



Toddlers and Preschoolers

First Edition

First Edition

Contributors to the First Edition:

Lisa Crawley, Writing Consultant

Morgan K. Gregson, Foundation Administrator, American Cleft Palate Craniofacial Association

Katy Hufnagle, MS, Speech-Language Pathology

Sally Peterson Falzone, PhD, Speech-Language Pathology

Nancy C. Smythe, Executive Director, American Cleft Palate Craniofacial Association

Ruth Trivelpiece, MEd, CCC-SLP, Speech-Language Pathology

Concepts originally presented in the American Cleft Palate Craniofacial Association publication entitled, *The First Four Years*, copyright 1980. Thank you to all those who contributed to the first, second and third editions of *The First Four Years*.

Edited by members of the 2010 ACPA Publications Committee.

All artwork created exclusively for the American Cleft Palate Craniofacial Association by Shoestring Creative Group.

Copyright © 2011 by American Cleft Palate Craniofacial Association. All rights reserved. This publication is protected by Copyright. Permission must be obtained from the American Cleft Palate Craniofacial Association prior to any reproduction.

Table of Contents

Forward	1
Medical and Dental Issues	2
Surgery	2
Care of the Ears	3
Hearing Testing.....	3
Care of the Teeth	4
Speech and Language Development	6
Psychosocial Issues	7
Summary	9
Appendix A: Glossary	10
Appendix B: Descriptions and Illustrations	12
For More Information	15

Forward

The years between a child's first birthday and entrance into school are fun, exciting, and filled with many new milestones and achievements. At the same time, they can also be overwhelming for parents as their children gain independence, test boundaries, and grow from infants into toddlers and preschoolers.

As the parent or caregiver to a young child with a cleft you will certainly experience these same joys and challenges, but you may also face additional physical and emotional concerns as your child grows and develops. This booklet provides an overview of the issues that may arise throughout your child's toddler and preschool years, as well as the various treatments and procedures used to address the unique needs of children with clefts.

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.

While this information is intended to serve as a general resource regarding the care and nurturing of children with clefts, please keep in mind that every child requires care and treatment specifically designed for his or her particular needs. Not every piece of information will be relevant to every child's individual circumstances. Your child'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 child'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 child's situation. Consult with your treating physician before proceeding to use any of the information presented in this booklet.

Medical and Dental Issues

Please refer to Appendix B: Descriptions and Illustrations

Surgery

You will want to maintain close contact with your team, or your individual surgeon if you have not yet found a team, regarding the proposed plan of treatment for your child. It is important to remember that no one can make any medical plan for your child or carry out any surgical procedure without your knowledge and consent.



Most children with clefts in the United States undergo surgery to correct their cleft lip and/or palate within the first year of life (for more information regarding this procedure and surgical care, please see our booklet entitled *Your Baby's First Year*). However, depending on your child's needs and the recommendation of your team, your child's surgery may be completed in two stages. In this case, the second stage will likely not take place until at least the second year of life, and in some instances, the long-term plan of care may involve several operations spread out over your child's growing years.

If your team or surgeon recommends a two-stage surgery (either **hard palate** first, **soft palate** later; or soft palate first, hard palate later), your child may be fitted for a palatal plate to be worn between the two surgeries. This treatment requires close cooperation between the surgeon(s) and the dental specialists on the team, primarily the **prosthodontist**.

Once your child's palate is completely closed (whether in one or two stages), further surgery will likely not be needed until the early school-age years, when in some cases, surgery to help correct the appearance of the lip and nose is recommended before the child enters first grade.

However, if your child's previous surgery has not completely closed the palate, which is necessary for proper speech, the team or surgeon may suggest other corrective procedures. The team or surgeon will fully explain all aspects of

these procedures, including what they entail, postoperative care, healing, and the need for periodic re-checks of speech.

As an alternative to these secondary surgeries, the team may suggest a **prosthetic speech aid**, such as a plate or lift, to help close the palate and improve speech. This type of device would be made by the prosthodontist, who will explain to you how the device works and how it should be used.

Care of the Ears

Children with clefts need close monitoring of their ears as they grow. Ear infections are quite common in small children, and those with clefts are particularly prone to problems because the muscles responsible for the opening of the Eustachian tubes (small tubes connecting the throat to the **middle ear**) are anchored in the soft palate. 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. The number of ear infections may decrease once the palate is surgically closed, but this does not happen in all children.

Your child's ears should be examined periodically by a primary care physician or an **otolaryngologist (ENT)**. If fluid is present in the middle ear, medication may be prescribed to dry it up. If the fluid persists, or if the child has multiple ear infections requiring antibiotics, a minor surgical procedure called a **myringotomy** may be scheduled. During this procedure, small slits are made in the **eardrums** 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 on their own and do not usually result in any permanent damage to the eardrum. Repeated myringotomies and PE tubes may be required in some cases.

Hearing Testing

Your child's ear care may also involve periodic hearing testing. In some cases, a mild or even moderate loss of hearing may be present without any noticeable change in the child's behavior. However, even a temporary loss can negatively impact a child's speech development and ability to process his or her environment.

Three types of tests may be used to assess the hearing of toddlers and preschoolers. They are typically administered by an **audiologist** who will explain the technique(s) used during each clinic visit, as well as the test results. He or she will also send the results to your child's otolaryngologist (ENT).

The first type of testing, called **acoustic immittance testing** or **tympanometry**, measures the response of the middle ear to sound. The second technique is



known as **otoacoustic emissions testing (OAE)** and measures the response of the **cochlea**, the hearing nerve that is part of the innermost portion of the ear.

The third type of testing available is **behavioral response audiometry**. The exact technique used for this type of assessment will change as the child matures. Infants and young toddlers will sit in a parent's lap while sound is delivered through speakers. Typically, each speaker has an animated toy on top of it that lights up and moves if the child turns toward that speaker in response to the sound. If the child always turns toward one speaker and not the other, it may mean that the hearing in one ear is significantly better.

Starting at about three or four years of age, children are asked to wear earphones and respond to sound by raising their hand or placing a small toy in a container. Through this type of testing, the hearing level of each ear can be measured separately.

Care of the Teeth

Proper care of the teeth is important for any child, but it is especially critical for children with clefts, who are more likely to develop dental issues. In fact, care of your child's mouth should begin at birth, well before the first tooth appears. A damp cloth can be used to clean the gums of young infants after each feeding and at bath time. Later, your pediatric dentist or team orthodontist can show you how to begin brushing your baby's teeth. Until your child is old enough to cooperate, you may need to cradle him or her in the crook of your arm, using one hand to hold the head steady and the other to brush the teeth with a soft toothbrush.

It is recommended that babies with clefts have their initial dental check-up when their first tooth emerges or by the end of the first year, even if no teeth have erupted. These checkups should take place twice a year or more often if

there are problems that require attention. Your dentist will advise you when regular cleaning by a dental hygienist should begin.

Prevention and treatment of cavities is also especially important in children with clefts. A cavity is an infection in the tooth that can potentially spread to other areas of your child's body and may impact cleft repair surgeries.



Your child's diet is equally important. Baby formula and breast milk are the only liquids that should be given in a baby bottle. However, putting babies to sleep with formula, milk, or juice in a baby bottle can lead to cavities. If your baby is soothed by a bedtime bottle, try warm fluoridated water.

When your child is old enough to be given juice or milk, offer it at mealtimes in a cup. Juice and milk contain a lot of sugar, which can damage teeth if the mouth is not rinsed out with water. If your pediatrician recommends you provide your child high-calorie supplements such as Pediasure, remember to clean your child's mouth afterward to avoid cavities. Also, your child's mouth should be rinsed with water after taking oral antibiotics or medications.

No child should be given soda pop or powdered drinks, which constitute "empty calories" and can lead to bad dietary habits as well as dental cavities. Snacks should be healthy, such as carrots, apples, etc., and not candy or gum. Discuss these issues with your **pediatrician** and dentist early in your child's life to keep his or her smile healthy and beautiful.

Appendix B includes a diagram of the primary teeth. By the end of the first year, most babies will have the four central incisors (two upper, two lower), the two upper lateral incisors, the two lower cuspids, and possibly their lower first molars.

By the age of two and a half, most children have all their baby teeth. Babies with clefts usually get all of their primary teeth, but some may be rotated, misshapen, or in an unusual location, particularly those nearest the cleft. Children with clefts are also often missing some of their permanent teeth. The missing permanent tooth buds can be identified later on **X-rays**. The dental specialists on the team will discuss with you how these teeth can be replaced, if necessary.

You may be surprised to learn that children with clefts can also have extra teeth. These should never be removed without consulting the dental specialists on the cleft palate/craniofacial team. In fact, your family/pediatric dentist should communicate with the members of your team regarding any special dental concerns.

Speech and Language Development

Palate surgery has advanced greatly over the past few decades, and the majority of children with clefts will develop good speech once their cleft is closed. However, some children may lag behind for a while, depending upon a wide variety of other factors, including their overall health, the condition of their ears and hearing, and the age at which their palate was successfully closed. Their speech and language development is also impacted by the same outside influences as that of any toddler or preschooler, such as how much opportunity they have to practice their language skills with parents and others around them.

A **speech-language pathologist (SLP)** should see your child fairly often in the first two or three years of life. Ideally, the SLP on the cleft palate/craniofacial team will provide this service. If this is not possible, the SLP on the team will help you find a local provider who will communicate with the team on a regular basis. The SLP will be carefully tracking speech and language development and will put in place or recommend an early intervention program if needed.

It is very common for children whose clefts involved the **maxillary alveolar ridge** (upper gum) to have minor speech problems due to misaligned or



misshapen teeth. Consonants such as “s”, “z”, “sh”, “j”, and “ch” may be affected. Of course, many children without clefts have similar difficulties, and they usually disappear when the child gets his or her permanent teeth, or in older children, when an orthodontist corrects the alignment of the teeth or when missing teeth are replaced with false ones. (NOTE: This treatment will not take place in the toddler or preschool years).

Unfortunately, it is not always easy to determine if a child’s teeth are responsible for a specific speech problem. SLPs are most concerned when a child is not pronouncing sounds and words correctly and is using the throat or glottis to produce speech instead of the mouth. Though “preventative therapy” is still somewhat new, early intervention can stop some children from developing this type of speech pattern or at least minimize the extent to which it is used, and you should discuss treatment of this issue with your SLP.

A child’s inability to be understood at an age-appropriate level can have negative effects on his or her continued language development. For example, the speech of three-year-olds who do not have clefts should be understood by family members. If the parents of a child of this age are repeatedly unable to interpret what the child is saying, they will not be able to reinforce communication efforts and the child’s language ability will not expand appropriately. The good news, however, is that this cycle is avoidable and your SLP can provide advice and guidance regarding your child’s speech development.

Psychosocial Development

Most parents worry at some point that their child may have difficulty interacting and fitting in with other children and adults outside the immediate family. These worries are often amplified when the appearance of a child’s face is different (even a very nicely repaired cleft will have some degree of scarring). In general, children develop awareness of both their own facial appearance and that of others around the age of four years. It is not uncommon to hear toddlers and preschoolers make comments about the appearance of other children. Sometimes, a child with a cleft becomes aware of his or her differences, including differences in speech, as young as two or three years of age.

Most teams have a **psychologist** or social worker who will work with your child and family. These services are routinely offered by most teams, and meeting with the team psychologist does not mean there is something emotionally wrong with your child. If a problem is detected, play therapy for the child and perhaps counseling for the family may be recommended.

Parents are encouraged to be open and honest with their children about their clefts and why their faces look different. Your team’s psychologist or social worker can also provide advice on how to respond to questions and teasing.

Giving your child some responses to use with inquisitive children or adults, such as “I had an operation when I was really little, and I’ll probably have another one later,” can be helpful in dealing with this issue. The child can also be given ways to answer questions about differences in speech.



The team psychologist can also assess your child’s developmental level. If there is no psychologist on the team, early assessments may be carried out by the social worker, pediatrician, SLP, or the pediatric nurse practitioner on the team. Some children with clefts or other craniofacial problems experience difficulty in school, but with the help of team members these potential issues can be detected and addressed early. The team members concerned with your child’s educational and psychosocial development will want to be in close contact with your child’s preschool teachers, school counselors, and/or other caregivers.

Preschool can give your child a wonderful sense of independence and achievement. Many parents are concerned about the quality of the preschool they choose. You will want to visit the school, talk with teachers and administrators, and probably take your child for an introductory visit before enrolling. If this is your first child, you may be a little hesitant about letting him or her venture into this new environment. Soon, however, you will discover the feeling of some independence of your own (a few free hours during the day!), plus the gratification of seeing the smile on your child’s face as he or she tells you about the school day.

Public school districts are required by law to offer speech and language therapy to any child age three years or over when such therapy is needed. They must provide these services even to children who may be enrolled in a private preschool, if the family lives in their district. Check with the preschool and with the local school district administrators to see what is available if you believe your child may be in need of speech or language therapy. However, if your child is younger than three and in need of therapy, do not simply just wait until he reaches age three. Remember that early intervention is the key,

and that the most important years for speech and language development are the first two years of life.

In the past few decades, there have been large-scale research studies on learning problems, reading problems, and problems in school achievement found in children with clefts. We now know that these problems occur more frequently than we had previously thought. This does not mean that your child will necessarily have such difficulties. However, it does mean that team members will be on the alert for any early signs of problems and will be prepared to help you get whatever services your child may need in the schools or through local care providers.

Summary: Getting Maximum Benefit from Your Cleft Palate/Craniofacial Team

Keeping the lines of communication open at all times with your child's team will help ensure that he or she receives the best possible treatment. You and your child will be best served if you: (1) see the team very early in your baby's life, (2) see your team as often as recommended or needed, (3) make it a habit to take all your questions to them, (4) contact them with questions and problems in between regular team visits, (5) provide team members with school information, including Individual Educational Plans (or IEPs) and (6) help to ensure regular contact between the team and your local care providers (e.g., pediatrician, dentist, surgeon, speech-language pathologist, psychologist, social worker, school counselors, preschool teachers).

Be sure to obtain and keep copies of all team reports. Having these reports handy will help you keep track of your child's treatment plan and inform new care providers. Remember, the sole reason for the existence of teams is to maximize the care your child receives.

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.

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.

BEHAVIORAL RESPONSE AUDIOMETRY – A type of hearing test that uses behavior to measure response to sound.

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)

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)

GLOTTIS – The middle part of the larynx (“voice box”) where the vocal cords are located.

HARD PALATE – The front part of the roof of the mouth containing bone covered by mucosa or pink skin. (see Appendix B: Descriptions and Illustrations)

MAXILLARY ALVEOLAR RIDGE – The bony ridge of the maxilla and mandible containing the teeth, commonly referred to as the upper gum. (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.

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

OTOACOUSTIC EMISSIONS TESTING – Commonly referred to as OAE, this type of hearing test measures the response of the cochlea.

OTOLARYNGOLOGIST – A physician specializing in the diagnosis and treatment of ear, nose and throat disorders. An otolaryngologist is commonly referred to as an ENT.

PALATE – The roof of the mouth including the front portion, or hard palate, and the back portion, or soft palate, also called the velum. (see Appendix B: Descriptions and Illustrations)

PEDIATRICIAN – A physician specializing in treatment of children.

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).

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

PSYCHOLOGIST – A trained and licensed professional concerned with the study of the mind and mental processes, especially in relation to behavior.

SOFT PALATE – The back part of the roof of the mouth containing muscles and mucosa or pink skin. The Latin name for the soft palate is “velum”. (see Appendix B: Descriptions and Illustrations)

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.

TYMPANOMETRY – Also known as acoustic immittance testing; a type of screening which measures the response to sound in the middle ear cavity.

X-RAY – The science of obtaining images of internal body parts by applying ionizing radiation; images may be recorded digitally, or on film or plates.

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.

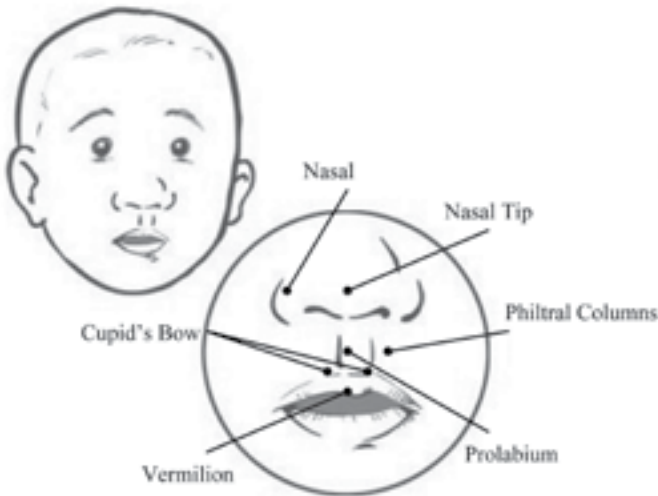


Figure 1: The Typical Lip and Nose

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).

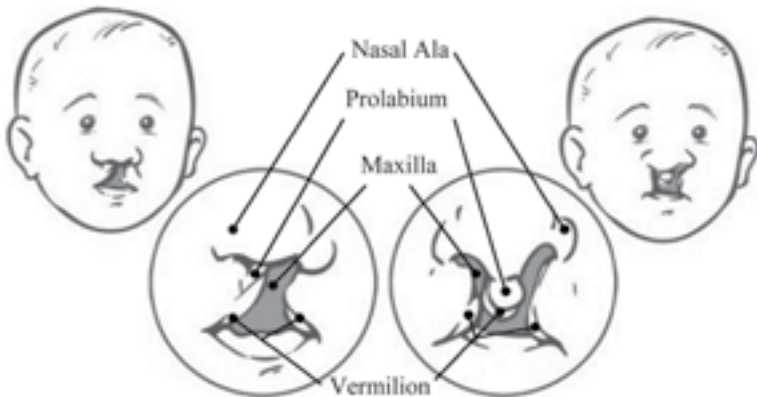
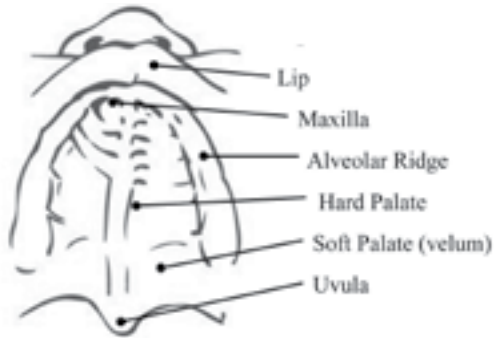


Figure 2A: The Unilateral Cleft Lip and Nose

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 4A: Bilateral Cleft Palate

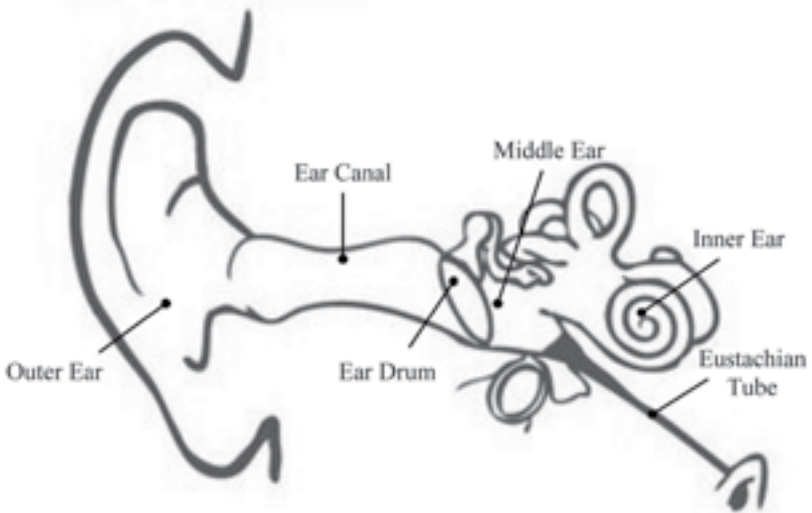


Figure 5: The Ear Canal

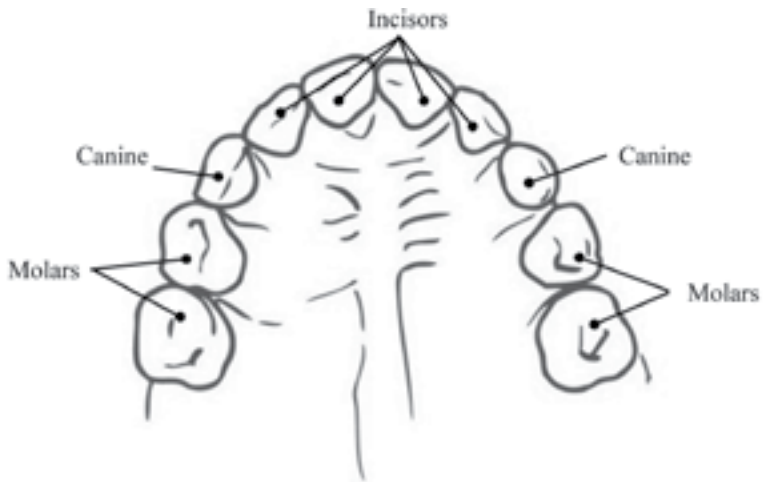


Figure 6: The Primary Teeth

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:

American Cleft Palate Craniofacial Association
510 Meadowmont Village Cir, Suite 377
Chapel Hill, NC 27517
info@ACPACares.org
ACPACares.org
919.933.9044

The American Cleft Palate Craniofacial Association (ACPA) maintains a growing collection of booklets and fact sheets that present an introduction to and explanation of many elements of cleft and craniofacial care and treatment. All publications are authored and revised by representatives of professional disciplines serving the field of cleft and craniofacial care and treatment.

A publications order form for institutions including current pricing, bulk order rates and shipping and handling fees may be accessed on www.ACPACares.org or by calling ACPA at 919.933.9044. 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@ACPACares.org or by calling.

To date, ACPA has shared over 7,000 Gund Teddy Bears with repaired cleft lips with children and families all over the world. Please visit www.ACPACares.org for more information about the bears.

If you are interested in helping us continue in our mission, please contribute to ACPA. Visit www.ACPACares.org or call to make your donation today! Thank you.

