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Repair of Cleft Lip and Palate
A Parent’s Guide

Steven R. Buchman, MD
Steven J. Kasten, MD
Carolyn Walborn, RN, MS, CPNP

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Parents of babies born with clefts have many questions and concerns, including the cause of the birth defect, the health of the baby, and the timing and sequence of operations and non operative treatments that the child will undergo. The purpose of this booklet is to provide parents and families of children with clefts with an educational tool and resource regarding the repair of the cleft lip and palate and subsequent treatment.

Cleft lip and palate refer to an abnormal opening of the lip and/or the roof of the mouth (palate). Lips form together as one piece during the sixth week of pregnancy and the palate during the last part of the first trimester. Therefore it is possible to have cleft lip alone, or with a cleft palate as well. Clefts of the palate can include just the back part of the roof of the mouth (soft palate) called a soft palate cleft. They may also include the hard boney part of the roof of the mouth (hard palate).

Cleft lips come in many shapes and sizes. A child can have a cleft on one side of the lip (unilateral) or on both sides of the lip (bilateral). The cleft lip can extend all the way to nose (complete cleft lip) or to skin below nose (incomplete cleft lip). A child may also have one type of cleft lip on one side and a different kind of cleft on the other side. Every infant is unique.

It is unclear what causes clefts, however they may be the result of environmental and genetic conditions, or a combination of both. Cleft lip and/or palate is a fairly common birth defect, affecting roughly 1 per 1000 Caucasians, 1 in 500 Asians and 1 per 2000 African Americans.

The goals in the treatment of cleft lip and palate are first, to ensure the physical health including the growth and development of the child with any type of cleft. The second goal is to enable the child with a cleft to obtain the same type of educational and employment opportunities as the child without a cleft, mainly because of an enhanced ability to communicate. The final goal is to provide the child with an acceptable cosmetic outcome.

A multidisciplinary team approach is the most beneficial to the child born with a cleft, because these children have a broad range of treatment needs that no one specialist can fulfill. The Cleft Lip and Palate Center at the University of Michigan is the largest program of its type in Michigan. Our multidisciplinary program is a group of experienced professionals with diverse expertise who collaborate to provide the highest quality, family centered care for each child. The outlook for these children in terms of appearance, function, and psychosocial well being is greatly improved by this innovative approach. Our team includes experienced professionals such as plastic surgeons, oral surgeons, speech pathologists, pediatric dentists, orthodontists, audiologists, neuropsychologists, dietitians, pediatric nurse practitioners and social workers.
Feeding Your Infant

A cleft lip or palate makes feeding your baby more difficult, but not impossible. Your baby must gain weight in order to grow and develop, and in order to begin surgical repairs of the cleft.

Often, problems with feeding a baby with a cleft stem from sucking. The baby with a cleft will want to suck like any other baby, but has problems making an airtight seal around a nipple. During a feeding, formula may come out of the baby’s nose. This is not a sign of choking. Holding the baby upright will help decrease this.

There are several different bottles designed to assist infants with cleft palates. One such bottle is called Mead Johnson Cleft Nurser. This is a squeezable bottle that helps with sucking. Using an orthodontic nipple, or a nipple with a larger surface area, is often very successful.

Another bottle designed for infants is a Special Needs Feeder. This is an unusual looking nipple, which can be attached to any bottle. This nipple has a reservoir, which can adjust flow rates.

The nipple can also be squeezed to assist the infant while sucking. A nurse with the Cleft Lip and Palate Team and/or a Speech Pathologist will be able to assist you with any feeding difficulties that you may encounter.

An infant with a cleft lip and/or palate often swallows more air than an infant without a cleft. Your baby will need to be burped more often. Burping your infant every 1 ounce may be necessary.

If your infant has breast milk or formula that comes through their nose (nasal regurgitation), do not be alarmed. This is very natural and can be helped by holding the infant in a more upright position. If necessary, any feeding may finish with a small amount of water to cleanse the nose and/or palate.

Adequate weight gain is the best indicator that your infant is feeding correctly. Your baby should be back up to their birth weight by 2 weeks of age. They should also gain at least 5 to 7 ounces per week. If it takes your baby more than 30 minutes to finish a feeding, they may be using too much energy and calories to eat. Modifying feeding techniques may be necessary. Call your Cleft Palate Team Nurse or Feeding Specialist if you are having concerns about feeding or weight gain.
Hearing and Speech

A baby born with a cleft palate is prone to ear infections. The problem may be related to the inability of the lower ear to drain properly. This allows a buildup of fluid, which can interfere with hearing or become infected.

An infant with a cleft palate will be monitored frequently for the presence of ear infections and hearing loss. Your child will be referred to an Otolaryngologist, or a physician specializing in ears. Ear infections can be treated with antibiotics. If the infection does not clear or fluid remains in the ear, tubes may be placed in the eardrum allowing drainage of the fluid. The ear tubes are often placed at the same time as the lip or palate repair. Your child’s ear will not look any different from the outside. Ear drops may be prescribed for a short period of time after the placement of the ear tubes.

After placement of the tubes, your child’s hearing and the functioning of the tubes will be tested at recommended intervals.

Speech sounds are affected in infants and children with a cleft palate. When we talk, sounds can be both nasal and oral. Sounds like “n” and “m” are nasal sounds with air directed through the nose to say words such as “mom” and “now.” All other consonants and vowels are orally produced. This means the nose is closed off by elevating the soft palate to build up sufficient air pressure in the mouth. As your infant with a cleft palate begins to babble you may notice their speech sounds nasal (hypernasality). After surgical repair of the cleft palate and speech therapy most children have a normal resonance or quality to their voice. Approximately 10-15 percent of children with a cleft palate may need an additional surgery on their palate to help correct the quality of their speech. These surgeries take place after thorough evaluation by a Speech Pathologist and usually after the child is at least 4 or 5 years old.
Most surgeries do not begin until your child is at least 3 months old and weighs at least 10 pounds. Waiting until this age gives the infant the best chance for a healthy recovery. There are some non-surgical treatments that can be started earlier to help prepare for surgery.

Parents of infants with a complete cleft lip, unilateral or bilateral, may be instructed on taping their child’s lip before surgery. By using special tape, cleft lips can be narrowed. The child’s gums and lips can often be brought to a closer, more natural position before surgery.

During surgery to repair your child’s lip, this close, natural position allows for less tension on the completed lip repair.

Lip taping does not hurt or bother your infant. Infants may eat, sleep, and play with their lip taped. For the best results from lip taping, a child’s lip should be taped 23 of 24 hours per day and there should be tension on the lip. Special tape and skin protectants are used to prevent any skin irritation.

Lip adhesion surgery requires an additional surgery for your child but is often the best option for wide unilateral or bilateral clefts that do not respond well with taping. Toddlers adopted from other countries who arrive with unrepaired cleft lips often have lip adhesions. The reason for this is that they often are not as tolerant as infants with tape and are old enough to take it off themselves! You and your infant will be seen on a monthly basis to help you with taping and to decide if lip adhesion is right for your infant.
Surgical repair of cleft lip is usually done around the age of 3 months. Optimum timing of repairs may differ from child to child depending on whether they had a cleft lip adhesion and other factors such as overall health. The repair of the cleft lip is done in the operating room under general anesthesia.

There are several methods of repairing cleft lip. The surgeon will choose the type of repair that is appropriate depending on the type of cleft lip your baby has. In the cleft lip operation, incisions are made and the skin and muscles are brought together to form a full lip.

After surgery, the child will spend a night in the hospital. There will be a small couch/bed next to your child’s crib so that you may stay with them. Postoperatively, the child will have stitches or sutures in their lip. The amount of sutures will depend on the extent of the cleft and the technique used by the surgeon for closure. The area around the sutures may be pink and swollen. To protect the lip from the child rubbing or pulling on the area, your doctor may order elbow restraints called “no-no’s”.

Feeding of your child may also change after surgery. Breastfeeding may not be possible for a few weeks after surgery. Follow your physician’s recommendation for the best type of feeding for your child. The Mead Johnson Nurser with extra squeeze assistance may be acceptable. Sucking and pacifiers should be avoided. An older child may be fed with a cup.

Your child’s pain can be managed with medication. By the time your child is ready to go home from the hospital he/she should not be experiencing much discomfort. Your doctor may prescribe Tylenol with codeine at discharge. Tylenol alone should be tried first. If Tylenol with codeine is needed it should be given with food as it can often cause stomach upset. Periods of irritability may be due to arm restraints or hunger. Tender loving care is recommended. Cuddling, rocking and talking to your baby are comfort measures that can be provided.

The suture line should be cleaned frequently to prevent crust formation and infection. The steri-strips over the incision should be left in place. You may use a cotton-tipped applicator and half strength hydrogen peroxide and water to gently clean around the nostrils and steri-strips. If the steri-strips come off, GENTLY cleanse the area. Petroleum jelly (Vaseline) may be applied to the area.

Your child can be discharged from the hospital the afternoon after surgery if he/she is taking liquids well. For some children, an extra night in the hospital is necessary. You child will return to the hospital in 5 to 7 days to have the sutures removed from their lip. There will be a scar on your child’s lip that will become less noticeable over time, but will never completely disappear.
The timing of repair of a cleft palate depends on the individual circumstances of each child. Cleft palate surgery may be delayed to address more urgent problems such as a heart, lung or breathing issues. Generally, it is performed when a child is around 9 to 18 months of age. Although the child may look normal from the outside, the cleft palate should be closed for several reasons, mainly to improve speech and to separate the mouth and the nasal cavity.

The cleft palate operation is done under general anesthesia in the operating room. The surgery requires incisions on either side of the cleft. The tissues and muscles are then rotated to close the cleft and rebuild the roof of the mouth. Absorbable sutures or stitches are used to close the incisions.

Care must be taken to avoid letting your child place hard objects or his fingers and hands in his mouth. Elbow restraints may be necessary, especially if your child is a finger or thumb sucker. Follow your physician’s recommendation for the best type of feeding method after surgery. Generally, a regular cup without a top is best. Spoons should only go just past lips, not deep in mouth. Sippy cups and pacifiers should always be avoided.

By the time your child leaves the hospital they need to be taking liquids without much difficulty. At this time, they should not be experiencing much discomfort. A prescription for Tylenol with codeine may be given to you at discharge however, often plain Tylenol is adequate. You child will remain on a very soft diet (nothing harder than scrambled eggs!) for a minimum of three weeks. Your surgeon will decide when to advance their diet at their follow up appointments after surgery.
Treatment of children with cleft lip and/or palate varies tremendously. No two children have the exact same needs. Some may need only one or two surgeries, others may need more. A goal of treatment is to achieve the best possible appearance, the finest speech and the healthiest, most excellent teeth as possible. This goal can be achieved through a child’s participation in a Multidisciplinary Cleft Lip and Palate Team.

Your child will start with yearly visits with the Multidisciplinary Team around the age of 3 years old. At that time your child’s specialists, (Plastic Surgeons, Oral Surgeons, Speech Pathologists, Orthodontists, Dentists, Nurses, Neuropsychologists, Dietitians and Social Workers) will all listen to your concerns and make recommendations for your child. Recommendations can be followed up locally (such as speech therapy) or at the University of Michigan.

Many parents often desire additional surgeries on their children with cleft lip and/or palate. It is important to remember that what appears as an irregularity at 3 years old may likely improve with time and as the child grows and their face changes. With each surgery, scarring occurs; therefore it is important to weigh all factors in deciding to proceed with additional surgery.

The following are additional surgeries that may or may not be recommended for your child:
- Lip Revision
- Alveolar Cleft Bone Graft Surgery
- Dynamic Sphincter Pharyngoplasty or Palatoplasty
- Rhinoplasty
- Orthognathic Surgery.

Lip Revision

Additional surgery on the lip may be suggested to improve the function or appearance of your child’s lip. The scar on the skin between nose and lip should be smooth and flat. The appearance of the lips should be as symmetrical or equal on both sides as possible. The muscle which allows us to pucker or kiss should work without difficulty. If the appearance of your child’s lips causes teasing by others or disturbs your child, lip revision surgery may be discussed with your surgeon. The goal of the surgery is to get the lip to have as normal an appearance as possible remembering that your child’s face will change. It is important for parents to remember that what appears as an irregularity at 3 years old may likely improve with time and as the child grows and their face changes. With each surgery, scarring occurs; therefore it is important to weigh all factors in deciding to proceed with additional surgery.
Alveolar Cleft Bone Graft Surgery

An alveolar cleft is a cleft or opening in the bone of the upper jaw underneath the gums. Not all children with cleft lip and palate have alveolar clefts. Bone is needed in the upper jaw underneath the gums so that permanent teeth can erupt, develop roots and be healthy. The bone in the upper jaw also supports the base of your child’s nose. At yearly Cleft Lip and Palate Team visits your child’s tooth development will be monitored by surgeons, orthodontists, dentists and with x-rays. Often, orthodontic treatment is recommended in preparation for alveolar cleft bone graft surgery. The surgery frequently takes place when your child is about 8 to 10 years old.

During alveolar cleft bone graft surgery, the Plastic Surgeon will take bone from your child’s hip and place it in the alveolar cleft. The gums and tissues are often rearranged or rotated to close any fistula or opening near the alveolar cleft. A very tiny pain catheter (tube) is placed at the site in the hip from which bone is taken. This allows your child to be up walking without much discomfort the day after surgery.

Most children spend one or two days in the hospital after alveolar cleft bone graft surgery. Your child will need to be on a soft diet for several weeks while the bone graft is healing. They will also need to avoid contact sports and rough play while their hip is healing. Our Cleft Lip and Palate Team will guide you on the need and the timing of alveolar cleft bone graft surgery.

Dynamic Sphincter Pharyngoplasty or Palatoplasty

A small percentage of children with cleft palates have difficulty with their speech. Sometimes too much air comes through their nose causing them to sound hypernasal. A Speech Pathologist may evaluate the child’s speech and determine that the reason for this speech deficit is that they can’t close the space between their soft palate and the back of their throat (velopharyngeal space). When this occurs it is called VPI or velopharyngeal incompetence or insufficiency. Additional surgery on your child’s palate can help correct this. Your surgeon will decide what type of surgery would be best for your child’s speech.

Dynamic Sphincter Pharyngoplasty (DSP) surgery takes two flaps from the sides of the throat to make a ring of tissue that makes the velopharyngeal space smaller. Sometimes your plastic surgeon will recommend pharyngoplasty surgery. In this surgery the plastic surgeon will lengthen the soft palate and reposition the muscles. Occasionally, fat is injected to the back of the throat to make the velopharyngeal space smaller. All of these operations have the goal of helping the palate function better so that less air escapes through your child’s nose during speech.
As Your Child Grows…

Rhinoplasty

Nasal surgery or rhinoplasty may be recommended to improve the appearance and function of the nose. The nose may appear flattened or there may be asymmetry (unequal or different on each side). Sometimes one side of the nose may be difficult to breathe out of (nasal obstruction) due to a small nostril or a deviated septum. A deviated septum is when the bone or cartilage in the center of nose is not straight. Surgery to revise the nose may take place when the child is in grade school or most often when the child’s face has completed all its growth. This is usually around 16 years old for girls and often 17 or 18 for boys. Your child’s Plastic Surgeon and the Cleft Lip and Palate Team will guide you and your child through any additional surgeries that are recommended and/or desired.

Orthognathic (Jaw) Surgery

Children who have had cleft lip and palate and subsequent repairs may have a resulting facial imbalance. Their teeth may not fit together properly (Malocclusion). In addition to an improper bite the upper lip may not project properly. “Orthognathic surgery” refers to surgery that changes the position of the upper jaws (maxilla) and/or lower jaws (mandible), allowing the teeth to fit together properly and giving the face the correct balance. Orthognathic surgery is not necessary on all children with clefts. It is generally delayed until the child is a teenager and the face and jaws are full grown. Orthognathic surgery is done by your Plastic Surgeon after your child’s teeth have been aligned by an orthodontist.
Summary

One in 750 to 1000 babies born in the United States this year will have a cleft lip, cleft palate, or both. The Craniofacial Anomalies Program at the University of Michigan Medical Center began as the Cleft Palate Center more than 70 years ago and has become one of the largest programs in the country.

Experience shows that surgical correction alone is not sufficient to ensure the physical and emotional well being of children born with clefts and other craniofacial problems nor is it possible for a single physician, dentist or therapist to evaluate and treat special medical, dental, educational, psychosocial and communication needs. Our multidisciplinary approach was developed in 1955. The team has grown to include 47 members from 22 medical and dental specialties, who are experienced in the care of children with cleft lip and palate. Many disciplines are involved in treating the children in our program, including Plastic and Reconstructive Surgery, Oral and Maxillofacial Surgery, Otolaryngology, Orthodontics, Audiology, Speech Language Pathology, Neuropsychology, and Pediatrics.

Many of the cleft lip and palate problems we treat occur because of the multiple factors over which one has little control. It is important to understand that our team has a great deal of experience in taking care of children with cleft lip and palate and the outlook for these children in terms of appearance, function, and psychosocial well being is excellent. We serve patients of any age with cleft lip and palate. For information regarding our program, please write:

Craniofacial Anomalies Program
C.S. Mott Children’s Hospital, Floor 3
1540 E. Hospital Drive, SPC 4212
Ann Arbor, Michigan 48109

or call: 734-763-8063 or 1-800-UofM-CAP (1-800-863-6227) toll free

Other resources include:

Cleft Palate Foundation
(1-800-24-CLEFT), www.cleftline.org

Wide Smiles
(1-209-942-2812), www.widesmiles.org
Definitions

• **Asymmetry**: Unequal or different on each side.

• **Alveolus**: The bony part of the gum through which teeth erupt.

• **Alveolar Bone Graft**: An operation in which bone is taken from one part of the body, usually the hip, and put into the gum in the area of the cleft.

• **Bilateral**: Relating to or affecting both sides.

• **Cleft Lip**: Separation of one side (unilateral) or both sides (bilateral) of the lip.

• **Cleft Lip Adhesion**: A surgical procedure in which the edges of the cleft lip are sewn together in an effort to help mold the underlying bone and the skin to a more normal position so there is much less tension on the final lip repair.

• **Cleft Palate**: A separation in the palate (roof of the mouth) that extends into the nasal cavity.

• **Complete Cleft Lip**: Cleft that includes the lip, possibly the dental ridge (alveolus), and extends into the nasal cavity.

• **Deviated Septum**: When the bone or cartilage in the center of the nose is not straight.

• **DSP or Dynamic Sphincter Pharyngoplasty**: A surgical procedure in which the surgeon takes two flaps from the sides of the throat to make of ring of tissue which will make the velopharyngeal space smaller, ultimately helping with speech quality.

• **Hard Palate**: The hard, bony part of the roof of the mouth.

• **Hypernasality**: A quality of voice in which too much air passes thru the nose during speech often making speech difficult to understand.

• **Incomplete Cleft Lip**: Cleft that includes only part of the lip and does not extend all the way to the nose.

• **Malocclusion**: A condition in which the upper and lower teeth are not properly aligned.

• **Mandible**: The bone that forms the lower jaw.

• **Maxilla**: The bone that forms the upper jaw.

• **Nasal Obstruction**: Difficulty breathing out of one side or both sides of the nose.

• **Nasal Regurgitation**: When food or fluid comes through a person’s nose.

• **Otolaryngologist**: A physician specializing in treating issues of the ears, nose, and throat.

• **Palate**: The roof of the mouth which includes the hard palate and the soft palate.

• **Pharyngeal Flap**: An operation in which a piece of tissue from the back wall of the throat is attached to the soft palate in order to improve speech.

• **Pharyngoplasty**: An operation where your surgeon will lengthen the soft palate and reposition the muscles in the back of the throat.

• **Resonance**: A quality given to voiced sounds or speech caused by vibrations in the mouth and nose.

• **Soft Palate**: The mobile, back part of the roof of the mouth.

• **Unilateral**: Relating to or affecting only one side.

• **VPI or Velopharyngeal Incompetence or Insufficiency**: Difficulty closing off the nose from the mouth while speaking, allowing too much air to escape through the nose, causing a speech defect.
University of Michigan
Pediatric Plastic Surgery

Craniofacial Anomalies Program
C.S. Mott Children’s Hospital, Floor 3
1540 E. Hospital Drive, SPC 4212
Ann Arbor, Michigan 48109

Phone: 734-763-8063 or 1-800-UofM-CAP (1-800-863-6227) toll free
Fax: 734-936-7815
Email: Surg-CleftCare@med.umich.edu
Program Coordinator: Marlene Chesney

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