



YOUR BABY'S FIRST YEAR

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Edited by members of the 2010 CPF Publications Committee

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FOREWORD

Anticipating the birth of a child is an exciting experience. However, for most expectant parents, feelings of anticipation and joy are mixed with some nervousness and concern about the huge responsibility that lies ahead.



The prenatal diagnosis or birth of an infant with a cleft lip and/or cleft palate comes as a surprise to many families. This often adds to the wide range of emotions you will experience regarding the arrival of your new baby. Many parents have never seen an individual with a cleft and they may have lots of questions about what this condition means for their child and their family.

The purpose of this booklet is to share general information that will help answer many common questions regarding cleft lip and cleft palate. It also provides advice, reassurance, and encouragement to parents and caregivers of infants with clefts.

This booklet has been prepared for the Cleft Palate Foundation (CPF) by healthcare professionals who are members of the American Cleft Palate-Craniofacial Association (ACPA) and by parents and patients who have experienced the physical and emotional concerns of cleft care first hand.

Technical terms are defined as they are mentioned. A **glossary** is presented in Appendix A, and all words in the glossary are bolded on their first reference.

Please keep in mind that every child requires care and treatment specifically designed for his or her particular needs. This booklet presents information in the order families typically face various situations. Not every piece of information will be relevant to every child's individual circumstances. Your baby's **cleft/craniofacial treatment team** (referred to as "team") may recommend a procedure or a plan of treatment that is not included in this booklet. You should always discuss the details of your baby's individual care with your team.

The content of this publication is provided solely for educational purposes. It is not a substitute for medical advice provided by a physician. It is intended for use by parents, caregivers, and nurses caring for infants

with cleft lip and/or cleft palate, not for those who are caring for infants with more complicated craniofacial conditions. The content does not represent the only, nor necessarily the best, information for your infant's situation. Consult with your treating physician before proceeding to use any of the information presented in this booklet.

OVERVIEW OF CLEFT LIP AND CLEFT PALATE

Please refer to Appendix B: Descriptions and Illustrations

In simple terms, a cleft is a separation of the parts of the lip or roof of the mouth that results when they fail to join during the early weeks of prenatal development (from week 5 to week 12 of the pregnancy). Babies may be born with a cleft lip, a cleft palate, or both.

A cleft lip is a separation of the two sides of the lip and often includes the bones of the upper jaw (**maxilla**) and upper gum (**alveolar ridge**), resulting in what looks like a split in the lip and upper gum. A cleft palate is an opening in the roof of the mouth. The presence of 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 fuse, or join together, in the developing fetus.

CAUSES OF CLEFTS

Clefts of the lip and palate are among the most common of all birth defects. Approximately one of every 600 newborns in the United States has a cleft lip and/or cleft palate. While cleft palates seems to occur in all racial groups equally, cleft lip with or without cleft palate is most common in families with Asian ancestry, and it is very rare in families with African ancestry.

Many possible causes are being investigated through research, but no single cause of cleft lip and/or cleft palate has been identified. We do know that the majority of clefts appear to be due to a combination of inherited factors (genes) interacting with certain environmental factors. The development of a cleft occurs very early in pregnancy and represents a problem over which a pregnant woman likely has no control.

Some parents want to learn more about the likelihood of having another child with a cleft. Because each family is different, this question is best addressed 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 (CPF) publishes a booklet providing more information on this topic entitled *Genetics and You*. CPF can also refer you to a cleft palate team that can arrange genetic counseling.

SHARING THE NEWS WITH FAMILY AND FRIENDS

Many parents struggle with sharing the news of their child's cleft with extended family and friends. As you learn more about clefts and cleft care, you will have more information to pass along to others. The better informed your family and friends, the easier it will be for everyone to see your baby as a healthy, typical child with a physical difference.

Your comfort with answering questions about the cleft will help set the tone for family, friends, and most importantly, your child. Simple, matter-of-fact answers to questions from children or adults are most useful. For example: "He was born with a cleft, a kind of hole in his mouth. The doctors will fix it soon," or "She was born with a separation in her lip, but the doctors will fix it in a few weeks." Children, and even some adults, often need reassurance that the cleft does not hurt the baby. Answering questions honestly and openly in front of your child helps nurture confidence. It also serves an important model for how your child may respond to questions from peers, teachers, and others who will be interested in the cleft throughout childhood and adolescence.

Families often enjoy photographing their new babies. Just like blue eyes or chubby cheeks, the cleft is part of your baby's unique individuality, and it should not prevent you from taking photos of your baby and your family. Children love to look at their own baby pictures and to hear stories about their birth, family visits, favorite toys, and other details that let them know they were special from the very first moment. By taking photographs from infancy onward, you have a means of reviewing with your child all the stages of development. Taking cues from your attitude, your child will realize that the cleft is only a part of who he or she is as a person. This approach will help foster the child's self-awareness and self-esteem.

CARING FOR A BABY WITH A CLEFT

Just like any other parent, your first and primary concern is for your infant to thrive and remain healthy. A baby with a cleft needs the same love, care, and attention as any other child, and your pediatrician and other specialists will work with you to ensure your infant's good health

and development. You can't spoil your new baby with too much love and attention, so be sure to spend plenty of time each day cuddling, cooing, playing, and interacting with your bundle of joy.

While caring for an infant with a cleft is the same as taking care of other babies in many respects, your child may require special assistance with some of his or her daily needs. Cleft lips and/or palates are generally repaired through surgery early in a child's life. Although treatment plans vary depending on a baby's individual needs, your child may need extra care both before and after surgery. More information regarding these surgical procedures is contained later in this booklet.

FEEDING

You should check with your child's doctor about feeding during the first year. The American Academy of Pediatrics recommends that babies stay on breast milk or formula until their first birthday, and solid foods should generally not be introduced until six months of age.

Babies born with a cleft lip-only are generally able to breast- or bottle- feed just like other infants. In most cases, babies born with a cleft palate are not able to create the suction needed to pull milk from a nipple and will need special bottles to ensure the adequate flow of breast milk or formula. For information regarding bottle- and breast- feeding, please see our CPF booklet and video series, *Feeding Your Baby*.

An infant born with a cleft lip and/or palate should be ready to eat solid foods at the same time as any other baby. Foods should be offered by spoon while the infant is in an upright position. Start with a thin mixture of cereal and formula/breast milk. As your baby gets used to the texture, the consistency of the cereal can be thickened.

Initially, your baby may sneeze the food out of his or her nose or you may see milk or food coming out of the nose. Eventually this new way of eating will become familiar and your child will adapt accordingly. You may need to wipe around your child's nose and mouth with a moist cloth to remove any excess food.

As always, it is important to establish a relationship with your primary care provider that is based on trust and a mutual sharing of information. That person should be your first contact when questions or concerns arise regarding poor weight gain, the transition to solid foods, any needed adjustments in formula, and the interpretation of information provided by other specialists.

DRINKING FROM A CUP

Babies with a cleft should also be able to use a cup at the same time as other infants. Most babies are ready to try a cup around eight to nine months of age. Many types of cups are available and you may want to try several, as your baby may drink better from one style of cup than another. It may also be helpful to establish cup drinking prior to palate repair, since many surgeons do not recommend an immediate return to bottle-feeding following this surgery. Babies should be drinking exclusively from a cup (not a bottle) by 12 months of age.

CLEFT TREATMENT AND REPAIR

Cleft treatment and repair will start early in your child's life to help ensure both good health and normal development. Treatment of your child's cleft may include a wide variety of measures such as surgery, dental work, and speech therapy. As mentioned previously in this booklet, it is important to talk to your child's team regarding an individualized treatment plan that will best meet his or her unique needs.

SELECTING A TEAM

One of the first and most important decisions you will make is the selection of the team of professionals who will help you manage your child's cleft care.

Most teams include professionals from the following fields (*for more information on the specialties, please refer to Appendix A: Glossary*):

Dentistry

oral-maxillofacial surgery, orthodontics, pediatric dentistry, prosthodontics

Medicine

genetics, nursing, otolaryngology (ENT—ear, nose and throat), pediatrics, plastic surgery

Psychosocial

psychiatry, psychology, social work

Speech and Hearing

audiology, speech-language pathology

CPF suggests that parents choose a team based on both its experience as a whole and the capabilities of the individual specialists serving on the team. After an initial consult and examination of the child, the

team will organize a long-term, comprehensive treatment plan. You can locate teams by contacting CPF or by asking your local physician or other healthcare provider.

You are an important member of the team, and should maintain close communication with them to express your child's needs and address individual concerns. Any plan of treatment or surgical procedure requires parental consent, and your input is vital to ensuring that your child receives the best possible care. Always be prepared to ask questions or request additional information and resources. *Please refer to Appendix C: Recommended Questions for the Team.*



SURGICAL REPAIR OF THE CLEFT

In many cases, your child's cleft lip and/or cleft palate will be corrected through surgery within the first year of life. The goal of lip surgery is to close the cleft with minimal scarring to create a natural appearance and ensure typical development of the face. The goal of palate surgery is to close the cleft so that the palate can function fully during eating, drinking, and speaking.

Both the timing and the technique of surgical repair can vary, and it is important that you are comfortable with your baby's surgeon and feel confident about his or her skills, experience, and credentials. Ask lots of questions and expect clear answers.

LIP REPAIR

In the United States, surgical closure of the lip usually occurs after the baby has demonstrated steady weight gain, has been screened for other health problems, and is healthy enough to undergo general anesthesia. The repair can be accomplished in one procedure, but is sometimes done in two stages. Lip surgery may require a hospital stay of one or two days, but in some cases, the operation will be performed on an outpatient basis.



Postoperative care will be discussed by your surgeon and/or nurse. After surgery, your baby's arms may be gently restrained with stiff material to

keep the hands away from the mouth and lips. Most teams recommend letting the baby return to bottle- or breast-feeding after lip repair (although not immediately after palate repair, see below). The lip scar will begin to look paler and more flexible within several months, although it takes over a full year to heal completely and will always be present.

PALATE REPAIR

In the United States, the palate is usually closed between six and eighteen months of age, but it may be done earlier or later in life depending on a variety of factors. Palatal surgery may be completed in either one or two stages depending on your child's needs and the recommendation of your team. The procedure typically involves a hospital stay of one to three days.

Following palatal surgery, you will need to take some special precautions when feeding your baby. Foods will have to be soft (perhaps liquefied) and the baby may need to drink from a cup for a few weeks. If your baby's developmental age allows, you may want to introduce cup feeding before the operation to ease this transition. The team will discuss postoperative care in detail with you.

As with lip repair, the baby's arms may be gently restrained for a brief time after surgery. Always ask questions and make certain you have a contact phone number for the team, should you need support in those first post-operative days.

PREPARING FOR SURGERY

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, and other baby items, and what you need to bring from home. It is often helpful to bring your baby's security blanket or favorite soft toy.



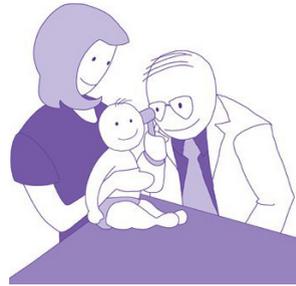
Your infant's surgeon will advise you about any special feeding techniques and dietary restrictions which will be required after lip and/or palate surgery. It is always helpful to obtain this information a few weeks before surgery so that you can familiarize yourself and your infant with any new equipment or techniques.

Additional surgery on the lip, nose, gums, or palate may be necessary as your child grows and matures. More information about cleft care and the growing child can be found in CPF's publications focusing on the toddler, school-aged child, and teenager.

CARE OF THE EARS

Please refer to Appendix B: Descriptions and Illustrations

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 air causes fluid to form and eventually accumulate in the middle ear. This condition is called **otitis media**. The fluid accumulation can then result in an infection. 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 (ENT) 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, 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 pressure equalization tubes (**PE tubes**) may be inserted 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 is usually performed when the child is under anesthesia for lip and/or palate surgery.

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 eardrum may be permanently deformed. In addition, children with persistent middle ear disease are more likely to have some loss of hearing. Unfortunately, even a mild, intermittent loss can adversely affect speech development. The child should be re-examined on a routine basis. Monitoring for ear disease and hearing loss is usually available during visits with the child's team.

HEARING TESTING

Because of problems with ear infections, children with cleft palate may experience some hearing loss which fluctuates over time. It will be worse at some times, less of a problem at other times. Consequently, it is important that parents make sure their child's hearing is tested regularly during the early years. Hearing tests can be performed on babies as young as one day old. This testing should be done by an **audiologist** who has the specialized training and equipment to test very young children. Sometimes, screening tests are done by nurses, speech-language pathologists, and other professionals. One type of screening, called **acoustic immittance testing** or **tympanometry**, measures the response to sound in the middle ear cavity. Another type of screening measures the response of the **cochlea**, the hearing nerve that is part of the innermost portion of the ear. This is known as **otoacoustic emissions testing** (OAE). These tests may result in referral for additional diagnostic testing.

SPEECH AND LANGUAGE DEVELOPMENT

The first two years of life are the most critical years for speech and language development. Parents often ask how well their baby will talk, and they are right to be concerned. If a child has an isolated cleft of the lip, speech should be typical or very close to typical as long as hearing loss or other problems are not present or persistent.

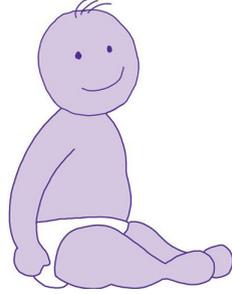
Approximately 80% of children with a cleft palate develop typical speech once their palates are repaired. Some children will require speech therapy; others may require further surgery, or a prosthetic speech aid in addition to speech therapy. A major goal of palatal surgery is to ensure good speech quality at the earliest age. The speech-language pathologist will consult with the surgeon and other specialists in planning the type of palatal surgery and the best age to schedule the operation.

Children with cleft palate tend to develop speech and language a bit more slowly than other children. Though speech may not sound typical before palatal surgery is performed, speech tends to improve and recover afterward. This catch-up process often continues for four or five years, and speech therapy may be necessary during some of these years to maximize speech quality.

For a variety of reasons, children with clefts are also at increased risk for some delay in language development. For example, early attempts at words may not be understood, and therefore not reinforced by parents. Because of these risks, periodic evaluation by a speech-language

pathologist who is knowledgeable about cleft lip and palate is important. The first evaluation should be scheduled between three and six months of age, with follow-up testing scheduled at six to twelve month intervals during the first few years.

A baby's speech and language can be evaluated even before the development of first real words. From birth onward, babies follow a well-documented course of speech and language development. The sucking, blowing, and chewing activities in which all babies engage involve the oral muscles which are eventually used for speaking. Months before babies say their first words, they make many cooing and babbling sounds and can communicate a variety of things to their parents and caretakers. These sounds and other social behaviors are important indications of speech and language development.



By six to eight months of age, the baby should be babbling, producing syllables that combine vowels and consonants (e.g., yaya, nana, nini, mama). If the palate is unrepaired at this age (and it usually is), there will be differences between what your baby is producing in babbling and what other babies without clefts are producing.

DENTAL CARE

Please refer to Appendix B: Descriptions and Illustrations

Your baby, like any other baby, will require good dental care throughout life. That care begins when the first teeth erupt. Those are usually the two lower central incisors (the two middle front teeth in the lower jaw) which erupt between six and nine months of age. The upper central incisors follow shortly after, between eight and ten months of age.

As soon as the first teeth erupt, they should be wiped with a damp cloth after each feeding, because the sugar in milk or formula causes decay. Because milk left on the teeth can cause cavities it is very important that your baby not go to sleep with a bottle of milk in his mouth. This causes what dental specialists call **bottle caries** (cavities) and the results are devastating to the teeth. If



you do put your baby to bed with a bottle for his comfort, put only water in the bottle, never milk or juice. And, of course, no baby should ever be given any type of soda, pop or sweetened drink.

By the end of the first year, most babies have four central incisors (two upper, two lower), the two lateral incisors in the upper jaw, the two lower cuspids, and possibly the lower first molars, for a total of ten teeth. Babies with clefts usually get all of their baby teeth, but may be missing some of their permanent teeth. These missing tooth buds will be identified later when x-rays are done (e.g., in the pre-school or school-age years). Babies with clefts that affect the maxillary alveolar ridge (upper gum) typically have some teeth that are turned or misshapen. The teeth most commonly affected are the upper incisors and the cuspids on the side of the cleft. The dental specialists on the team will discuss with you how these problems will be treated as your child grows.

SOURCES OF SUPPORT FOR PARENTS

USING THE INTERNET

There is a vast amount of information on the internet about cleft lip and palate. Unfortunately, some of it is inaccurate, outdated and unreliable. Remember, anyone can place information on a website. You should look for websites that offer objective, educational information that can be verified by members of your team. You may also check with the Cleft Palate Foundation (www.cleftline.org) for reliable internet resources.

FUNDING FOR TREATMENT

Your team coordinator or the hospital's social services department should be able to provide you with information regarding financial aid in your area. Your own private or group health insurance will usually cover a portion of the cost of treatment after a certain deductible is met. There are also federal and state programs such as Champus, Medicaid, and Children's Special Health Services. Some private and non-profit agencies provide funds or special services to meet some needs of children with clefts.

If a private insurance company initially rejects payment for treatment, you should discuss the case with the company. If the bill is rejected because the reviewers are not aware of the problems associated with clefts, helping them understand may result in the company providing

coverage. You should ask your team coordinator or your physician to assist you in the appeal process. Also, in many states there are laws prohibiting insurance companies from denying payment for medical needs stemming from **congenital** birth defects such as cleft lip and/or palate.

PARENT/PATIENT SUPPORT GROUPS

Parents who have a baby with a cleft lip and/or palate may find it helpful to connect with other families with similar experiences. In some parts of the country there are parent/patient support groups. These are organizations of individuals and families who meet to share common concerns and ideas. These groups often prove to be a continuing source of support for the individuals involved. Members of your local cleft palate team, your local health care providers, or the Cleft Palate Foundation can put you in touch with parent/patient support groups in your region. Support groups are also available on the internet.

MENTAL HEALTH PROFESSIONALS

As the parent of a child with a cleft lip, cleft palate, or both, you already understand the surprise of being told that your child has a condition 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 possibly painful feelings that initially may seem overwhelming. These feelings are not unusual, and subside as 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 family and friends, and then from support groups composed of other parents who have faced the same problems and concerns. 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 team or physician will be able to recommend someone. If paying for such help is a problem, 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.

CLOSING WORDS: REFLECTIONS FROM A 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.

APPENDIX A: GLOSSARY

Acoustic immitance testing: Also known as tympanometry; a type of hearing test which measures the response to sound in the middle ear cavity.

Alveolar ridge: The bony ridge of the maxilla and mandible containing the teeth, commonly referred to as the gum (see *Appendix B: Descriptions and Illustrations*).

Audiology: The branch of medicine concerned with the sense of hearing. An audiologist is an individual with a degree, license, and certification in audiology who measures hearing, identifies hearing loss, and participates in rehabilitation of hearing impairment.

Bottle caries: Cavities caused by milk or formula left on a baby's teeth. These cavities often form when a baby is put to sleep with a bottle of milk in his mouth.

Cleft/craniofacial treatment team: An interdisciplinary team of specialists who work together, and with the family, to create and update an individual's health care plan as it relates to cleft lip/palate.

Cochlea: The hearing nerve that is part of the innermost portion of the ear (see *Appendix B: Descriptions and Illustrations*).

Congenital: A disease, deformity, or deficiency existing at the time of birth.

Eardrum (tympanic membrane): The membrane at the inner end of the ear canal which separates the canal from the middle ear cavity. This membrane vibrates and transmits sound to the middle ear (see *Appendix B: Descriptions and Illustrations*).

ENT: Abbreviation for otolaryngologist; an individual who specializes in the diagnosis and treatment of Ear, Nose and Throat disorders.

eustachian tube: The air duct that 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 (see *Appendix B: Descriptions and Illustrations*).

Genetics: The study of heredity and how qualities and characteristics are passed on from one generation to another by means of genes.

Maxilla: The upper jaw (see *Appendix B: Descriptions and Illustrations*).

Middle ear: The portion of the ear behind the eardrum. It contains three

small bones that transfer sound from the eardrum to the inner ear (see *Appendix B: Descriptions and Illustrations*).

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

Oral-maxillofacial surgery: The branch of dentistry concerned with management of dental and skeletal deformities.

Orthodontics: The branch 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 (see *Appendix B: Descriptions and Illustrations*).

Otoacoustic emissions testing: Commonly referred to as OAE, this type of hearing test measures the response of the cochlea.

Otolaryngology: The branch of medicine that specializes in the diagnosis and treatment of ear, nose and throat disorders. An otolaryngologist is commonly referred to as an ENT.

Pediatric dentistry: The branch of dentistry concerned with the care of children's teeth.

PE tubes: Pressure equalization tubes; tiny tubes that are inserted into the ear during a myringotomy to allow air to enter the middle ear and prevent fluid from reforming in the eardrum.

Prosthetic speech aid: A removable plastic appliance that provides a structural means of achieving velopharyngeal closure (separating the nose from the mouth).

Prosthodontics: The branch of dentistry concerned with the replacement of teeth and related mouth or jaw structures by artificial devices.

Psychiatry: The branch of medicine dealing with the diagnosis and treatment of mental disorders.

Psychology: The branch of medicine concerned with the study of the mind and mental processes, especially in relation to behavior.

Social work: A human service field which may involve specialized training in social welfare, individual, family, group and community health services.

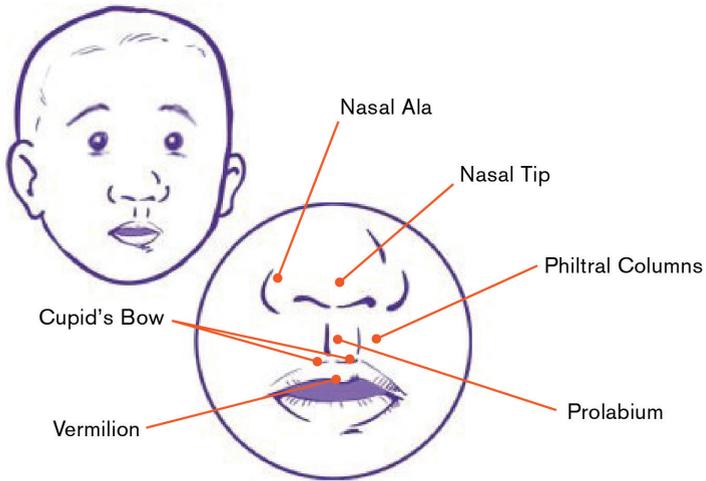
Speech-language pathology: The branch of medicine concerned with disorders that affect a person's speech, language, cognition, voice and swallowing (dysphagia). A speech-language pathologist is an individual

with the necessary academic training and experience to be certified or licensed to diagnose and treat disorders of speech, language, and communication.

Tympanometry: Also known as acoustic immitance testing; a type of screening which measures the response to sound in the middle ear cavity.

APPENDIX B: DESCRIPTIONS AND ILLUSTRATIONS

Figure 1 illustrates a typical 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 red portion of the lips (vermilion) 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 is also separated.



*Figure 1:
The Typical Lip and Nose*

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 2A). If the cleft occurs on both sides of the lip, it is called a bilateral cleft lip (Figure 2B).

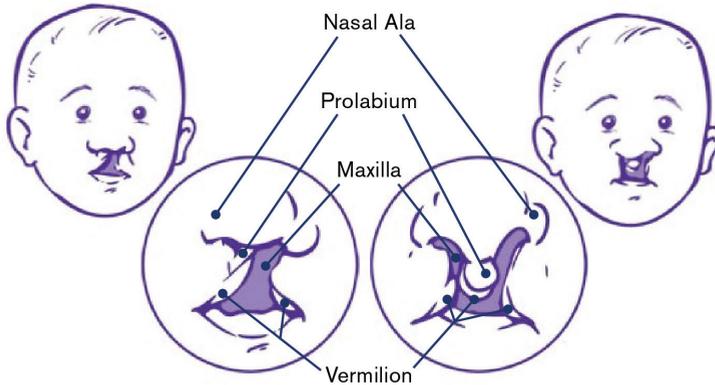


Figure 2A:

The Unilateral Cleft Lip and Nose

Figure 2B:

The Bilateral 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 illustrates a typical palate and labels its parts.

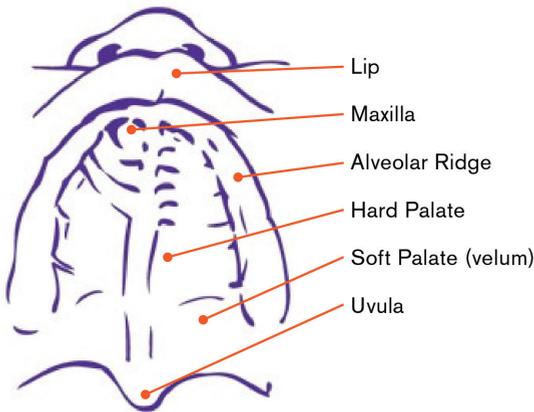


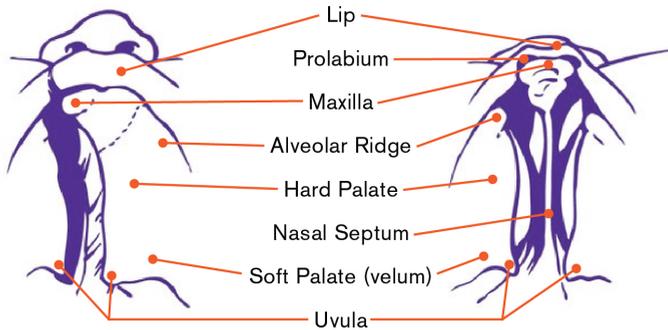
Figure 3:

The Typical Palate

Cleft palates vary in extent and in two different dimensions: back-to-front, and side-to-side. Clefts that involve only the palate, not the alveolar ridge or the lip, are sometimes referred to as isolated cleft palate or cleft palate only. This distinguishes them from clefts involving the

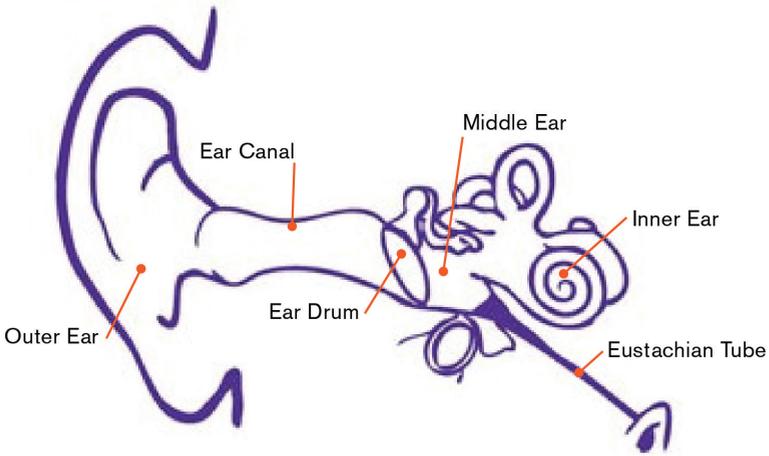
lip and alveolar ridge. Isolated clefts of the palate may vary from 1) a notching or slit in the very back, 2) clefts extending further back into the soft palate, 3) clefts involving all of the soft palate and part of the back portion of the hard palate as well. A complete isolated cleft of the palate extends all the way through the soft palate and hard palate, up to an area just behind the alveolar ridge.

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 lip, gum and/or palate. Figure 4A illustrates the intraoral view of a complete unilateral cleft palate while Figure 4B shows a complete bilateral cleft palate. In incomplete clefts (unilateral or bilateral), there is partial attachment of some of the structures.

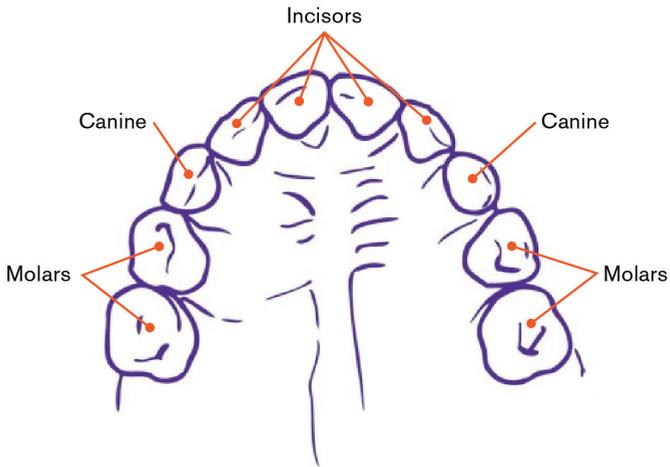


*Figure 4A:
Unilateral Cleft Palate*

*Figure 4B:
Bilateral Cleft Palate*



*Figure 5:
The Ear Canal*



*Figure 6:
The Primary Teeth*

APPENDIX C: RECOMMENDED QUESTIONS FOR THE TEAM

This appendix is provided solely for educational purposes. It is not a substitute for medical advice provided by a physician. It is intended for use by parents, caregivers, and nurses caring for infants with cleft lip and/or cleft palate, not for infants with more complicated craniofacial conditions. The content does not represent the only, nor necessarily the best, information for your infant's situation. Consult with your treating physician before proceeding to use any of the information presented here.

1. How many different specialists participate on the team?
2. What are the qualifications of the individual members of the team?
3. What kind of experience does the team have?
4. Are parents invited to the team meetings?
5. How does the team communicate:
 - a. with each other?
 - i. Face to face conference?
 - ii. email?
 - iii. written reports?
 - b. with patients and families?
 - i. face to face conference?
 - ii. phone?
 - iii. email?
 - iv. written reports?
6. Who will be the team contact person after our baby has surgery?
7. Does the team prefer a particular cleft palate nurser over another?

FOR MORE INFORMATION

This booklet and many others have been produced by:

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