



# THE SCHOOL-AGED CHILD



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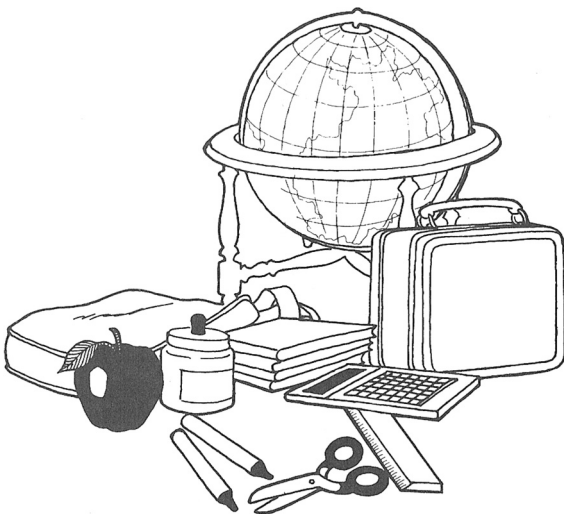
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# Foreword

This booklet is a continuation of a developmental series produced by the American Cleft Palate-Craniofacial Association. The first booklet, *The First Four Years*, was written for the parents of babies born with clefts. This next booklet in the series discusses some of the concerns parents may feel as their children begin kindergarten and elementary school and progress on to middle school (ages 5 to 12 years). During these school years, the child's focus widens to include not only the family, but the larger world of neighborhood and school as well. Children may become concerned about how they look and talk. They may worry about making friends, being teased, doing well in school, and being included in activities. Parents want their children to be successful and to develop a good self-concept. However, children born with clefts sometimes need help to achieve these goals. The purpose of this booklet is to suggest ways to help these children.

This booklet was written for families. It is intended to be shared with the child with a cleft, other family members, friends and teachers. Section One focuses on the medical, dental and speech decisions which must be made to promote the best appearances and good speech. Section Two focuses on the school experience. It stresses the importance of maintaining normal hearing, explores the possibility of learning problems, and the options for managing them, and discusses how children can handle teasing and increase their ability to make friends. The section concludes with a teacher's presentation of what it means to have a child with a cleft or craniofacial birth defect in the class.



# Background Information

Cleft Lip and/or palate is one of the most common birth defects, affecting about one out of every 600 individuals. Despite this fact, children and families affected by clefts may feel alone and isolated. Most families had never heard of cleft lip and palate until their child was born. Many children seldom see another child with a cleft. Information about cleft lip and palate, as well as contact with other affected individuals, and their families, can assist people in obtaining care, choosing among care options, and reducing a sense of isolation.

Children with cleft lip and/or palate can reach their maximum potential when care is provided by a team of specialists from a variety of healthcare fields. This is because children with clefts are at higher risk than others for differences in facial growth, dental abnormalities, speech problems, ear infections and hearing loss, and some types of learning disabilities. Because these problems are interrelated, the child is best served by a team of professionals who are experienced in cleft care and who communicate with each other to plan and provide treatment. The American Cleft Palate-Craniofacial Association maintains a list of such cleft palate/craniofacial teams in the United States, Canada and other countries. This list is available to families and professionals through the [www.cleftline.org](http://www.cleftline.org). It is also important that children and families are offered the opportunity to meet and talk with other families affected by cleft lip and palate. Such support may help the child and family to feel less alone and provide opportunities for sharing and friendship.

Treatment of cleft lip and/or palate varies with each child, because no two children have exactly the same needs. For example, some children may require one or two operations, while others may require more. Speech therapy is needed by some children and not by others. Because each child is unique, treatment must be individualized for each child.

The causes of cleft lip and palate are not well understood. Research programs are currently attempting to improve understanding about how these disorders may be caused by inheritance (genetic factors) or by conditions within the womb (environmental Factors). As of this writing, no simple cause/effect relationships have been found between either genetic or environmental factors for most cases of clefting. While it is advisable to plan all pregnancies so they occur when the mother and the developing baby may have the benefit of prenatal care provided by a qualified physician, the lack of prenatal care does not necessarily increase the chance the child will be born with a cleft. Families already affected by clefting should request a consultation with a geneticist (a specialist in genetic factors) to estimate the chance that future children, their affected child's children, and the offspring of their affected children may also have clefts.

# Achieving the Best Possible Appearance, Speech and Teeth

## **Facial Appearance: Surgical Considerations**

Entering elementary school is a milestone for your child. As horizons expand, he or she will be influenced by a variety of new adults and children. You want your child to enter this new situation with confidence. Most of this confidence will come from your support, encouragement and approval. You will also want your child to look as good as possible and be able to speak as clearly as possible when entering school. Detailed evaluations by a cleft palate team prior to this time will address any special problems your child might have. If needed, surgical correction will be recommended when the team feels the time is right, considering your child's overall health and development.

A few children only need the initial cleft lip and/or palate surgery performed in the first years of life. Scarring may be minimal, and appearance may be relatively unaffected. Speech may be easily understood. Many children, however, will need more surgery as they grow and develop to improve their appearance and their speech.

One important advantage of having your child seen by a team of cleft experts is that all aspects of his or her care can be coordinated, and trips to the operating room can therefore be minimized. Sometimes it is possible to combine procedures and save time, money and discomfort. This is best done with regular evaluations by the cleft team as a whole, with input from all of the cleft care specialties.

In general, the fewer the number of operations that your child has, the better. Although it is tempting to want to touch-up procedures, it is also important to understand that with each surgery, more scarring occurs. Remember that your child is continuing to grow. What may appear to be an irregularity now may improve with time. Young men's facial features continue to develop until they are 16 to 18 years of age, and young women's faces until they are 14 to 16 years of age. If too many operations are done during these times of active growth, they may interfere with the natural development of your child's face. Therefore, it may be best to delay certain operations for growth reasons.

Delaying touch-up surgery, however, is not always the best choice. Some children feel more psychological pressure than others. For psychological benefit, your surgeon may recommend a touch-up operation even though it would not be recommended at that time if only physical development were being considered. As long as everyone understands that additional surgery





may be necessary in the future, there is nothing wrong with choosing to win a small battle while waiting to win the war.

Consultation with your surgeon and other members of the cleft team will help you decide which operations at which times are best for your child. Surgical decisions and techniques are, and should be, as different and special as your child. It is important that you understand in advance exactly what the surgery will involve and what is expected after the operation, so you can help your child prepare for and recover from it.

### ***Appearance and Function of the Lip***

How do you decide if additional surgery on the lip is best for your child? The appearance of the upper lip should be as balanced as possible, with both sides matching. The scar between the nostril and upper lip should be smooth, flat, and match the skin color. The center of the upper lip should have graceful curves (what is sometimes described as the Cupid's Bow). The red portion of the lip ideally should be equally full on both sides. The muscle which allows the lip to pucker (to suck from a straw, whistle or kiss) should be united under the skin repair. There should be balance in position and size between the upper and lower lips. If the lips do not appear almost normal, and if the difference disturbs your child, or causes teasing or staring by others, a touch-up operation before starting school may be a good idea. Touch-ups tend to be more common in double (bilateral) than in single (unilateral) cleft lip. In either case, the goal is to get the lip to have as normal an appearance as possible.

### ***Appearance and Function of the Nose***

If your child has a cleft lip, the nose is probably also affected. Usually, the nostril on the side of the cleft initially appears flattened. While this may have been corrected at the time of lip repair, some flattening may remain. The bones and cartilage on the inside of the nose that divide it into right and left

halves may also be out of position, interfering with nasal breathing. Touch-up nose surgery can be done together with lip touch-up or alone.

How do you decide if additional surgery on the nose is best for your child? First of all, the nose should have right/left balance (symmetry). The tip of the nose should be elevated from the lips, and the nasal air passage should be open on both sides. The goal is to have a nose with a normal appearance and open air passages. Final surgery on the nose is often postponed until the teenage years when the face has achieved full growth.

### ***Appearance and Function of the Teeth and Gums***

What about your child's teeth and gums? For many children with clefts, the top front teeth erupt in a crooked position. Additionally, your child may be missing teeth, have malformed teeth and/or have extra teeth, especially in the region of the cleft. The way that your child's upper and lower teeth come together may not be normal either. Attentions to these problems now may prevent additional problems later. Your child's doctors may recommend that some x-rays be taken of the teeth, the jaws, and/or the skull to determine the exact situation so they will be able to plan the best course of treatment.

If your child's cleft went through the gum, there may not be enough bone for support of the permanent teeth that may be ready to appear in the area of the cleft. If appropriate steps are not taken, those teeth may be lost. In this situation, filling the cleft gap with bone (bone graft surgery) may be helpful. A bone graft is an operation designed to provide the permanent teeth with bone support when they erupt. The operation involves taking a very small amount of your child's bone from one place (usually the hip, head, ribs or leg) and placing it in the area of the cleft near the teeth. (The bone cannot come from another person's body because your child's body will not accept it.) Sometimes an artificial source of bone may be used for the graft. It is important to perform bone graft surgery before the permanent teeth erupt next to the cleft. This usually occurs between ages 5 to 10 years. Another benefit of a bone graft is that it may help support your child's lip and nose and make the left and right sides of the face look more alike. Your surgeon should explain bone grafts to you in greater detail if one is recommended.

Some children with clefts have a small hole, called a fistula, in the gum and/or the roof of the mouth (palate), which may allow air and/or food to pass from the mouth into the nose. Some of these fistulas in the gum are so small they may not cause any obvious problems, and the child may not even be aware of their presence. However, many fistulas in the palate interfere with speech. If your child has a fistula in the gum, it will probably be closed during bone graft surgery. A fistula causing a speech problem should be closed as soon as the problem is identified.

Sometimes orthodontic treatment is necessary before the bone graft, and it is almost always necessary after the bone graft. Orthodontic treatment will improve the position of your child's teeth. Sometimes the way the top and bottom jaws grow is affected by the cleft. When there is a jaw growth problem, the dental, surgical and speech members of your child's cleft team should consult with each other to determine the best plan of treatment. Occasionally jaw surgery (orthognathic surgery) on one or both jaws provides the best function and appearance. Such surgery should be coordinated by your orthodontist and surgeon. If this surgery is necessary, it usually is not until facial growth is completed in the mid to late teen years. While jaw surgery will affect lips and nose appearance, lip and/or nose revision may still be done earlier if it is considered psychologically beneficial to do so.

Another approach to having the upper and lower jaws meet together for normal function and appearance is called distraction osteogenesis. This process allows new bone to be formed through gradual separation by placing a device either inside the mouth or outside of the skin. In areas where there is not enough bone, distraction osteogenesis has provided good results without the additional need for bone grafting. And because of this new bone formation, the chance of relapse is minimal.

During this procedure, your child will be taken to the operating room and the distractor device will be placed in the jaw. After several hours or days, depending on the age of your child, the device is gradually turned to start separating the bones. Children are initially fed with intravenous fluids (IVs) and then by mouth. Parents usually are able to complete the distraction course at home, with regular visits to the surgeon's office. Once the process is completed, several weeks are allowed for the new bones to harden and then the device is removed.

## **Speaking Clearly: Speech and Language Considerations**

Will your child's speech be affected by the cleft? In general, we expect four-year-old children without cleft palate to produce speech that is understandable almost all of the time. However, not all consonant sounds may be produced perfectly at this time, and it may take another four to five years before all sounds are produced correctly. So you should understand that the speech characteristics of most children, even without cleft palate, are not perfect by first grade. Many years ago, it was fairly common for children with repaired cleft palate to start school with untreated speech problems that set them apart from their classmates. Although this still may be true for some children, improved surgery, early identification of speech concerns, and earlier treatment have resulted in more understandable speech, better articulation, and less nasal sound quality by the time children with cleft palate enter school. Therefore we now believe that the speech expectations for children with repaired cleft palate should be

much the same as those for children without clefts.

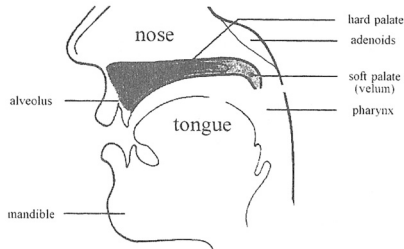
There are, however, exceptions. We expect some children with cleft palate to make the same kinds of errors in language usage and speech sound production as children with developmental delays. In addition, some children with cleft lip and palate may be at higher risk for other speech differences. Causes for this include an inability to seal off the nose from the mouth sufficiently for normal speech, dental problems affecting precise sound production, and recurrent middle ear problems and hearing loss.

By the time your child has reached the age of five years, he or she should have been evaluated regularly in order to identify any problems with speech and language development and also, hearing and health of the middle ears. These evaluations may have been done by your cleft palate team or by others, such as the school speech-language pathologist or an ear doctor. Perhaps your child has participated in speech treatment already. It is important for you to know that the Federal government requires states to provide speech/language evaluation and treatment services for individuals between 3 and 21 years of age. (Individuals with Disabilities Education Act or IDEA, Public Law 101-476). Your state has a mandated (required) program to provide evaluation and treatment for children with speech and language needs over the age of three years.

### ***Speech Production***

So that you can better understand your child's speech problems, and participate in treatment decisions, it is important for you to understand how speech sounds are made.

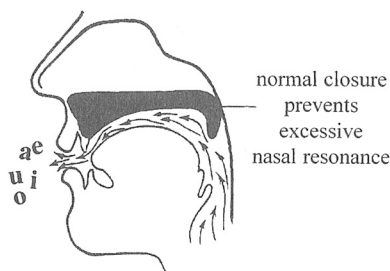
Figure 1 shows the structures used to produce speech. We will concentrate on those involved in velopharyngeal closure (velum=soft palate, pharynx=throat), since these are the ones most likely to cause problems for your child's speech. The term velopharyngeal closure refers to a closing or sealing off of the nose (nasal cavity) from the mouth (oral cavity). This closure is important for good speech for both vowel and consonant sounds.



**Figure 1**

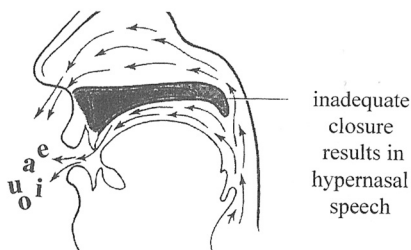
**The human speech mechanism.** Human speech is produced by the functioning of many complex structures in the mouth and throat.

For production of many speech sounds, the soft palate lifts up and stretches back against the back wall of the throat (posterior pharyngeal wall), as seen in Figure 2. This action separates the nose from the mouth. If this separation does not occur, as in Figure 3, the result is “nasalized” speech. Excessive nasal resonance of the vowel sound A-E-I-O-U will occur throughout conversational speech. We describe speech with too much nasal resonance as being “hypernasal”.



**Figure 2**

**Normal closure during vowel production.** The raising of the soft palate normally closes off the nose from the mouth and prevents vowels from sounding nasal.



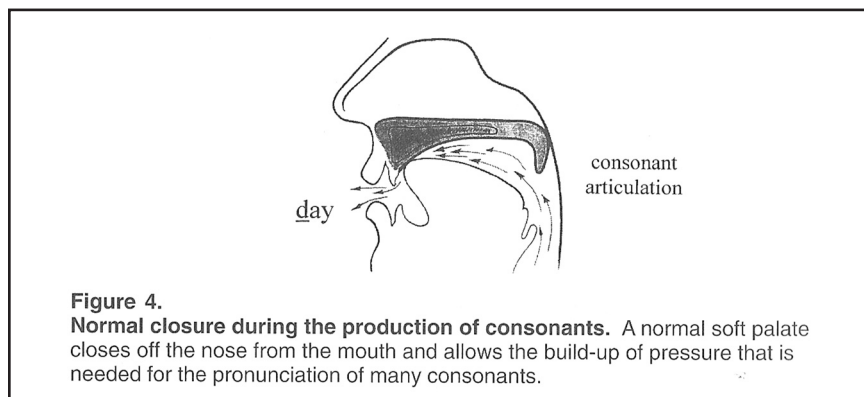
**Figure 3**

**Inadequate closure during vowel production.** If the soft palate cannot completely close off the nose from the mouth, nasal-sounding vowels will be produced.

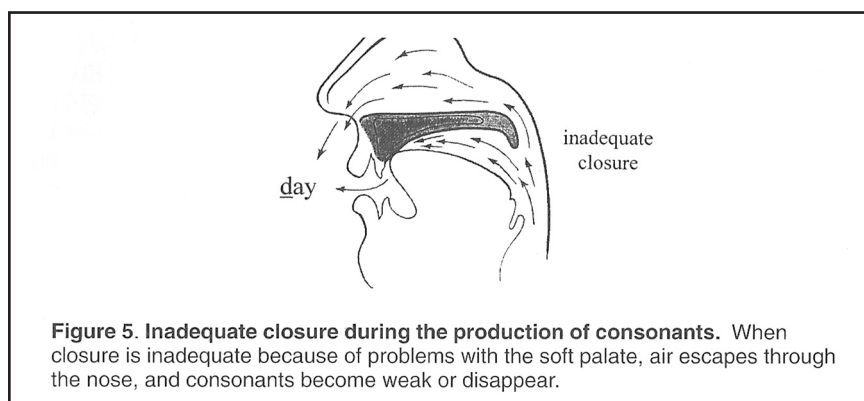
Velopharyngeal closure is important for the production of consonants as well as vowels. By closing off the nose from the mouth, the speaker directs airflow into the mouth and creates the air pressure required for almost all consonant sounds (Figure 4).

There are specific names for groups of consonant sounds. These are plosives (p, b, t, d, k, g), fricatives (s, z, sh, f, u, th), and affricates (ch and the dj sound). Consonants are produced in different parts of the mouth. For example, p and b are produced with the lips, t and d with tongue tip just between the upper teeth, and f and v with the upper teeth touching the lower lip. Figure 4 shows the place of production (articulation) for the d sound in the word “day.” You can see that the only way to build up air pressure behind the

tongue is to close off the nose and direct the airflow into the mouth – that is, to achieve velopharyngeal closure. In Figure 5, you can see how the air “escapes” into the nasal cavity and out the nose if the soft palate and the throat do not work normally. This condition may result in either weak consonants, consonant sounds that are accompanied by extra noise due to air coming out of the nose (audible nasal air escape), or abnormal production of consonants that are hard to understand.



There are only three consonant sounds that do not need velopharyngeal closure to be produced correctly, and these are called the “nasal consonants.” They are m, n, and the ng sounds. For those sounds, the soft palate must stay down so that lots of sound and air can move into and through the nasal cavities.



### ***Management of Speech Problems***

The ability to create velopharyngeal closure is necessary for good speech. Inadequate velopharyngeal closure is the most frequent cause of speech problems in school-aged children with cleft palate. When a child cannot achieve velopharyngeal closure, an operation (such as pharyngeal flap or pharyngo-

plasty surgery) or a speech prosthesis may be needed. The decision to physically improve velopharyngeal closure is made only when the specialists on the cleft palate team and the parent(s) agree that the child cannot produce acceptable speech even with the help of speech therapy. These treatment decisions should be made before the child reaches age 5.

It is not always simple, however, to make a decision concerning the adequacy of velopharyngeal closure for speech. Children sometimes learn unusual ways of making speech sounds. These incorrect speech patterns can make it difficult to evaluate the adequacy of the velopharyngeal closure mechanism, because the child is not using the mechanism properly. Speech-language pathologists are listening for these patterns and will work with your child to help correct them.

The speech-language pathologist's main task is to determine if your child's speech structures are adequate to produce good speech. The important questions for speech-language pathologists are:

- (1) How is the child speaking now?
- (2) Can the child learn to do better with the present velopharyngeal closure mechanism?
- (3) If the mechanism is not working well, why is it inadequate?

In order to answer these questions, several types of examinations may be performed to test the speech mechanism. First, the speech-language pathologist will listen to your child speak spontaneously and repeat standard words and phrases while making detailed notes about the accuracy and quality of the speech sounds your child produces. Depending on the results, other examinations may be recommended to supplement the speech evaluation. For example, one test involves placing a small tube with a camera in the nose to videotape the velopharynx during speech tasks (nasendoscopy). Another test records x-ray pictures on videotape while your child speaks (videofluoroscopy). The results of tests such as these will help determine whether your child could benefit from speech therapy alone or will need surgical management or a prosthesis.

If the speech-language pathologist decides that your child's speech can improve without additional surgery, then speech treatment should take place until speech is judged to have improved as much as possible. On the other hand, if the speech-language pathologist decides that your child's speech cannot be improved because velopharyngeal closure does not occur, then he or she will recommend additional surgery or sometimes a speech prosthesis. The choice of which type of physical management treatment to use depends upon the reason for the inadequacy, the general health of the child, and the experience and preferences of the care providers. As with any type of treatment, you should always ask about benefits, risks, and alternative methods of

management. If physical management is necessary, speech therapy will either continue or be delayed until after surgery is completed or the prosthesis is designed. After either surgery or the introduction of a speech prosthesis, speech therapy will probably be needed to help your child adapt to the new mechanism. The important thing for you to remember is that the procedures that are recommended (surgery, prosthesis, or speech therapy) are designed to help your child achieve the best possible speech result.

Most of the time, velopharyngeal closure will be adequate, or potentially adequate, following the original repair of the palate that took place when your child was a baby. There are some instances, though not very common, in which velopharyngeal closure may have once been considered adequate, but with time, evidence of problems with closure begins to be heard in speech. That is, hypernasality of speech and audible nasal air escape may start to emerge. Therefore, regular visits to your interdisciplinary team are important to monitor your child's speech. There should be frequent communication between the team, the school speech pathologist, and the parent(s).

There are two possible reasons why hypernasality may develop in 10 to 14 year-olds. The most likely cause is shrinkage of the adenoid tissue, which grows on the back wall of the throat above the soft palate. This tissue can help in velopharyngeal closure by providing an extra little "pillow" for the soft palate to close against during speech (see Figure 1). It is normal for the adenoids to grow during childhood and then begin to shrink. The age at which the adenoid pad begins to shrink is difficult to predict. In fact, there are even a few adults who have large adenoids, but most of us have little adenoid tissue by the time we are 17 or 18 years old. If your child's soft palate is short, it may still be possible to achieve adequate velopharyngeal closure during speech as long as the adenoid pad is present. However, when this pad begins to shrink, it is possible that a short soft palate will not be able to keep up with the shrinkage, and velopharyngeal closure may become a problem. For this reason, you should be very cautious about having your child's adenoids removed.

Velopharyngeal closure problems may also become apparent as a natural consequence of normal growth of the face. The normal pattern of growth of the face is in a downward and forward direction, which tends to carry the hard and soft palate away from the back wall of the throat. Thus, a palate which could make closure in a small child may not be able to do so in an older child. Although this condition is relatively uncommon, it is another reason why your child's cleft team wants to follow him/her until growth is complete.

### ***Dental Problems and Speech***

If your child's cleft went through the gum, he or she may have dental differences that can affect speech. Missing teeth, extra teeth, and/or teeth positioned out of place are common conditions. Your child's upper and lower teeth or jaws may not fit together very well either. Normally, the upper teeth



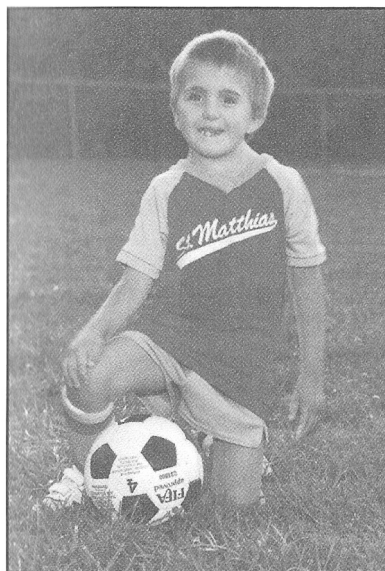
close in front of the lower teeth, but in some children with clefts, the teeth on top (upper jaw) are in back of the bottom teeth (lower jaw). In addition, children between the ages of five and ten are losing their baby teeth so their permanent teeth can come in. All of these dental and jaw conditions can be hazards to precise speech production (articulation), especially for sounds like s, z, sh, ch, and j. During the school years, orthodontic appliances that are worn for a period of time, can create hazards to precise articulation. The speech-language pathologist can work with your child to help make speech as clear as it can be during these times. Eventually, the teeth and dental structures will be more favorable for speech articulation.

### **Hearing and Speech**

By this time, if your child's ears have been well managed, his or her hearing should be at least close to normal. Regular monitoring of hearing and ear function is important and can be done in the school setting. If hearing problems are suspected by you or identified by school personnel, an immediate visit to your family physician or ear, nose, and throat (ENT) specialist is very important. Your speech-language pathologist or educational audiologist (hearing specialist) can suggest a classroom seating position that will be most helpful for your child.

As a final note, most children know when other children have speech problems, which introduces the very real possibility of teasing. A child with a cleft lip and palate has the option of saying, "Back off! My doctors aren't finished yet!" If your school-aged child's speech is noticeably different from that of his or her classmates, provide your child with the information to deal with potential problems. It is important that his or her teachers also understand the status of treatment and what can be expected during the current school year.

*Our seven-year-old son, Joseph, just recently began to be teased about his speech by the boys on his school bus. Joseph wanted them to know why he sometimes had difficulty with speech. So his speech therapist presented a brief explanation of cleft lip and palate to his second grade class. Joseph shared his pictures with his classmates. The best part came when his teacher and all the children placed large marshmallows in their mouths*



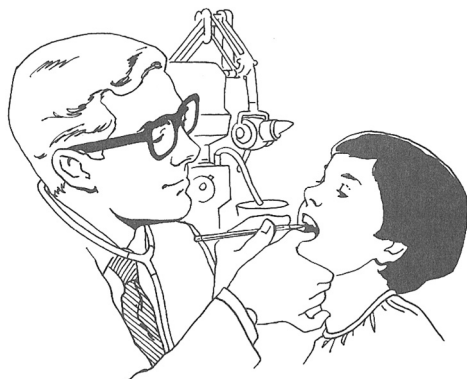
*and tried to talk. All benefitted and learned a little about speech impairments. Joseph's self-confidence has increased as a result of this class program.*

Anita and Michael Lange, (Joseph's parents)  
St. Louis, Missouri

## **Creating an Attractive Smile: Dental Considerations**

Most children do not have perfect teeth. An attractive smile may be the result of extensive dental work combined with proper care of the teeth. Children with cleft lip and palate have special concerns related to their teeth and jaws, but, fortunately, much can be done to minimize these problems.

Treatment of a cleft is most efficiently and effectively done in conjunction with a multidisciplinary cleft team. The team includes all relevant medical and dental specialists who recommend as a group what should be done and when



treatment should be carried out. Dental specialists on the team may include pediatric dentists (who specialize in the care of children's teeth), orthodontists (who specialize in tooth movement and the orthopedic movement of jaws), prosthodontists (who make appliances which either replace teeth or help compensate for a short or poorly functioning palate), and oral and maxillofacial surgeons (who perform surgery on the mouth and jaws).

### ***The Role of General Dentistry***

The prevention of tooth decay is of primary importance for children of all ages. All children should have their teeth examined regularly for signs of decay and infection starting in early childhood. The dentist can offer valuable advice about ways to maintain good oral hygiene. Brushing and flossing are very important. Applications of fluoride can also help strengthen children's teeth and prevent decay, especially if fluoride has not been added to the drinking water. When decay develops in the primary (baby) teeth, the dentist will

usually make every effort to save them. The primary teeth are important because they preserve space for the permanent teeth underneath them. If a primary tooth is removed, the other teeth may drift into its place and reduce the space available for the permanent tooth. If all efforts fail and a baby tooth must be removed, a space maintainer should be placed to hold open the space for the permanent tooth.

Children with clefts are more likely to experience tooth decay for several reasons. First, the teeth next to the cleft sometimes have a defective enamel covering, so that decay can develop quite quickly. A cap or layer of plastic filling material can be used to protect that tooth. In addition, the teeth surrounding the cleft often erupt in crowded or abnormal positions, making cleaning difficult. Finally, some children eat only soft foods due to missing or out-of-place teeth, which can increase the chance of decay by making cleaning difficult. Because of this increased risk, children with clefts should be very careful about brushing their teeth properly and frequently, not eating too much refined sugar, and seeing a pediatric dentist regularly for preventive care.

### ***The Role of Orthodontics***

The goals of orthodontic treatment are three-fold: function (a bite which works well), aesthetics (a bite which looks good), and stability. Treatment is planned with all of these needs in mind. Orthodontic treatment does not usually begin before the eruption of permanent teeth, but some treatment (such as palatal or upper jaw expansion) may be done at a younger age. Palatal expansion is accomplished by placing an appliance on the tongue (lingual) side of the upper jaw teeth to widen the dental arch. This process is often performed along with a bone graft, which corrects the defect in the gum at the cleft site. Orthodontic tooth movement is carried out through the use of wires, bonded brackets, and bands, which are cemented onto the teeth. The springiness of the archwires moves the teeth to a new position, and the position of each tooth is progressively corrected using different wires. Occasionally, an appliance worn outside the mouth (headgear) is used to move the upper teeth back or to influence the growth or position of the upper jaw. Oral hygiene is a special concern among all orthodontic patients, since the orthodontic appliances provide many additional places for food particles to lodge. If meticulous oral hygiene is not followed, decay can easily result.

Children with clefts can have any or all of the typical orthodontic problems of children without clefts — crowding, overbite, crossbite — but having a cleft may bring additional problems. Since the cleft site has no bone, there may be one or more teeth missing, the teeth may be defective in their shape or enamel covering, or they may erupt in an abnormal position. A cleft palate is also associated with an increased chance of posterior crossbite, where the top molars bite inside the bottom ones. The size of the whole maxilla (upper jaw) may be affected as well. It may fail to grow in coordination with

the lower jaw, leading to an anterior crossbite (upper front teeth behind the lower ones). Consequently, the middle part of the face may appear to be depressed or sunken-in. This problem usually requires the combined efforts of the orthodontist and the surgeon to correct. First, the teeth are placed properly within their respective jaws, and then the upper jaw is surgically moved forward. This may be done through traditional orthognathic surgery or with the use of distraction osteogenesis. Orthodontic treatment alone cannot solve the problem, since merely tipping the teeth will place them in an unstable position, and the teeth will quickly move back to their original positions.

When the teeth have all been orthodontically moved to their proper places and surgery is completed, the appliances are removed and, if necessary, retainers are placed. Retainers are passive appliances which do not put any force on the teeth, but just hold them in the new position. A retainer is required for at least one year after treatment and is extremely important in ensuring that the orthodontic result will last.

### ***The Role of Prosthodontics***

Despite all of the care given, some children with clefts will have missing or misshapen teeth. The dentist who most often replaces teeth is called the prosthodontist. There are several ways to replace missing teeth. The simplest and least expensive method is to make a denture or partial denture with artificial teeth attached. The biggest drawback to this method is that it is not permanently attached, which may not be socially acceptable to the patient. Missing teeth can also be replaced by a fixed bridge. This appliance consists of a series of caps or crowns joined together and cemented to the teeth on either side of the empty space. This is a relatively permanent restoration and can look very natural, but it is expensive and usually requires cutting adjacent teeth. Bridges also require good oral hygiene to prevent tooth decay. The newest and most ideal way to replace a missing tooth is with a dental implant. Implants are cylinders which may be made from a variety of different materials and are inserted into the bone beneath the empty space. After about six months, the implants become part of the surrounding bone. Once this has occurred, artificial teeth can be attached to the implants. Implants are expensive because of the cost of the materials. They also require excellent oral hygiene and are unsuitable for growing children or individuals with very narrow ridges of bone.

If your child has a problem with velopharyngeal closure resulting in speech that sounds too nasal, one method of treating the problem is with a speech prosthesis, which is also constructed by the prosthodontist. This removable, retainer-type appliance is made of plastic and comes in two types: lift and bulb (or obturator). The lift appliance is designed to raise a soft palate that is already long enough to reach the back of the throat but does not do so due to movement problems. In a patient with a shorter soft palate, an extension of

plastic on the back of the prosthesis, called a speech bulb, blocks the flow of air into the nose, keeping it in the oral cavity and allowing for clearer speech production. Prosthetic speech aids can be made for children at almost any time. Should the members of the cleft palate team recommend one, the prosthodontist will examine the child, take dental impressions of the oral cavity, and make an appliance which is particularly tailored for the child. The prosthodontist and speech-language pathologist will work together during the design of the appliance to ensure that it effectively improves your child's speech. The appliance should be checked periodically to be modified as required by growth.

*Our son Daryl is now eight years old. Original surgeries are complete, speech therapy is progressing very nicely, and the orthodontist has begun palatal expansion. Daryl continues to be very outgoing and has a true love of life – until his self-doubt sets in as a result of peer pressure. During one of these temporary setbacks, Daryl told a new boy in school who had been “bugging” him that he got the scar on his lip from falling off his bicycle. He told me that if he and the boy ever get to be friends, he will tell the boy about his cleft. Daryl says that he tries to “just be myself and let my friends help.” I believe it is important that we as parents provide our children with the support and encouragement they need to develop the inner strength that comes from believing in themselves. The cleft should never be used as a “crutch.”*

Jody and Daryl Robinson  
Pasadena, Texas

# Making School a Good Experience



## Hearing What the Teacher Says: Protecting Hearing

Good hearing and a good school experience go together. Protecting your child's hearing is especially important if he or she has a cleft palate, because children with cleft palate are at a greater risk for hearing problems than children without clefts. Since children with cleft palate have a disruption in the muscles which ensure good middle ear function, over 90% of them have recurrent or persistent ear infections or fluid build-up. About two-thirds of children with cleft palate have had ventilation (PE) tubes in their ear drums to try to eliminate this problem. However, when present, infections and fluid can both cause a measurable hearing loss. Although the loss is usually mild, hearing may still be impaired enough so that sounds presented at normal conversational levels are barely heard. As a result, children with a mild hearing loss often misunderstand or do not hear what their teachers are saying. Examples of speech sounds that are soft in volume and are easily missed if there is fluid or infection in the middle ear are the th in three and the p in cap.

### **Testing Hearing**

Most children with cleft palate know how to take a hearing test. Since these children were very young, they have accompanied an audiologist into a sound suite, put on earphones, and responded when they heard different tones or speech. This test determines if there is a hearing loss and, if so, the kind of loss it is. The type of hearing loss caused by fluid and infection in the middle ear is known as a "conductive" hearing loss, which is usually correctable. About 15% of children and adults with cleft palate have a "sensorineural" hearing loss. This means that there is a problem in the inner ear which is not medically treatable. For these patients, a hearing aid may be recommended.

Impedance audiometry is a test that can identify middle ear problems. A tube with a rubber tip is placed in the air canal, and a small amount of air is directed through the rubber tip to the ear drum. The air makes the ear drum

move, and a machine called an impedance bridge records the movement. The graph of the movement is called a tympanogram and tells the audiologist whether there is a middle ear problem. If a problem is discovered, your child will be referred to a pediatrician or to an ear, nose, and throat (ENT) specialist.

If your child has had ear surgery and has ventilating (PE) tubes in his or her ear drums, it is important to keep water out of the ears. As a general rule, when children with tubes in their ears go swimming, they should use ear plugs. Ventilating tubes should also be checked periodically to be sure the openings in the tubes are not clogged with fluid or wax. Your doctor will let you know how often your child needs to be seen for check-ups.

### ***Other Types of Hearing Tests***

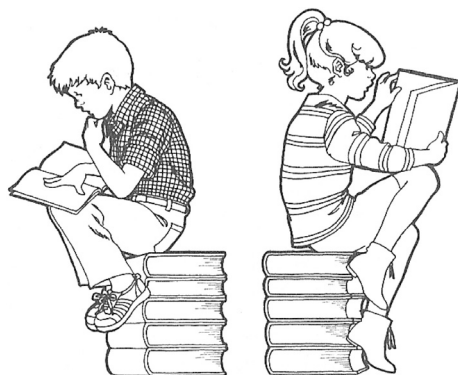
The audiologist may also perform other types of tests that are important in evaluating a child who is experiencing problems in school. Tests for auditory discrimination measure a child's ability to detect, discriminate, and understand subtle differences in speech. Auditory discrimination is tested by having a child repeat a word or point to a picture of the word when the word is spoken at a comfortable loudness level. These tests are also done with background noise to see if the child may be having trouble in a relatively noisy place like a busy classroom, the lunchroom, or the school bus. Some children may also have problems understanding what they hear. Central auditory processing (CAP) tests allow the audiologist to understand how your child processes the speech that is heard.

### ***Types of Help Available***

For children who do not need a hearing aid but who still have trouble listening in noisy places like a classroom, a personal FM unit may be helpful. The child wears headphones like those on a Walkman, and the teacher wears a small microphone. Similar equipment can also be used in an entire classroom with the teacher wearing a microphone and with speakers placed around the classroom.

Special tutoring or therapy is available for children with problems in speech discrimination or central auditory processing. The audiologist can usually recommend services within the community to address your child's specific needs. It is important for both parents and teachers to realize that some children may have problems at school not because they are not paying attention, but because a specific problem with the auditory system is present.

Throughout childhood, your child's hearing should be tested periodically to ensure healthy ears and establish optimum listening and learning conditions. If a hearing problem is discovered, your child's teachers should be informed so that the best learning environment can be provided for him or her.



## **Making Good Grades: Learning to Read, Spell and Write**

Most children born with cleft lip and palate do as well in school as other children their age. However, some children with clefts experience specific learning difficulties even though they have normal intellectual abilities. There are a number of factors associated with clefting which may increase the likelihood of learning problems. These include fluctuating hearing loss (see "Hearing") and the possibility of specific problems learning to read, speak, or write, which will be discussed in this section. Both parents and teachers need to be aware of these factors.

### ***Learning Problems or Disabilities***

An estimated 10% to 20% of school children have learning disabilities, the most common source of school-learning problems today. Most people have heard the term "learning disability," but few people really understand what it means.

Specific definitions of learning disabilities vary from region to region. However, there are some basic principles which are common to most definitions. In general, learning disabilities are related to weaknesses in one or more of the psychological processes which influence learning. These processes include: (1) language-expressive (speaking), receptive (listening), and associative reasoning (the ability to understand new ideas or the relationships between ideas or objects); (2) memory (visual and/or auditory; short-term and/or long-term recall); (3) visual perception skills (the ability to copy designs and/or orient oneself in space); and/or (4) motor coordination.

Studies have shown that some specific learning problems do occur more frequently in children with clefts. These include early developmental reading problems, short-term memory problems, and associative language (comprehension) problems.

Some children with clefts have an increased risk for reading and learning problems which are probably related to early speech and language delays. More specifically, an early speech delay may affect beginning reading skills. In



addition, children with clefts tend to have more verbal/language problems than other children. Early identification and treatment of these problems is important. If a child with a cleft is displaying any problems learning color names, numbers, or the alphabet sounds once he or she has begun school, then a thorough psycho-educational evaluation should be performed.

Some children with clefts are at a higher risk of having verbal/memory problems, which interfere with the child's ability to remember words, recall spelling lists, and memorize math facts. Early recognition of this learning characteristic can result in treatment and teaching methods that can correct or avoid many difficulties. If this memory problem is not recognized, parents and/or teachers may think that the child is not trying, is inattentive, or does not have the ability to learn. It is important to have the child's memory assessed if any of these symptoms occur. Memory can be evaluated in several ways, including comparing verbal versus visual memory and memory for isolated facts versus memory for general information.

There is increasing evidence that some children with clefts experience a language problem which is more serious than just a memory problem. This type of problem is called an "associative language" or "comprehension" problem. Studies suggest that it may occur more frequently in children with cleft palate only; however, children with cleft lip and palate may also have it. Children with an associative-language problem have difficulty understanding verbal directions, changing from one activity to another, and comprehending what they read, even when they can read the individual words. If the problem is not identified and treated, these children may be inappropriately labeled as slow learners, or even as mentally retarded. This condition should be evaluated by a professional trained and experienced in testing children with speech, hearing, and/or oral and written language disorders. Often this professional is a psychologist or neuropsychologist.

Neuropsychological tests are especially designed to identify learning problems or disabilities. Because most intelligence tests involve following verbal directions, children with associative-language deficits may receive IQ estimates that are quite low and may be invalid measures of their true ability. A complete diagnostic evaluation of learning problems should include a detailed evaluation of memory (visual and auditory), associative-language skills (verbal and nonverbal), visual-motor functions (drawing and writing), visual-spatial abilities, and attention testing, along with an individual assessment of academic skills (not a group test from school). If parents or teachers have questions about how to obtain this type of evaluation, they should contact their local cleft palate or craniofacial team, a major university, or a large teaching or private hospital. Information is also available through the American Cleft Palate-Craniofacial Association.

## **Treatment**

Careful diagnosis of any of these learning problems usually leads to recommendations for specific ways of teaching the child to read, write, spell, or do math which may differ from what is done in a regular classroom. Some children need to work several times a week with a special resource teacher who instructs them in specific learning strategies, while they continue to receive most of their education in a regular classroom. Children with more extensive problems (such as associative-language disabilities) may need to receive all of their education in a self-contained, learning-disability classroom, where these approaches can be used at all times.

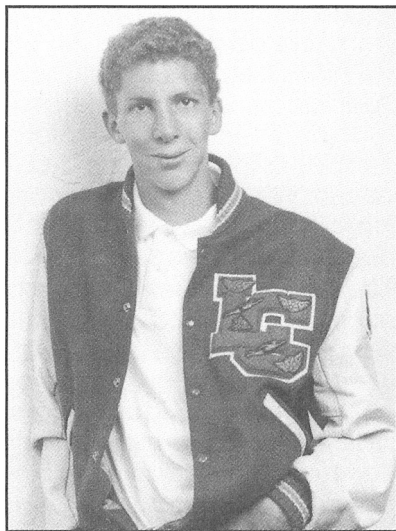
Most researchers agree that the most successful way to treat problems with reading, writing, or spelling is to teach the child by using strategies which draw on his or her strengths. For example, if a child has difficulty with short-term memory but has good abstract-reasoning skills, it is best to avoid a sight/word approach to reading (e.g., flash cards, whole-word learning) and instead use the child's strong abstract-reasoning skills to teach reading through phonics. This child may also profit from learning strategies for memorization, such as rhymes, verbal associations, or visual images.

A child with an associative-language problem may also benefit from language therapy, which is different from speech therapy. For example, the teacher may read the child a short passage and then ask the child to retell the story in his or her own words in order to increase comprehension. The same procedure is repeated as children learn to read stories on their own. Other children with associative-language problems may have difficulty with sound blending (putting together a series of letters to make a word, such as "c" - "a" - "t"). These children may need to be taught using a whole-word approach rather than a phonics approach. \* It is also possible that children with associative-language problems may need to be taught reading through the use of combined oral and visual approaches; still others may need to have material taped.

In summary, most children with clefts do not experience learning problems. However, parents and teachers should be aware of the signs of these learning problems so they can recognize them and seek assistance if necessary.

**\*Note:** Teachers should not avoid using a phonics approach for reading and spelling with all children who have a cleft or a speech problem. The presence of a speech problem does not automatically mean that a child has a sound-blending problem. If a child with a cleft is experiencing learning difficulties, he or she must have an evaluation and diagnosis before a specific method of treatment can be identified.

*I'm a senior in high school, and I was born with a cleft lip and palate. One thing I have found to be true is that how I see myself determines who I am. I like who I am. I had a series of operations up to age 14, and I went to speech therapy. The last operation enabled me to speak clearly with no need for more therapy. However, I still had a crooked nose that stood out plain as day. A few kids teased me and treated me differently. They didn't know how to react to me because they didn't understand. The doctors promised me that when I stopped growing I would have an operation to straighten my nose. They kept their promise. Today I feel very comfortable with my looks.*



*My cleft has not kept me from sports. I made the varsity swim team and water polo team. I have also wrestled. I have been a Scholar Athlete through high school. I'm proud of my grades because I also have a learning disability. I plan to attend college and become a mechanical engineer, and I know I can.*

Geoff Mueller  
Flintridge, California

## **Handling Teasing and Making Friends**

Most children are teased about one thing or another at some time. Children with cleft lip and palate may be the targets of teasing as a result of being seen as different by their peers. Other children may not understand why a child with a cleft looks and/or speaks differently, and your child may become an easy target for a cruel remark. The self-concept of a teased child can suffer long-term damage from the feelings of inferiority this ridicule can cause.

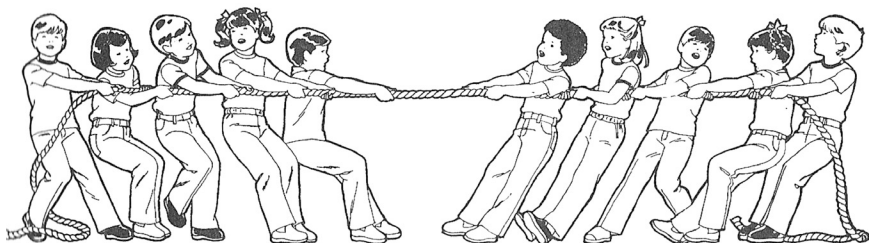
Fortunately, this is a cycle which can be broken. Educating both the individual and the peer group about clefting can result in greater acceptance and can reduce the instances of teasing from fellow students. There are several important steps in this process.

Self-Education: For many children, school will be the first time they are required to answer questions about their cleft without a parent or other adult to help. The first step in preparing for this experience is role-playing actual questions and answers with your child so he or she is comfortable talking about the cleft. Use age-appropriate language which will give enough information but not overload other children. For example:

Role-playing parent – “What happened to your lip?”

Role-playing child – “I was born with a split in my lip. It is called a cleft lip. The doctors fixed it. This is a scar from an operation.”

Being ready to answer questions removes an element of surprise from the encounter and makes responding easier.



### ***Deciding How to React to Teasing***

Both the parents and the teased child tend to react to teasing. Parents often feel very angry at children who tease their son or daughter. You may feel like rushing out to confront the teaser, his or her parents, or the teacher. However, before you do anything, it is a good idea to ask your child how he or she wants to handle the situation. Allow your child to express his or her feelings, and guide your actions by what will make him or her feel most comfortable.

Regardless of a person's age, when he or she is teased it is natural to feel like a victim. It is also common to feel powerless and hurt. However, it is empowering to remember that the teased person has various choices of action. In fact, once the initial comment is made, the person being teased is the one in the power seat. He or she can decide how to respond. A first step is to think about the person who did the teasing and what was said. The decision on how, or if, to respond can be made by analyzing the WHO, WHAT, and WHY of the remark.

WHO did the teasing? A friend, acquaintance, stranger, or bully?

WHAT was the tease? Was it a mean comment, or maybe a joke that went wrong? Was it based on lack of understanding?

WHY did the tease occur? Was it a single comment, or has there been a history of teasing?

Looking at these three factors, the child can decide how to respond. The choices include ignoring the remark, responding with a joke or good-natured tease, or educating the teaser. For example, a new classmate may make a remark based on a lack of knowledge. Since this is someone with whom your

child has regular contact, educating him or her with a simple explanation may be a good course of action. For a known bully, however, a firmer response may be required.

The child with the cleft should be aware of how his or her body language affects the response. In other words, how you look when you answer is as important as what you say. When responding to a bully, crying or withdrawing reinforces the teasing. The child must look and sound in charge by planting his or her feet firmly and speaking up.

Many individuals find that responding with humor is a successful strategy in some situations. Developing a repertoire of quips can throw the teaser off guard. The person being teased can then refocus the situation and bridge the gap in communication without becoming defensive.

Parents may wonder if role-playing teaches children to expect problems. Experience has shown that being prepared for social encounters and having open lines of communication between the child, parent, and teacher provide the healthiest setting for the development of a sense of competence and self-worth.

There is evidence that role-playing gives children a noticeable self-confidence boost in social situations. As a result, the expected teasing may never even materialize.

Educating the Group: Because teasing is often a group activity performed in front of an audience, educating the group can also change the outcome. If the other students disapprove of the tease, it will be unsuccessful. Educating them will also satisfy their curiosity, promote acceptance and empathy, and prevent scapegoating. This task can be accomplished in several ways. In his or her own class, the student with the cleft may choose to write or give a speech about the condition. For more self-conscious children, a general discussion in the class can focus on the reasons why others may look or sound different, rather than singling out one individual.

However, there is sound evidence that most teasing occurs outside of the classroom peer group. In fact, the most likely teasers are those who do not have an opportunity to get to know the student as a classmate. The schoolyard and school bus are common settings for teasing. A school assembly dealing with disabilities and individual differences is an excellent forum for students who don't know your child personally to ask questions and have their curiosity satisfied.

These preventative measures can also be initiated at home. Repeated positive reinforcement from family members builds self-confidence and leads the child to believe that he or she is worthy of respect from peers.

*My name is Lisa, and I am twenty-two years old. I was born with birth defects which were mainly facial. I have had over forty reconstructive operations, so I feel I am qualified to talk to parents and to young people with similar problems. The following "ingredients" make up what I think of as "Lisa's Recipe for Life. "*

- 1. The love and support of parents who really listen to what you say and compliment you on your accomplishments is most important. Parents who show their faith in you by letting you try things, even things you might fail to achieve, help you to foster independence and self-sufficiency.*
- 2. I had to learn to tell the difference between the feelings that everyone experiences and those that pertain to my physical problems. I had to remind myself that every teenager worries about being attractive. They wonder if they are too tall/short or too fat/skinny. They wonder if any boy/girl will ever be interested in them. I found that even the most attractive, athletic, intelligent, wealthy, etc., teenager has his or her own insecurities.*
- 3. I felt it was my job to allow others to get to know me by getting involved in school and special projects. People fear what they do not know.*

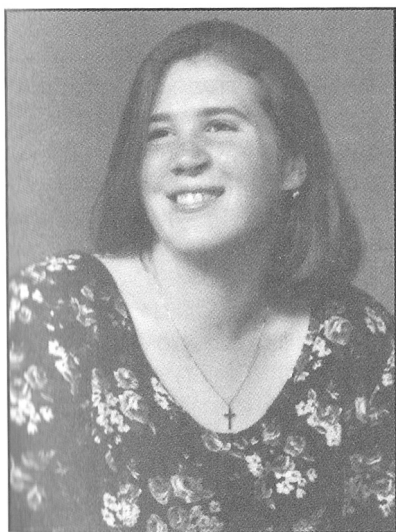
Lisa Gutierrez  
Houston, Texas

**Making Friends:** A student who enters school feeling good about himself or herself will give the message to others that he or she would be interesting to get to know. How can you help develop this trait in your child?

Early exposure to other children teaches social skills and a sense of belonging. Meeting others with clefts, either children the same age or older individuals who may be role models, is very valuable, as it provides your child with a special link to those with the same concerns. Offering the opportunity for your child to interact with others will also provide practice for building social skills.

Developing a special ability or talent gives a child an aura of expertise and builds self-confidence. Belonging to teams and clubs both in and out of school will also provide chances for him or her to make friends with others who share similar interests.

A child with a cleft may have to work a bit harder to get others to look past his or her difference. Being interested in others, developing a sense of humor, and knowing how to be a good friend are all important skills which will help your child to make friends more easily. Encouraging your child's behavior through positive reinforcement will teach that this extra effort has successful results.



*I'm 15 years old, and I find it helpful to remember that I am not the only person with a cleft. It is a big comfort for me to know that. My cleft hasn't really bothered me, because I have friends with clefts, too. Some children don't get to see other kids with clefts very often. My suggestion is to remember that you are not the only one. Other people with clefts have made it, and so can you!*

Jen Onyx  
Limekiln, Pennsylvania

## A Teacher Talks to Other Teachers

In your years as a teacher, you may only have one or two children with cleft lip and palate in your class. In the classroom, they generally should be treated like any other student. If a student with a cleft begins to exhibit any behavioral or learning problems, he or she should be approached and assessed as any other student would be.

There are a few potential problem areas for a child with cleft lip and palate of which you may need to be aware. First, because cleft palate increases a child's susceptibility to ear infections, he or she should be checked regularly for any hearing loss. A hearing loss may impact (1) where you should position yourself while teaching so that the student is certain to hear you, and (2) how you should arrange classroom seating, depending on your teaching style and the room arrangements.

Second, if the child has any visible signs of the cleft (e.g., a scar on his or her lip), you may want to keep a "third ear" attuned to whether the child is experiencing any harassment or teasing from other students. One of the preventative approaches a teacher can take is to do an activity like a magic circle, in which you lead a group discussion of the various ways in which we are all different. This activity can lead to a more accepting attitude of differences among people. Also, if there appears to be a specific teasing problem between the child with the cleft and one or two other students, you might sit down with these few children to find a resolution (e.g., help them to talk about their fears and to learn what mutual interests they may have).

Third, sometimes a child with a cleft needs to receive speech therapy. As with all pull-out services, this can draw attention to the child and make him or her feel different. If you can help the child to leave the room in a subtle way, it will help to prevent negative attention from being directed at the student at such times.

Fourth, it is important to remember that many children with cleft lip and palate have had repeated hospitalizations and surgeries prior to entering school. It is not unusual for them to need additional surgeries between the ages of 5 and 12 years. They may miss some school time. It is important to make every effort to help them keep up with the class so they do not fall behind and again become the object of negative attention. Support from you and their classmates at this time is also helpful. Teachers of older children might have the class make Get Well cards for the child having surgery. Funny cards are especially appropriate. Receiving these cards makes the child feel popular and more eager to return to school.

Fifth, because of the potential involvement of the ears, teeth, and speech mechanism, it is possible that the child will have many medical appointments. Although parents should try to schedule them during non-school hours, it is impossible for all appointments to be made around the school schedule. We,



as teachers, need to be understanding, both with the child and the family. As much as possible, we need to cooperate in seeing that the child does not miss important instructional and informational materials presented on those days of absence. It helps to remember that these medical appointments are essential for the child's successful habilitation.

A child with cleft lip and palate will likely progress in a regular way through all the developmental stages. Generally, there is no connection between a cleft and a child's intelligence. Most children with cleft lip and palate do quite well in school, although recent research has shown an increased risk of some learning disabilities in a small portion of the cleft population (primarily in children with clefts of the palate only). Your approach to assessing a child with a cleft should be no different than with any other child. However, if the student is having difficulty learning, you should recommend a diagnostic psychoeducational evaluation immediately so that the appropriate educational planning can be done. Intervention at the earliest possible age can improve a child's ability to learn and can prevent secondary problems with self-esteem and behavior, which often develop when a child is having difficulty keeping up in school.

As with all your students, it is important to meet with the parents of a child with a cleft. They can share information with you about their particular child's history of medical appointments, surgeries, etc. Keep in mind that the treatment process is different for each child, depending on the severity of the cleft and how the child's physical development progresses as he or she grows older. When conferencing with these parents, try to remember that they must balance not only work, home, and family, but also many medical appointments, surgeries, insurance claims, and other unusual demands on their time and energy. At times, they may appear defensive or fragile; your encouragement can make a difference to them.

A child with a cleft needs to be seen from a holistic perspective. If you are understanding about occasional absences from school, supportive around surgery times, careful not to draw attention to him or her during pull-out times, and attentive to any social interaction difficulties, the child will move through the year in your classroom as smoothly as the other students will. Should you wish more detailed information about cleft lip and palate, try reading this entire pamphlet along with others that are available from the American Cleft Palate-Craniofacial Association (see the end of this booklet for more information).

Having a child with a cleft lip and palate in your classroom is another opportunity for you and the other students to learn about differences. The key to successful learning and social development for this child, as for any child, is a positive self-concept. You can contribute to that positive self-concept by offering your skill in teaching and the gift of your compassion to this 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 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.

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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.cleftline.org](http://www.cleftline.org) for more information about the bears.

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



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