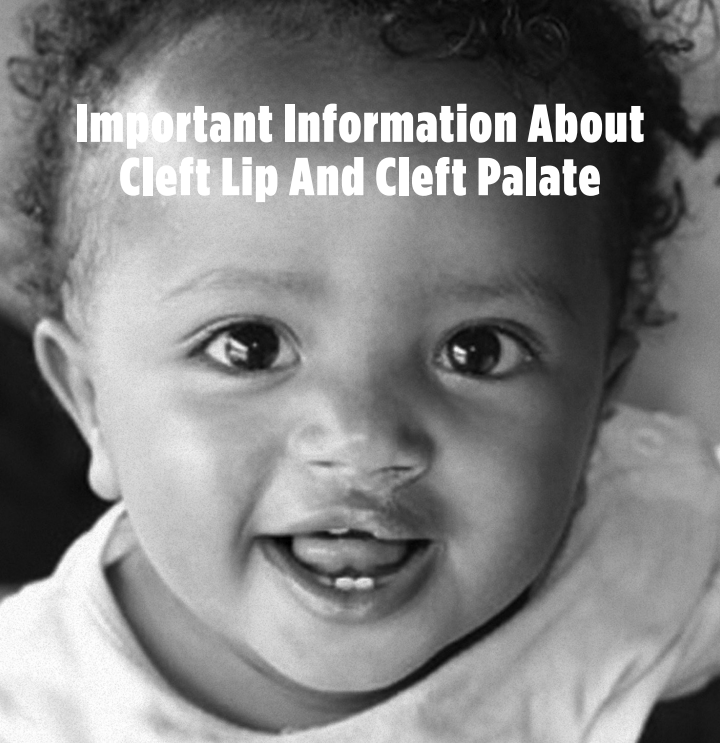


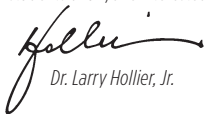
# Important Information About Cleft Lip And Cleft Palate



**SmileTrain**

Changing the World One Smile at a Time

*Smile Train's Medical Advisory Board is comprised of some of the best and the brightest cleft experts in the world. The information included below is intended to help women and couples who are thinking about becoming pregnant; women who are pregnant; anyone who has a family history of clefts and is concerned about having a baby with a cleft lip and/or palate; children, men and women who were born with clefts and their parents and families; and anyone who wants to learn more about the birth difference itself. As the Chair of Smile Train's Medical Advisory Board, I hope you find this information to be a helpful guide to understanding cleft lip and/or palate. Please visit [smiletrain.org/health](http://smiletrain.org/health) for more cleft resources for patients, their families, cleft medical professionals, medical students or anyone interested in learning more about clefts.*



Dr. Larry Hollier, Jr.

### **What is a cleft lip or palate?**

A cleft occurs when certain body parts and structures do not fuse together during fetal development. Clefts can involve the lip and/or the roof of the mouth (which is made up of both hard and soft palate). Cleft lip and/or palate can be unilateral, involving only one side of the mouth, or bilateral involving both sides. Clefts are a common birth defect with an estimated 200,000+ new babies with clefts born every year globally. Many of these children will never receive the reconstructive surgery and comprehensive cleft care they need and will suffer their entire lives with untreated clefts. The information in this brochure is relevant to all children born with cleft lips and/or palates; however, children in low and middle income countries often receive treatment at a later stage than children born in developed countries. This is often due to poverty, limited awareness and lack of medical resources, but Smile Train is working 365 days a year to help these children in need.

### **When do clefts occur? How common are they?**

Clefts occur very early in the development of the fetus, and many women may not even know they are pregnant when the cleft is formed. It is important to listen to doctors' medical advice and stop smoking and drinking alcohol as soon as a woman learns she is pregnant as exposure to tobacco and alcohol has been linked to cleft and other birth defects. The crucial time for head and face development of a fetus is between the 3rd and 12th week of pregnancy. A lip typically fuses within 8 to 10 weeks after conception and a palate usually fuses within 10 to 12 weeks. There are varying opinions on the actual incidence of clefts, but most experts agree that in part it depends on ethnicity. Some experts say that the highest cleft incidences are among Asians (approximately 1 in 500 births). Caucasians have an average incidence of 1 in 700 births and individuals of African descent have the lowest incidence of approximately 1 in 1,200 births. Globally experts typically estimate an incidence rate of approximately 1 in 700 births.

### **What are the causes of cleft lip and palate?**

No one knows exactly, but most experts agree that the causes of cleft lip and/or palate are multifactorial, meaning they may include a genetic predisposition, as well as environmental exposures such as drug and alcohol use, smoking, maternal illness, infections, or lack of

Vitamin B9, also known as folate. In most cases, it is difficult to determine what factor(s) caused a cleft lip and/or palate, but research is ongoing to better understand the condition. A woman is at a higher risk for having a baby with a cleft lip and/or palate if she is a teenager or over 35 years old, or is exposed to certain medications, chemicals, and infectious diseases that can disrupt the normal development of a fetus. These exposures are referred to as teratogens. Some specific examples of teratogens include alcohol, cigarette smoke exposure, seizure medications, thalidomide, chemotherapy, radiation, as well as certain diseases and infectious agents such as rubella, cytomegalovirus, genital herpes, chicken pox, fifth disease, toxoplasmosis, diabetes and hyperthermia. The duration and frequency that the fetus is exposed to teratogens can influence the severity and impact of a birth defect. Since clefting causes very obvious physical changes, a cleft lip or cleft palate often is easy to diagnose. A prenatal ultrasound may determine if a cleft exists in an unborn child. If the clefting has not been detected in an ultrasound prior to the baby's birth, a physical exam of the mouth, nose, and palate can confirm the presence of cleft lip or cleft palate after a child's birth. There can be subtle forms of cleft palate such as a bifid uvula. Additionally, diagnostic testing can be done to determine if other abnormalities are present as in syndromic cases.

### **Can clefts be repaired?**

Reconstructive surgery for clefts has evolved over more than half a century and today's techniques and procedures have come a long way. Most experts agree that cleft lips should generally be repaired around 3-6 months after birth. Cleft palates are typically operated on between 9 and 18 months of age. However, surgeries at even later ages are also successful treatment options for patients. Most children with clefts undergo a series of surgeries as they grow up. Depending on the severity of the cleft and other factors, a child could undergo a number of surgeries during his or her first 20 years. A team of medical experts should be involved in the treatment of children with a cleft lip and/ or palate because the defect can affect their nutrition, speech, hearing, dental development, appearance and self-esteem.

### **How soon can clefts be repaired?**

While some parents may request that the cleft be repaired soon after birth and before the child goes home from the hospital, surgery on a newborn can be dangerous because of the very small size of the child and can result in a less-than-optimal repair. Most cleft lip and palate treatment centers prefer to wait to perform the initial lip repair until the child is at least 12 weeks old. There are several reasons for this timing. First, when the child weighs between 10 to 13 pounds and is healthy and vigorous, he or she is better able to tolerate general anesthesia and surgery. Children at 3-6 months of age are significantly larger than newborns, which facilitates the technical requirements of the surgery and results in



better aesthetic and functional outcomes. Second, the waiting period allows for ample time to thoroughly diagnose the extent and characteristics of the cleft and any additional associated conditions that might be present. Additionally, this delay allows parents to adequately plan an immediate and long-term course of treatment. Cleft palate surgery can be more complicated than cleft lip surgery. Each of these surgeries is done on an inpatient basis, with a short stay in the hospital. Additional revision surgeries may be done on the lip and/or nose before the child starts school. Some children may need additional surgery on their palates to improve their speech and sometimes require a small bone graft to unite the bone in the area of the cleft in the upper jaw. If the upper jaw does not grow properly during facial growth as the child gets older, a jaw surgery may be necessary during the mid-late teen years to move the jaw to a normal position. Lastly, a “finishing” rhinoplasty, or nasal reconstruction surgery, may be done later in the teen years once the face is fully developed.

### **How should a cleft team be selected?**

A cleft affects the part of a child that is central to his or her personality: the face. So it is not surprising that a cleft lip and/or palate can have wide ranging effects when uncorrected. After the birth of a child with a cleft, it is important for parents to select a team of medical professionals that will provide ongoing cleft-related care for their child. In every area of the United States, there are qualified health professionals caring for children with cleft lip and/or palate and other craniofacial anomalies. However, because children born with clefts will often require a variety of services over a period of years, it is recommended that an interdisciplinary team of specialists be selected for their expertise and their proximity. After a successful surgery, the team may only need to see the child periodically during their growing years. Professionals in the local community may provide routine treatment such as general dental care, orthodontics, speech therapy and pediatric care. Travel to a cleft team will usually be limited to several trips a year in the early years, and will perhaps eventually decline to one visit per year in later years.

### **Who should be on a cleft team?**

When an interdisciplinary cleft team works together with the family, treatment goals can be individualized for each child, and the parents and healthcare providers can make the best choices for treatment by consulting with each other. Growth plays a key factor in the ultimate outcome of treatment, therefore the child should be assessed thoroughly and regularly by the team until young adulthood. The principal role of the interdisciplinary team is to provide integrated case management for the child and to assure the quality and continuity of care and long-term followup. With more specialists participating on the team, the more likely every aspect of treatment can be considered during the team evaluation.

The cleft team members will be determined by the availability of qualified personnel and by the types of patients served by the team. When the team cannot provide all the services required by its patients, team members are responsible for making appropriate referrals, and for communicating with professionals to whom patients are referred. This arrangement will

allow treatment plans to be coordinated and carried out in an efficient manner. Although not all patients will need each type of specialist, the team may include:

- A surgeon to perform necessary cleft repair surgeries (plastic surgeon, oral/maxillofacial surgeon, or craniofacial surgeon)
- A pediatrician to monitor overall health and development
- An otolaryngologist, an “ear, nose and throat” doctor who specializes in problems that may arise for a child with a cleft
- An audiologist who assesses hearing
- A nurse to help with feeding problems and to provide ongoing supervision of the child’s health
- A speech-language pathologist who assists with speech and feeding problems
- A geneticist to screen patients for craniofacial syndromes and help families understand the chances of having more children with clefts
- A pediatric dentist and other dental specialists such as a prosthodontist, who makes prosthetic devices for the mouth if needed
- An orthodontist to straighten teeth and align the jaws
- A psychologist, social worker or other mental health specialist to support the family and child and to assess adjustment problems
- A team coordinator to facilitate the patient’s care and treatment plan among the various members of the team.

The purpose and goal of cleft teams are to ensure that care is provided in a coordinated and consistent manner with the proper sequencing of evaluations and treatments within the framework of the patient’s overall developmental, medical and psychological needs.

### **What to expect on the day of surgery?**

As a parent prepares for their child’s surgery, it is very important that they follow the advice and instructions given by the cleft team. A child must be of a healthy weight without any infections that could delay surgery. It is important that the patient has an empty stomach (the patient’s medical team will provide specific requirements on timing). Patients will have a blood test and other tests if needed. If they are ill, the surgery may be postponed to ensure the patient’s safety. The child will be given a general anesthetic so that they will be asleep during the surgery and not able to feel any pain. After the surgery is completed they will be monitored in the Post Anesthetic Care Unit (PACU) before being transferred to the recovery ward.

### **How can a child with a cleft be successfully fed?**

One of the most critical problems confronted by parents will be difficulty in feeding their child. Before surgical repair, the split in the lip or mouth may affect the normal action of sucking that is vital for feeding. After cleft repair, post-surgical complications may make feeding neonates and infants difficult, requiring specialized care.

During the period before surgery, parents are generally concerned about the problems of feeding and bonding. A number of feeding approaches are available to parents of children with clefts, but some trial and error may be necessary in finding a method that works best.

Breastfeeding has been viewed as especially important in facilitating bonding. This has to do in part with the physical as well as psychological interdependency of breastfeeding. However, successful, effective bonding is not dependent on breastfeeding and can take place when other methods of feeding are used. The important thing is that the baby is held and nurtured. Holding the baby during feeding, allowing ample time for feeding, permitting them to play and talking to them are ways to ensure that bonding takes place.

Some babies with clefts have difficulty breastfeeding. It is important to monitor, with a doctor, the weight of the baby. While some babies may not have the ability to suckle sufficiently to breastfeed, some do. If a family wants to breastfeed their child with a cleft, they should express this preference to their cleft treatment team.

The principal problem of breastfeeding a baby with a cleft is obtaining enough suction to pull milk from the breast. Sometimes the breasts do not fully fill with milk until several days after the delivery. If this is the case, mothers may wish to pump their breasts regularly until there is ample milk and then try again. However, if the breasts have sufficient milk, but the child cannot suckle, they may need to bottle or cup feed. Some mothers who feed their babies with a bottle or cup make their breast milk available by expressing the milk with a breast pump. Regardless of the method of feeding used, it is important to monitor, with your doctor, the weight gain of the baby to ensure proper nutrition.

When feeding a baby, he or she should be cradled in the parent's arms in a semi-sitting position with the infant's body upright and tilted slightly backward. This position helps the baby swallow and also prevents the flow of formula or milk into the nose. Often, a baby with a cleft swallows more air when feeding than a baby without a cleft. For this reason, babies with clefts should be burped often.

Some parents worry that their infant will choke during feeding. Choking is usually caused by milk striking the back of the throat and is often the result of feeding too rapidly. Parents should make sure the nipple opening is just large enough to allow the milk to flow freely with very little pressure against it. If milk pours out when the bottle is inverted, the opening is probably too large. Many children with cleft lip and/or palate feed slowly. Therefore, it is important to allow adequate time during feedings. However, if too much time is taken because of an inadequate technique, the infant may tire of feeding before an adequate amount of milk or formula is obtained.

Most children with cleft lip and/or palate have been successfully fed by using bottles or cups. There are a number of adapted bottles and devices that increase the ease and safety of feeding. Parents are normally given information on how to use these feeding devices and where to buy them before taking their baby home from the hospital. Some of these devices are the cross-cut nipples, the neck feeding device, the Breck feeder, and the infant paced feeding valve. There are also nipples with attached flaps or wings that prevent leakage from the baby's cleft lip; and in some cases, a child with a cleft palate may need to wear a prosthetic palate called an obturator to help them eat properly. Cleft teams can help assist parents in selecting a feeding technique that best meets their baby's needs.

## **What is Pre Surgical Infant Orthopedics?**

Often referred to as PSIO or NAM (nasal-alveolar molding), this treatment may be recommended for children who have moderate to severe cleft lip and/or palate because it has the potential to decrease clefts' size and effects on the nose. If recommended by a surgeon and caregivers agree to the treatment, PSIO is applied when a child is 1 – 6 weeks of age and continues until primary cleft surgery is completed. PSIO may include taping across the lip, a palate obturator and/or a device to lift and remodel the cleft nose. It is usually applied by an orthodontist and caregivers make daily adjustments at home and bring their child for follow-up on a regular basis. Studies suggest that PSIO improves immediate cleft surgery outcomes and decreases the need for future cleft revision surgeries.

## **How are cleft lips repaired?**

During fetal development, certain components of the upper lip do not form normally. Cleft lip repair is a type of reconstructive surgery to correct this abnormal development to address function and appearance. Cleft lips come in a broad range of severity. Some can be as mild as a slight notch in the upper lip, and others are as severe as a total separation of the lip all the way up into the nose. Cleft lips can involve a single cleft (which is known as a unilateral cleft) or a cleft on both sides of the lip (bilateral cleft).

Usually, a surgeon will operate on a cleft lip when the baby is between 3 and 6 months of age. This surgery is relatively simple, safe and quick. Some cleft lip surgeries take as little as 45 minutes.

For cleft lip surgery, the child will be under general anesthesia. The surgeon makes incisions to free up tissue and then reconnects it the way it should have been joined originally. The function of the muscle and appearance of the "Cupid's Bow," the curve in the middle of the upper lip, can be completely restored and often the difference of the nose can be improved as well, either during the initial surgery or later.

## **How are cleft palates repaired?**

During fetal development, certain components of the roof of the mouth can fail to form normally. Cleft palate repair is a type of plastic surgery to correct this abnormal development to restore function. The severity of a cleft palate can range from a small hole in the back of the roof of the mouth to a major cavity that runs all the way from the front to the back of the mouth. A cleft palate can occur on one side or both sides of the upper mouth. Speech production, feeding, maxillofacial growth and dentition are just a few important developmental stages that may be affected in children with cleft palates. This surgery can be more complicated and difficult than cleft lip surgery, and it is typically performed at a later age, usually at 9-18 months of age.

For cleft palate surgery, your child will be under general anesthesia. The surgeon will cut tissue on both sides of the cleft palate and then bring the tissue and muscles



together in the center of the palate, being very careful to leave enough length so that the child will be able to eat and speak normally as they grow older. Sometimes a child will need more than one surgery to close the palate. Ideally, children with cleft palates are operated on before they learn to speak to avoid the development of speech impediments. However, many children who undergo cleft palate repair require speech therapy following surgery.

### **How do you care for your child after surgery?**

To prevent injury, promote healing and maintain the patient's comfort, it is important to follow the instructions given by the cleft team after the surgery. The cleft team will instruct parents on how to gently clean around the lip stitches with a soft cotton swab and water twice a day to keep the wound clean and remove any clots or crusts. The parent(s) may also be instructed on how to apply cream (or emollient) to the skin wound after it heals (not later than 4 weeks post-surgery). The cleft team will demonstrate how to massage the lip with the cream when the wound heals. However, in some cases, no cleaning or wound care is required at all. If the child seems to have discomfort, parents should consult the cleft team.

A short course of antibiotics can be prescribed for the child after surgery. In most cases, dissolvable stitches are used, and there is no need to have any stitches removed after surgery. Sometimes doctors may use stitches that need to be taken out 5 to 7 days after surgery. This procedure will be done during a visit to the cleft team for aftercare.

The cleft team will also instruct parent(s) as to when the child can resume feeding, eat solids, or begin other activities, based on his/her age and type of operation. They will explain the importance of returning for a follow-up visit.

### **What are common medical problems that children may face?**

- **Hearing:** A child with a cleft palate is more susceptible than other children to inflammation of the middle ear, which can result in hearing loss. An audiologist, a specialist in hearing problems, is often a part of cleft care teams. Periodic visits to an audiologist can determine whether there is any hearing loss and, if so, its nature and extent. Children with clefts who have ear problems respond well to treatment and their problems tend to decrease with age. Small ventilation tubes may be inserted in the eardrum to permit drainage and improve air circulation. Parents should discuss this procedure with an ear, nose and throat (ENT) surgeon. This is a minor procedure that can be done during or after cleft palate surgery.
- **Teeth:** If the child's cleft involves the bony gum ridge that contains the upper teeth, there may be some differences in the development of the teeth. All the permanent teeth may not appear, and those that do develop may not be positioned correctly. Children with cleft are more prone to dental caries than unaffected children. A pediatric dentist should be consulted starting at 18 months old or earlier, and then seen every 6 months. Eventually, other dental specialists may also be needed, such as orthodontists, oral surgeons or a prosthodontist to provide bridges or partial dentures to replace missing teeth.



- **Speech and Language:** Like all children, a child with a cleft will begin learning about speech from the very first day of life. The baby will probably also make sounds similar to those made by most babies. However, the development of normal speech habits can be affected by clefts since these defects involve the lip and palate. Early surgical repair usually provides a much improved mechanism for speech. As the child grows, the development of speech and communication skills should be followed closely by a speech development professional. A speech-language pathologist is a healthcare professional that provides speech-language therapy, and this may be provided in a medical setting, school setting, private clinic or home-based intervention program. Speech-language therapy will provide the child with the knowledge and skills to achieve normal speech and communication for his or her age or developmental level. The goals of therapy include:
  - Establish correct articulatory placements
  - Maximize oral pressure for the pressure consonant sounds (plosives, fricatives and affricates)
  - Maximize oral-pharyngeal articulatory function

### **What are psychosocial challenges that children may face after cleft repair?**

All parents want their children to develop a positive self-image, make friends, do well in school and mature into well-adjusted, productive adults. Parents of children with clefts share these same hopes and dreams, but often wonder whether their child's cleft will deter him or her from reaching these goals. It is important for families to work with their cleft team to effectively approach challenges involving the physical manifestation of a cleft lip and/or palate and its impact on functions in speech and hearing and on appearance.

Research indicates that children with clefts are at a slightly higher risk of having psychosocial challenges. One study revealed that parents of children with cleft lip and/or palate perceive their children as less independent and confident. Despite such perceptions, most professionals believe that there is no such thing as a "cleft palate personality" – there are as many different personalities among children with clefts as there are among children without them.

It is not surprising, however, that children with clefts are sometimes less than completely satisfied with their facial appearance and speech performance. Some studies have suggested that adolescents with cleft lip and/or palate report higher dissatisfaction with their physical appearance than their peers without clefts; this is especially the case among young women. Some experts suggest that parents and their children discuss approaches on how best to handle negative social situations related to their cleft lip and/or palate. Children entering school should learn proper (and age-appropriate) terms related to cleft. The ability to confidently speak about their condition to others may limit feelings of awkwardness and reduce negative social experiences.

As children get older, they may require additional surgeries to reshape their noses, lips, gums and palates until they are in their early twenties. During this period, it is essential that they receive support from their families and friends to ensure that their self-esteem and self-confidence are intact and developing appropriately.

## **Will children with clefts have challenges with learning?**

Parents of children with clefts are also concerned about their child's academic achievement. In general, parents can expect achievement to be within normal limits. While some children may have speech and/or hearing issues that can impact their education, the goal for all children with clefts is to achieve the same learning milestones as their peers.

Most children with cleft lip and/or palate develop normal speech after their palate is closed, but many children will need further surgery and/or speech therapy to improve their speech. The speech of children born with cleft palate may be difficult to understand because of one or more of the following communication problems:

- *Language delay:* Children born with cleft palates can be slow to begin to speak, develop vocabulary and coherently put sentences together.
- *Articulation problems:* Children born with cleft palates may have difficulty pronouncing sounds correctly and frequently develop incorrect patterns to compensate for their structural differences. Speech therapy is beneficial in teaching proper placement of the lips and tongue for speech sounds and in aiding parents to learn techniques to help their children speak well.
- *Hypernasality:* The speech of children born with cleft palate often sounds overly nasal. This is a resonance disorder, caused by an abnormal amount of sound in the nasal cavity during the production of oral speech sounds. Children with severe hypernasality may need additional surgery and speech therapy to speak clearly and be understood by others.
- *Nasal air emission:* Children born with cleft palate may have a leakage of airflow through the nose. This emission occurs when the speaker is trying to build up oral air pressure for consonant sounds.
- *Compensatory articulation errors:* These are misarticulations (pronunciation problems) due to mis-learning. They occur when articulation placement (function) is altered in response to a lack of oral airflow because of velopharyngeal insufficiency (disorder resulting in the improper closing of the soft palate muscle in the mouth during speech).
- *Voice problems:* Children born with clefts may develop vocal nodules that occur when they increase their volume in an effort to make themselves heard and understood.

Parents should consult with their cleft team if any learning problems arise with their child as the cause may be related to a function of the cleft or a completely unrelated issue.

## **Will any complications become apparent in life?**

For parents and children affected by a cleft lip or palate, there is every reason to believe that together they will overcome the physical and emotional challenges and lead a healthy and happy life. In recent years, together medical professionals and families have made great advances in treating cleft lip and palate. Today, a child with a cleft is expected to develop into adulthood with an acceptable appearance, dental function and communication and social skills.

Of course, individuals with repaired clefts will not be perfect in every respect – as there are imperfections in all of us. Children born with clefts should have the same aptitude for educational, vocational and social achievement as individuals without clefts.

As children with clefts become adults, some will continue to be concerned about their speech and facial appearance. However, a study that interviewed adults with cleft lip and palate reported a high degree of satisfaction with their jobs and their marriages. In a larger study, only minor differences were found between those questioned who had clefts and people without clefts in regards to marriage, education, vocation and general social factors.

Although individuals with clefts generally make positive social and psychological adjustments, this does not mean that some individuals may not experience challenges. Fortunately, there are many available resources if assistance is needed. The child's interdisciplinary cleft team can help to identify potential problems and recommend appropriate professional services if needed. The psychologists and social workers on the cleft care team are available to guide families through these difficult times. The good news is that most children with cleft lip and/or cleft palate grow up to be healthy, happy adults. Parents with a child who has difficulty with self-esteem or other psychosocial situations should contact a child psychologist or social worker for support and management.

### **Can clefts be prevented?**

There are many factors, including genetics, family history, environment and nutrition that may increase or decrease the likelihood of cleft lip and/or palate. There is a lot of research actively investigating the etiology and prevention of clefts. Many of these studies have found a link between insufficient folate and the occurrence of cleft lip and/or palate, whereas others have found no correlation. Research has shown that taking multivitamins containing folic acid (synthetic form of folate) before conception and during pregnancy may reduce the risk of a cleft. Most experts agree that reducing exposure to teratogens will reduce risk of a cleft. If your family has a history of clefting, you may want to meet with a genetic counselor to discuss the chances of having a baby with cleft. Genetic testing can be done prenatally or postnatally for rare syndromes with clefting such as van der Woude, velocardiofacial, Stickler, and Treacher Collins syndromes.

### **How can parents reduce the risk of having a child with a cleft?**

Pregnant women or those considering becoming pregnant should speak to their doctor about any medications they are taking or may consider taking. It is important to avoid teratogens (chemicals, drugs, etc.), drinking alcohol or smoking and excessive amounts of vitamin A early in pregnancy. Expectant women should take multivitamins to ensure sufficient levels of the B vitamin folic acid. The recommended daily dietary allowance of folic acid for pregnant women is 400 micrograms. Always follow a doctor's recommendations when beginning a vitamin regimen.



## Does insurance cover cleft treatments?

Most children require multiple cleft treatments over the course of their life. While working with a cleft team can seem costly, there are many insurance options that help make care affordable for families of all financial backgrounds. Depending on private health insurance, federal and state resources, or non-profit agencies, there are ways to achieve coverage for cleft treatments. Please visit [smiletrain.org/health](https://smiletrain.org/health) for helpful links on this important issue.

## Other sources of information:

In addition to this valuable information, Smile Train offers thousands of pages of information regarding cleft-related medical journal content, news articles and stories, important cleft resources for patients, their families, cleft medical professionals, medical students and leading cleft organizations around the world. Please visit the world's largest cleft-related website at [smiletrain.org/health](https://smiletrain.org/health).



Wang Li  
Our first  
patient

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