way. It means that the two sides of the palate did not join together (fuse) as the unborn baby was developing. Cleft palates can vary in extent; an incomplete cleft palate involves just the back of the soft palate, while a complete cleft palate extends the length of the palate to just behind the gums (Figure 3 right).

**Figure 3: The Normal Cleft and Palate**



Because the lip and palate develop separately, it is possible for a child to have only a cleft lip, only a cleft palate, or both a cleft lip and cleft palate. When clefts of the lip and palate occur together they can involve one side (unilateral) or both sides (bilateral) of the palate (Figure 4).

**Figure 4: Unilateral and Bilateral Cleft Lip and Palate**



## **Causes and Frequency of Cleft Lip and Cleft Palate**

It is natural for parents to wonder why the cleft occurred and what may have caused it. While many possible causes are being investigated through research, no single cause of cleft lip, cleft palate, or both has been identified. We do know that the majority of clefts appear to be due to a combination of inherited factors (genes) probably interacting with certain “environmental” factors. Clefing occurs very early in a pregnancy and represents a problem over which a pregnant woman probably has no control. Most families want to know the chances of having another child with a cleft. Because each family is different, this question is best answered by your own doctor or by specialists known as genetic counselors. These specialists may be physicians who concentrate on the study of **genetics** and birth defects (dysmorphology) or persons with a masters or doctoral degree in genetics. The Cleft Palate Foundation has a booklet providing more information entitled ***The Genetics of Cleft Lip and Palate***. CPF can also refer you to a cleft palate team where genetic counseling can be arranged.

Clefts of the lip and palate are among the most common of all birth defects. While isolated cleft palate seems to occur in all racial groups equally, cleft lip with or without cleft palate is most common in Asians. It is less common in whites, and least common in blacks. Approximately one out of every 700 to 750 infants born alive in the United States has a cleft lip and/or cleft palate.

# The Care of an Infant Or Young Child With Cleft

The first and primary concern is for your infant to thrive and remain healthy. Your **pediatrician** and other specialists will work with you to insure your infant's good health and development. A baby with a cleft needs the same love and care required by any other baby; however, there are some aspects of care that differ, and these will be discussed.

## **Feeding an Infant with a Cleft**

Infants with an isolated cleft of the lip or a minimal cleft of the soft palate rarely have feeding problems. They can usually be fed like any other infant. However, infants with a cleft of most of the hard and soft palate may have difficulty creating adequate suction on the nipple, because of the opening in the roof of the mouth. All of these infants need proper nourishment and a pleasurable, gratifying feeding experience. For infants with any type of cleft, as for infants without clefts, the two primary choices are breastfeeding and bottle feeding.

While there are differences of opinion about breast feeding an infant with a cleft, health care professionals agree that breast milk is the best food for babies. Breast feeding an infant with a cleft requires adjustments in technique and considerable patience. It may work for a baby with cleft lip but rarely works for a baby with cleft palate. Nursing may need to be facilitated by using a breast pump and then bottle feeding the pumped milk. If a mother chooses to breast feed, her physician or a lactation consultant can help her establish an effective nursing pattern. If these attempts fail, the mother should provide alternate feeding. Prolonged frustration with feeding is not good for the infant's nourishment or mother-infant bonding.

The alternative to breast feeding is bottle feeding. If the mother's milk is not used, a formula with the appropriate nutritional composition will be recommended by the infant's doctor. A variety of nipples and bottles are available for an infant with a cleft. The use of a squeezable bottle and a soft, premature (premie) nipple with an enlarged opening usually works successfully. The larger opening allows the milk to flow more freely. The nipple should be angled away from the cleft, and the infant will feed better if held in a semi-upright position. The infant should be burped frequently because infants with clefts tend to swallow more air than those without clefts.

Although feeding an infant with a cleft may take extra time at first, the time needed for each feeding should steadily decrease. If your infant requires 45 minutes or longer per feeding, he/she may be working too hard and burning up calories required for weight gain. In this case, your physician or feeding consultant should be contacted.

A final word of advice about feeding your baby — be flexible. Try several techniques before you decide which is best. The Cleft Palate Foundation has a booklet called **Feeding An Infant with a Cleft** which provides more detailed information. Remember, whichever method of feeding you use, that method is successful if your baby is receiving adequate nourishment and gaining weight steadily, and if you are comfortable when feeding your baby.

## **Telling Family and Friends about the Baby's Cleft**

At the time of your infant's birth it is sometimes hard to find the right words to explain to others about the cleft. As you learn more about cleft conditions you will find it easier. Professionals and support groups for parents can answer your questions. (See AboutFace on page 20 of this brochure). The better informed your family and friends are, the easier it will be for everyone to see your baby as a normal child with a physical difference which will require **surgery**, dental work, and possibly speech therapy.

Simple, matter-of-fact answers to questions from children or adults about your child's cleft help to establish an attitude of normality toward your child. For example: "He/she was born with a hole in his/her mouth. The process of coming together did not finish in the womb. The doctors will fix it soon," or "He/she was born with a separation in his/her lip, but the doctors will fix it in a few weeks." Children, and even some adults, need reassurance that the "hole" doesn't hurt the baby. Answering questions honestly and openly in front of your child as he/she begins to understand language will help him/her to feel confident.

Taking pictures is usually an important event following the birth of a baby. The cleft is a part of your new baby, and you do not want to deny that fact. The pictures you take do not need to be like the clinical poses the professionals need for their records. You should take pictures of this child just as you would any child. Most children enjoy reviewing their own baby pictures; by taking pictures from infancy onward, you have a means of reviewing with your child his/her stages of development. From the attitude you take, your child will realize that although he/she was born with a cleft, that is only a part of the total person. This approach seems to foster the child's self-awareness and self-esteem.

## **Cleft Lip/Palate-Craniofacial Anomalies Teams**

One of the more important decisions you will make regarding your child's care is the selection of the surgeon who does the initial surgery. Thus, very early in your child's life, you should be aware of Cleft Lip/Palate Teams and **Craniofacial Anomalies** Teams. Such teams consist of groups of specialists who are primarily interested in the care of children who have clefts and other craniofacial anomalies. Most teams include representatives from the following

fields: medicine (pediatrics/genetics, nursing, plastic surgery); speech and hearing (audiology, **otolaryngology, speech-language pathology**); dentistry (**oralmaxillofacial surgery, orthodontics**, pediatric dentistry, **prosthodontics**); and psychosocial (social work, **psychology**, psychiatry). The Cleft Palate Foundation suggests that parents choose a team based upon the experience of both the team as a group and the individual specialists serving on the team. The advantage of the team approach is that the child's treatment and care can be systematically and comprehensively planned. After examining a child, the team members meet together and recommend a program for the child's treatment. The team coordinator then forwards the recommended outline of treatment to the family and also to local doctors and specialists who may also participate in the child's care. Parents can locate teams by asking their local physician or other health care provider, or by contacting the Cleft Palate Foundation.

## **Surgical Repair of the Cleft**

The objective of surgery on the lip is to close the cleft so that scarring will be minimal, the appearance is natural, and the face develops normally. The goal of palate surgery is to close the cleft so that the palate can function normally during eating, drinking, and speaking. There are variations in both the timing and the technique of surgical repair from surgeon to surgeon and team to team. It is important that you are comfortable with your baby's surgeon and feel confident about his/her skills, experience, and credentials. Ask lots of questions!

**Lip Repair:** Surgical closure of the lip usually occurs after the baby has demonstrated steady weight gain, has been screened for other health problems, and is not at unusual anesthetic risk. The repair may be accomplished in one procedure, but sometimes it is done in two stages. Lip surgery sometimes requires a hospital stay of one or two days to allow the baby time to begin drinking sufficient liquids so that intravenous fluids can be stopped. In some cases, the operation may be performed on an out-patient basis. After surgery, the baby's hands may be restrained with stiff material to keep them away from the mouth and lips. Postoperative care will be discussed by your surgeon and/or nurse. The lip scar will begin to look paler and more flexible within several months, although it will always be visible.

**Palate Repair:** The palate is usually closed between eight and eighteen months of age, but closure may be done earlier or later in life depending on a variety of factors. Palatal surgery usually involves a hospital stay of one to three days. Occasionally, a blood transfusion is necessary during palatal surgery. Ask your surgeon how to plan for a safe transfusion, should it be necessary. Sometimes a child will be fitted with an acrylic (plastic), removable palatal appliance to be worn between various surgical procedures.

Once again you will need to use special care in feeding your baby. Foods need to be liquified, and the baby may need to drink from a cup for a few weeks. Therefore, if your baby still drinks exclusively from a bottle, it is helpful to familiarize him/her with drinking from a cup before surgery. As with lip repair, the baby's hands are usually restrained for a week after surgery. These changes do not seem to upset most babies for the brief time they are necessary. The doctors and nurses on the team will discuss postoperative care in detail with you.

Before your baby is admitted to the hospital, there are a number of details you will need to handle, including arrangements for accommodations and meals, care of your other children, and the routine for your baby's care. You will need to check what the hospital provides in terms of diapers, formula, etc., and what you need to bring from home. It is often helpful to bring the baby's "security blanket" or favorite toy.

Additional surgery will very likely be necessary as your child grows and matures. Some of the areas which often require further surgery are the lip, nose, gum, and palate. More information about operations in the older child can be found in the Cleft Palate Foundation's publications on the school-aged child and the teenager.

## Care of the Ears

Children with clefts of the palate have an increased risk of having ear infections. These problems are the result of inadequate function of some of the palatal muscles, which open the **Eustachian tubes** (small tubes connecting the throat to the **middle ear**). When the Eustachian tubes do not open effectively, air cannot enter the middle ear. This lack of ventilation causes fluid to form and eventually accumulate in the middle ear. This condition is called **otitis media**. The fluid can then become infected, causing the child to experience a fever and painful earache (acute otitis media).

Because of the frequency of this problem, children with clefts of the palate should have their ears examined by their primary care physician or an otolaryngologist (an ear, nose, and throat or "ENT" specialist) within the first few weeks of life. If fluid is present in the middle ear, medication may be prescribed to "dry up" the fluid. If the fluid persists, and especially if there is a hearing loss, or if the infant has multiple ear infections requiring antibiotics, a minor surgical procedure called a **myringotomy** may be scheduled. This procedure consists of making a small slit in the **eardrum** to drain the fluid. Following drainage, tiny tubes may be inserted (Pressure Equalization or PE tubes) in the slits to allow air to enter the middle ear and prevent fluid from reforming. Once the tubes are out, these small slits heal readily and do not usually result in any permanent damage to the eardrum. This operation, "myringotomy and tubes," is usually performed when the child is under anesthesia for lip and/or palate surgery.

Parents need to realize that fluid in the middle ears does not always result in symptoms like earaches that are easy to detect. However, constant fluid in the middle ear creates a risk that the ear drum may be permanently deformed. In addition, children with persistent middle ear disease are more likely to have some loss of hearing which adversely affects speech development. Consequently, children with clefts of the palate should have frequent ear examinations. The first one should be scheduled no later than one month after birth. Thereafter, the child should be reexamined on a routine basis.

## Hearing Testing

Because of problems with ear infections, children with clefts of the palate may experience some hearing loss which changes over time. Consequently, it is important that parents make sure that their child's hearing is tested regularly during his/her early years. Preferably this testing should be done by an **audiologist** who has the specialized training and audiometric equipment to test very young children.

Parents often wonder how babies and very young children can have their hearing tested. Audiologists have a variety of techniques for testing the hearing of babies, even newborns. These same tests can be used with infants and toddlers until they are mature enough to participate in other types of tests. For these children, a test called ABR (Auditory Brainstem Response) can evaluate the brain's response to sound for each ear. If a baby should fail the initial ABR screening, then a longer, full ABR test can be conducted. Results of this test can determine if a hearing loss is present. Depending on how the test is done, results may indicate whether the problem is in the middle ear or the inner ear.

Once a baby is between 4 and 7 months of age, testing called behavioral audiometry can be done. In this test, the baby is placed in a quiet, sound-treated room with the parent. Sounds are fed into the room through speakers, and the baby's response to sound is observed by the audiologist. Responses like turning toward the source of the sound (localization) make it obvious when the baby hears the sound. Some audiologists also utilize toys that light up when the baby localizes the sound correctly; this technique is also very effective. Once the baby is several months of age, a test called impedance audiometry is very valuable. This test can measure whether the ear drum is mobile. If the ear drum cannot move, there may be fluid in the middle ear space behind the ear drum.

When a child reaches 2 1/2 to 3 years of age, a technique called play audiometry can be used. In this test the child wears earphones and is trained to do something whenever a sound is heard. For example, the child might drop a block into a container whenever he/she hears a sound. By the age of 4 1/2 to 5 years, children can respond to the tests routinely utilized with adults.

A young child who experiences some degree of hearing loss is at risk for other problems. A hearing loss may cause problems with speech and language development. In addition, a loss in hearing may result in a habit of inattention which could lead to future language or learning problems. This is why frequent hearing checks are important for young children with clefts of the palate.

## Speech Development

The parents of an infant with a cleft often ask how well their baby will talk. Speech-language pathologists have studied the speech development of many children with clefts, and their findings may be used as a guide. If a child has an isolated cleft of the lip, and no other problems, then speech should be normal or close to normal. Approximately 80% of children with a cleft of the palate develop normal speech once their palates are closed. Many of these children will require speech therapy to achieve the best speech. The others may require further surgery, or a **prosthetic speech aid** in addition to speech therapy, to improve their speech. A major goal of palatal surgery is to ensure good speech quality at the earliest age. The speech-language pathologist may consult with the surgeon and other specialists in planning the type of palatal surgery and the best age to schedule the surgery.

Children with clefts of the palate tend to develop speech and language a bit more slowly than other children. They may not sound normal before palatal surgery is performed, but they tend to “catch up” afterward. This “catch-up” process often continues for four or five years, and speech therapy may be necessary during some of these years. Children with clefts are also at increased risk for some type of **language disorder**. For these reasons periodic **evaluation** by a speech-language pathologist knowledgeable about cleft lip and palate is important. The first evaluation should be scheduled by 3 to 6 months of age with follow-up testing scheduled every 6 to 12 months during the first three to four years.

Parents sometimes wonder how a baby’s speech and language can be evaluated before the infant even begins to speak. From birth onward, babies follow a well-documented course of speech and language development. The sucking, blowing, and chewing activities that all babies engage in involve the oral muscles eventually used to speak, and the proficiency of these activities can be charted. Months before babies say their first words, they already make many cooing and babbling sounds, and they can communicate a variety of things to their parents and caretakers. The rate and order of this development can be recorded. Once the child begins to talk, the individual speech sounds and the words the child understands and uses can be measured and compared to norms. Use of these developmental milestones allows speech-language pathologists to recognize problems that may require intervention before the child begins school.

Parents have a crucial role to play in their child’s speech development. We know that the interactions between parents and their small children are interdependent: each influences and is influenced by the other. One easy way to stimu-

late a child's speech development is for the parent to follow the child's lead. When the baby makes a sound, the parent can imitate that sound, then wait for the child to respond (count to ten silently) before repeating the sound. Once this "game" is established, the parent may change the sound and see if the child will follow the parent's lead. When a child is imitating sounds, words usually follow. Enrollment in either a "Parents as Teachers" or "Birth to Three" program can help parents learn how to stimulate their infant.

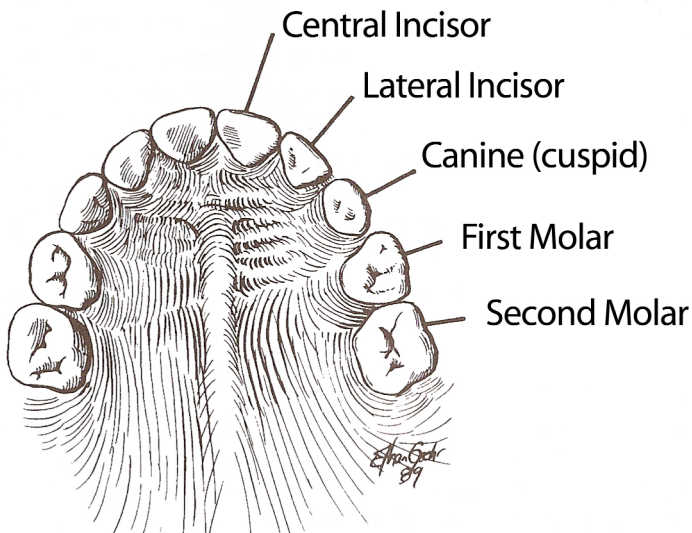
Parents need to interact with their child with a cleft just as they would with any child who is learning to talk. Encourage and respond to the child's intended meaning even if these first words sound different or have a nasal quality. Parents who talk with their child about what is happening, play nursery games with them, and read to them are providing good speech and language stimulation.

A final question parents have is whether speech therapy is always necessary. Some children may need to be involved with their parents in a program of speech and language stimulation, others may need therapy during the "catch up" period, while still others may not require any therapy during the preschool years. However, all children need to be evaluated routinely to determine their individual need.

## Dental Care

Children with clefts of the lip and palate need the same dental care as children without clefts. Parents should wipe the first erupted teeth with a damp washcloth after each feeding and begin routine brushing after solid foods are regularly eaten. Routine dental care with a pediatric or family dentist usually

**Figure 5: Primary Teeth**



begins at three years of age. Children with clefts may also have special dental problems associated with the cleft. A cleft may affect the alveolar ridge (upper gum containing the teeth). Consequently, some teeth may be incorrectly shaped, out of correct position, or entirely missing. There may even be extra teeth. The teeth most commonly affected are the upper incisors and cuspids on the side of the cleft (see Figure 5).

The dental treatment of children with clefts may best be coordinated among several dental specialists interacting on a team that begins to follow the baby at birth. The dental specialties may include pediatric dentistry, orthodontics, oral-maxillofacial surgery, and prosthodontics. These specialists are all concerned with the size and shape of the jaws, the position of the teeth within the jaws, and the prevention of decay. To assist in planning treatment for the child with a cleft, comprehensive dental records may need to be created. These records include impressions of the upper and lower teeth, x-rays, and photographs.

The pediatric dentist is trained to care for the special dental needs of the child. These needs may include fillings, cleanings, space maintenance, and all other types of routine care.

Special dental appliances (protheses) may be fitted in the mouths of some infants with cleft palates to assist them in feeding or to control the shape of the upper jaw. At later ages, obturators (speech appliances) may be used to close palatal openings and to provide assistance in obtaining better speech. A prosthodontic specialist generally places these appliances in consultation with other specialists on the team.

The orthodontist and the oral-maxillofacial surgeon usually are not involved in the care of the young child with a cleft. Their roles in cleft care are discussed in the Cleft Palate Foundation's publications on the school-aged child, the adolescent, and the adult.

## **Psychological Aspects**

Clinical psychologists and other mental health professionals serve on some cleft palate-craniofacial teams. Sometimes parents feel that seeing a mental health professional means there is something seriously "wrong" with them or with their child. This is not true. Most people need some help adjusting to having or being a child with a birth defect. The mental health professional is on the team to provide that help. Some teams routinely provide clinic services from a mental health professional. These services usually include an interview to help identify concerns or problems. Other teams may provide the services only when they are requested.

Parents, children, or both may need the help of a mental health professional. Parents can experience shock, anger, guilt, depression, and confusion following the

birth of an infant with a cleft. They may also have to deal with the stresses of hospitalizing their child for surgery, coping with financial strains, and juggling child care and work schedules. Brothers and sisters of the child with a cleft may have mixed feelings about this new family member. Parents may be faced with new problems involving child management and discipline. The team mental health professional can assist parents in coping with these new problems of living.

Children with clefts may have adjustment problems of a psychological nature starting as young as two years of age. They may have concerns about the way other people react to their speech or appearance. Psychologists can provide guidance to help children develop their self-confidence and deal appropriately with teasing. By three years of age, children can learn to answer simple questions about their appearance or speech. They can say, "I was born with a split here (pointing). The doctor fixed it," or "My mama says I'll talk better soon." Children ages two to four can also experience fears about the hospital and surgery. They may cry and get upset when they have to go to the hospital. Sometimes children try to cope with these problems by acting shy or avoiding people. Other times they may become more dependent on their parents or act immature for their age. Parents can help their children with these problems by requesting play therapy for the child or counseling education for themselves.

The clinical psychologist also participates with other team members in assessing the child's overall level of development. This information is especially important when parents are planning for school placement. Being able to perform successfully in school immediately increases a child's self-esteem.

A cleft lip and/or palate poses several expected adjustment problems for both the child with a cleft and his/her family. The role of the psychologist or mental health professional is to assist the child and the family in coping with these problems.

## **Preschool Education**

Services for children with special needs and for their parents are expanding and improving within the educational system. In 1986 Public Law 99-457 was signed, requiring that special educational services be provided for children from birth to three years of age with identifiable disabilities. Your state education department has a system in place to meet the requirements of the law. You may contact your governor's office to obtain more specific information regarding the implementation of PL 99457 in your state.

The services that may be provided by the public schools include an assessment and a written Individualized Family Service Plan (IFSP) developed by a multidisciplinary team and the parents. Case management services must be provided for the child and parents. Special educational services may include: special education, speech-language pathology, audiology, psychological services, parent training, and medical services for diagnostic purposes and early intervention.

Even if children with clefts may not require the specialized services mandated by PL 99-457, parents still wonder about part-time or full-time preschool. For all children, the preschool experience presents many advantages and perhaps some disadvantages that parents should consider. However, the advantages and disadvantages relate more to the type of preschool chosen than to the concept of preschool in general. In order for a preschool experience to be good for any child, the teachers, aides, and other caregivers must be caring people who understand child development. Preschools should capitalize on the fact that young children learn through play. They need to have pleasurable, exciting, first-hand experiences with peers, materials, and adults. They need time to explore, reflect, share, listen, and discover. The preschool experience gives children the opportunity to relate to adults outside of the home and become a part of a group with a daily routine. The child can experience a feeling of being “special” outside of the family and look forward to going to a place where people are waiting and excited to see him/her. When all of this is present, the advantages of a preschool can be tremendous.

The preschool experience provides some advantages for the parents as well as the child. Parents can observe their child in a group of other children and can see not only how their child interacts but also how other children of the same age function. Parents can observe other adults relating to their child, and they can get advice from professionals trained to understand preschool children. Also, preschool gives parents a time to get other work accomplished or have individual time with other children in the family who may be feeling “left out” because of the attention focused on the child with a cleft. Knowing their child is in a good preschool can allow both parents to work without feeling that they are cheating their child.

Before enrolling your child in any preschool, check the school thoroughly. Make certain the atmosphere and activities will be pleasurable and enriching for your child. Meet and find out about the teachers and other caregivers who will actually interact with your child. Are these persons interested in understanding your child, and do they appear excited about the possibility of having him/her as a student? Do the other children appear relaxed and happy in their play in contrast to the rigid classrooms where preschoolers are expected to behave like children in grade school? Do other parents appear satisfied with the preschool? If these answers are positive, then enroll your child on a trial basis. When you find the right preschool, this experience can foster the development of good communication skills, socialization with peers, and learning through play.

# Sources of Support for Parents

## **Parent/Patient Support Groups**

Many parents who have a baby with a cleft lip and/or cleft palate feel isolated and alone. They often say that it is very helpful to be able to talk to other parents of children with clefts. In many parts of the country there are local parent/patient support groups. These are organizations of affected individuals and their families who meet to share common concerns and ideas. These groups often prove to be a continuing source of support for the individuals involved. AboutFace is one such organization with local chapters throughout the United States and Canada (see page 20 of this brochure for more information). Members of your local cleft palate team, your local health care providers, or the Cleft Palate Foundation can put you in touch with AboutFace chapters and other parent/patient support groups in your region.

## **Funding for Treatment**

Financial resources to help pay all or part of the costs of treating a child with cleft lip and/or palate fall into three general categories. Your own private or group health insurance will usually cover a portion of the cost of treatment after a certain deductible is met. When buying future insurance be sure to check if the coverage applies only to surgery or if it also includes such crucial aspects as dental care and services such as hearing testing, speech and language testing and treatment, and psychological testing and/or counseling. There are also federal and state programs such as Champus, Medicaid, and Children's Special Health Services (formerly called the Crippled Children's Program). Some private and nonprofit agencies provide funds or special services to meet some needs of children with clefts. Your social worker or team coordinator should be able to provide you with information regarding financial aid in your area.

If a private insurance company initially rejects payment for cleft services, you should discuss the case with the company. If the bill was rejected because the reviewers did not understand the problem of clefting and the habilitation procedures required, such a discussion could result in the company paying the bill. You should contact your cleft palate-craniofacial team coordinator or your physician to assist you in the appeal process.

## **Mental Health Professionals**

As the parent of a child with a cleft lip, cleft palate, or both, you already understand the shock of being told that your child has a birth defect that will require treatment, possibly over a period of years. In addition you must still make all the adjustments required of any new parent. The first step in coping successfully is learning to acknowledge and accept the unfamiliar and painful feelings that may seem overwhelming during the first few years. These feelings are not unusual and will not go away unless you learn to deal with them. Parents need to take time during the first year to begin to learn acceptance and to give their feelings a chance to surface and heal.

Initially parents may seek comfort and support from their family and friends. They can also speak to other parents who have children with clefts. Knowing that someone else has faced what you are facing is often both informative and comforting. However, if the emotional pain is not reduced after the first six months of your child's life, or if it significantly interferes with your ability to function at home, at work, or in your relationships, you may want to speak to a qualified mental health professional. Your cleft palate-craniofacial team or your physician may be able to recommend someone. If paying for such help is a problem, then the team coordinator or your physician may be able to refer you to a mental health facility that accepts fee reductions or third party payments. The emotional health of the parents is essential to their ability to help their child.

# Glossary

**ALVEOLAR RIDGE** – The bony ridge of the maxilla and mandible containing the teeth (see Figure 3, page 5).

**ARTICULATION** – The process of forming speech sounds.

**ARTICULATION TEST** – An evaluation which provides information about how speech sounds are formed.

**AUDIOGRAM** – A record of hearing levels or sensitivity.

**AUDIOLOGIST** – A person with a degree, license, and certification in audiology (science of hearing) who measures hearing, identifies hearing loss, and participates in rehabilitation of hearing impairment.

**COLUMELLA** – The central, lower portion of the nose which divides the nostrils into right and left.

**COMMUNICATION DISORDER** – An interference with a person's ability to comprehend others or express themselves (usually in verbal form).

**COMPREHENSION** – Knowledge or understanding of spoken or written language.

**CONGENITAL** – A disease, deformity, or deficiency existing at the time of birth.

**CRANIOFACIAL ANOMALY** – A visible, structural and/or functional difference affecting the head (cranium) and/or face.

**CROSSBITE** – A dental condition where the upper teeth are behind the lower teeth rather than in front of them.

**DENASALITY** – The quality of voice that lacks normal nasal resonance for /m /n/ ng (“head cold” sound).

**DENTAL ARCH** – The curved shape formed by the teeth in their normal position.

**EARDRUM** – Tympanic membrane which vibrates and transmits sound to the middle ear.

**E.N.T.** – The abbreviation for ear, nose, and throat.

**EUSTACHIAN TUBE** – The air duct which connects the nasopharynx (back of the throat) with the middle ear; usually closed at one end, opens with yawning and swallowing; allows ventilation of the middle ear cavity and equalization of pressure on two sides of the eardrum.

**EVALUATION** – Assessment. Test.

**EXPRESSIVE LANGUAGE** – Communication of one’s ideas, desires, or intentions to others, usually through speech or printed words.

**FISTULA** – An abnormal opening.

**GENETICS** – The science of heredity (how things pass from one generation to the next).

**HARD PALATE** – The front part of the roof of the mouth containing bone covered by mucosa (pink “skin”).

**HEARING IMPAIRMENT** – A loss in hearing which may range from mild loss to complete deafness.

**HEREDITY** – The total of the physical characteristics, abilities, and potentialities genetically derived from one’s ancestors.

**HYPERNASALITY** – Greater than normal nasal resonance or vocal tone heard during speech (escape of sound or noise through the nose).

**HYPONASALITY** – Denasal. A lack of normal nasal resonance during speech.

**LANGUAGE DISORDER or IMPAIRMENT** – Inability to communicate normally and effectively due to problems with comprehension or expression of language.

**MALOCCLUSION** – A deviation from normal occlusion, that is, incorrect positioning of the upper teeth in relation to the lower teeth.

**MANDIBLE** – The lower jaw.

**MAXILLA** – The upper jaw.

**MIDDLE EAR** – The portion of the ear behind the eardrum. It contains three small bones which transfer sound from the eardrum to the inner ear.

**MYRINGOTOMY** – A minor surgical procedure in which a small slit is made in the eardrum to allow fluid to drain from the middle ear.

**NASAL EMISSION or NASAL ESCAPE** – An abnormal flow of air through the nose during speech. Usually indicative of an incomplete seal between oral and nasal cavities.

**NASAL SEPTUM** – The “wall” that divides the nose into right and left halves. It normally joins the roof of the hard palate like an “inverted T”.

**NASOPHARYNGOSCOPE** – A lighted telescopic instrument used for examining the passages in the back of the throat. Useful in assessing velopharyngeal function.

**OCCCLUSION** – Relationship between upper and lower teeth when they are in contact. Refers to the alignment of teeth as well as relationship of dental arches.

**ORAL CAVITY** – The mouth bounded by the teeth in front and the soft palate at the back.

**ORAL-MAXILLOFACIAL SURGERY** – The specialty of dentistry concerned with management of dental and skeletal deformities.

**OROFACIAL** – Relating to the mouth and face.

**ORTHODONTICS** – The specialty of dentistry concerned with the correction and prevention of irregularities and malocclusion of the teeth and jaws.

**OTITIS MEDIA** – Inflammation of the middle ear with accumulation of thick, mucous-like fluid.

**OTOLARYNGOLOGIST** – An “ear, nose and throat” physician specializing in the diagnosis and management of head and neck disorders.

**PALATAL INSUFFICIENCY** – A lack or shortness of tissue that prevents the soft palate from contacting the back of the throat (pharynx).

**PALATE** – The roof of the mouth including the front portion, or hard palate, and the back portion, or soft palate (also called the velum).

**PEDIATRICIAN** – A physician specializing in treatment of children.

**PEDIATRIC DENTISTRY** – The specialty of dentistry concerned with the care of children’s teeth.

**PHILTRAL COLUMNS** – Normal ridges in the skin of the central upper lip connecting the peaks of the Cupid’s bow to the back of the nose.

**PREMAXILLA** – The small bone in the upper jaw which contains the upper four front teeth. Normally connected with the side segments of the upper jaw (maxilla) but separated in some clefts.

**PROLABIUM** – The central area of the upper lip beneath the center of the nose (columella) and between the philtral columns.

**PROSTHESIS** – An artificial substitute for a missing body part.

**PROSTHETIC SPEECH AID** – A removable plastic appliance which provides a structural means of achieving velopharyngeal closure (separating the nose from the mouth).

**PROSTHODONTIST** – A dentist who specializes in providing prosthetic appliances for oral structures.

**PSYCHOLOGIST** – An individual with the necessary academic training and experience to be licensed to practice psychology as a profession.

**RADIOGRAPHY** – Photographic film or plate depicting images of internal body parts. X-ray.

**RESONANCE** – Vocal quality associated with the vibration of air in the oral and nasal cavities.

**SOFT PALATE** – The back part of the roof of the mouth containing muscles and mucosa (pink “skin”). The Latin name for the soft palate is velum.

**SPEECH-LANGUAGE PATHOLOGIST** – An individual with the necessary academic training and experience to be certified or licensed to diagnose and treat disorders of speech, language, and communication.

**SPEECH DEFECT** – Deviation of speech from the range of normal.

**SPEECH VIDEOFLUOROSCOPY** – A tape recorded x-ray examination of the speech mechanism during function, focusing on the soft palate (velum) and walls of the throat (pharynx). Useful in assessing velopharyngeal function.

**SURGERY** – One of several medical specialties focused on the restoration and repair of various external defects.

**UVULA** – Small, cone-shaped muscular process hanging at the back of the soft palate.

**VELOPHARYNGEAL CLOSURE** – The closing of the nasal cavity from the oral cavity which directs air used in speech through the mouth rather than the nose. It requires interaction of the muscles in the palate and the back of the throat.

**VELOPHARYNGEAL INCOMPETENCE** – Inability to achieve adequate velopharyngeal closure despite structures that may appear normal.

**VELOPHARYNGEAL INSUFFICIENCY** – A structural or functional disorder resulting in the inability to achieve adequate separation of the nasal and oral cavities.

**VELUM** – The Latin name for the soft palate.

## Closing Words: Parent to Parent

As a parent of a child with a cleft lip and palate and as a past president of a cleft palate parents' society, I have learned much about clefts. Still I cannot offer "words of wisdom" or absolute truths. However, from the depths of my heart I can share my thoughts on your child with a cleft. Be strong, for it is from you that your child will draw strength. Be knowledgeable about cleft procedures and new medical advances so you and your doctors can decide and design a program for your child in a relationship of respect and trust. Share your experiences with others. You will find that you are not alone and discussions spawn solutions to problems that we all share.

Most importantly, you will direct your child's future. Make sure your child is given all possible programs of development starting at birth so that by school age he/she has progressed naturally into the mainstream. These programs are available through the state and through school districts, but you as a parent must make them work for your child. You must instill self-esteem and project a bright future for your child. Learn by your mistakes, and strive for the best medical and educational resources for your child.

Above all else, be kind and patient with yourself. While the birth of a child with a cleft seems very overwhelming in the beginning, the experience of countless parents testifies that this fact will not continue to dominate your life. You will begin to see beyond the cleft to the love, the sense of fun and mischief, the wonder and sensitivity, and all the traits that define the unique character of your child. You will begin to appreciate that you can have the same hopes and dreams for your child born with a cleft as for any other child.

## For More Information:

*Las publicaciones de la Fundación del Paladar Hendido también se ofrecen en español. Favor de llamarnos para recibir copias en español.*

This publication and many others have been produced by:

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The Cleft Palate Foundation (CPF) maintains a growing collection of booklets and factsheets that present an in-depth introduction to and explanation of many elements of craniofacial care and treatment. All publications are authored and regularly revised by representatives of professional disciplines serving the work of craniofacial care and treatment.

A publications order form for institutions including current pricing, bulk order rates and shipping and handling fees may be accessed at the CPF website or by calling 1.800.242.5338. All fact sheets are available at the website as open-access, PDF documents. Families, patients, students and other individuals may request complimentary packets of publications by emailing [info@cleftline.org](mailto:info@cleftline.org) or by calling 1.800.242.5338.

To date, the Cleft Palate Foundation has shared over 7,000 Gund Teddy Bears with repaired cleft lips with children and families all over the world. Please visit [www.cleftline.org](http://www.cleftline.org) or call 1.800.242.5338 for more information about our bears.

If you are interested in helping us continue in our mission, please contribute to the CPF Cleftline Fund. Visit [www.cleftline.org](http://www.cleftline.org) or call 1.800.24.CLEFT to make your donation today! Thank you.



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