

WELCOME

A Guide to Cleft Lip and Palate Care

Gillette Children's Specialty Healthcare is a leading provider of cleft lip and palate repair surgery for babies, children and adults. Our craniofacial team provides expert evaluations and treatments for cleft lip, cleft palate and associated symptoms. Led by a team of board-certified craniofacial and plastic surgeons, our center is among the nation's largest and most comprehensive.

Our surgical techniques maximize functional and cosmetic outcomes, even in the most complex cases of cleft lip and palate. After surgery, many instances of the condition are unrecognizable at a conversational distance.

We offer all the services needed to guide you through the treatments your child needs as they grow and develop.

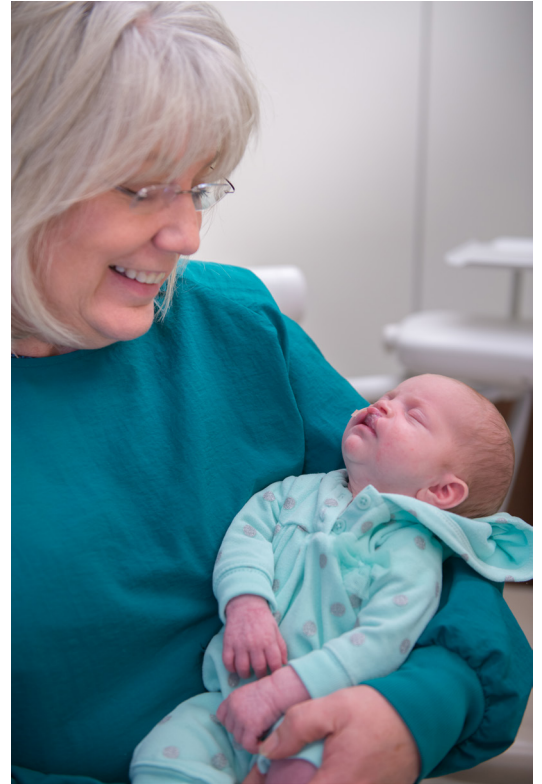
Our comprehensive treatment plans can start at birth or whenever your child arrives in your family. Each year, Gillette treats children with clefts who've been adopted from outside the United States and who, therefore, might undergo cleft-repair surgery in childhood rather than infancy. For such children, we shorten the typical repair timeline in an effort to reduce the cleft's effect on speech, tooth and hearing development.

This guide contains information about cleft lip and palate definitions, types of clefts, feeding strategies and our team approach to care. You'll also learn about cleft lip and palate treatment guidelines and how to prepare for surgery.

We know having surgery is a significant event. Gillette will help you through the process and provide additional information about your child's upcoming surgery. Our *Planning for Your Surgery* guide will be mailed to you several weeks before a scheduled surgery.

We encourage patients and family members to be involved in evaluating and making treatment decisions. We're glad you're here.

Welcome!



Cheryl Anderson-Cermin, DDS specializes in caring for children who have cleft lip and palate.

Gillette Children's Specialty Healthcare

About Cleft Lip and Palate

What is a Cleft Lip and Palate?

Cleft lip (a separation in the upper lip) and cleft palate (a split in the roof of the mouth) are the most common types of craniofacial malformations. Each year, the conditions affect one in every 690 babies born in the United States.

Clefts occur during the fourth and eighth weeks of pregnancy, when the sides of the lip and roof of the mouth don't fuse as they should. Clefts can occur on one side (unilateral) or on both sides (bilateral) of the lip and/or palate.

The lip and palate develop separately so it's possible for a child to have a cleft lip, a cleft palate or both. Almost 70 percent of babies with cleft lip also have cleft palate. Mild clefts might appear as a notch in the lip. Severe clefts can cause a large opening from the lip through the nose.

Causes of Clefts

Although no one knows exactly what causes clefts, some medical specialists believe that both genetic (inherited) and environmental factors (such as medications or vitamin deficiencies) play roles. Prevalence of a cleft increases modestly if the mother is older than 35 years old when pregnant. Either parent can pass on the gene or genes that cause clefts.

Biological children of a parent with a cleft have a 4 to 6 percent chance of also having clefts. When a child has a cleft but neither biological parent has a cleft, there's a 2 to 8 percent chance that biological siblings of the child will also have clefts. When a parent and a biological child both have clefts, the chances are even greater that the parent's future children will have clefts.

Clefts occur more often among the Asian population and among certain groups of American Indians. They occur less frequently among African Americans. More males than females have cleft lips alone or cleft lip with cleft palate. However, more females than males have cleft palate alone. Up to 13 percent of babies with clefts have additional birth abnormalities (some of which aren't readily apparent).

Types of Cleft Lip and Palate

Cleft Lip

In most cases, clefts occur only in the upper lip; they typically don't affect the lower lip. With a unilateral cleft lip, a gap appears under one nostril. The side of the nose that's affected might be down and back or look lower than normal. With a bilateral cleft lip, a deep split might extend from the lip into both nostrils, causing the nose to look broader and shorter than normal.

Cleft lips can be complete or incomplete. A complete cleft involves the entire lip and, typically, the alveolar arch (part of the maxilla or upper jawbone that holds the teeth). An incomplete cleft involves only part of the lip.

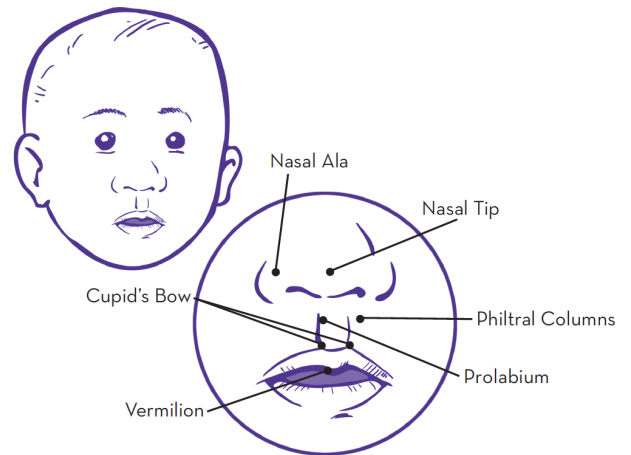


Figure 1: The Typical Lip and Nose

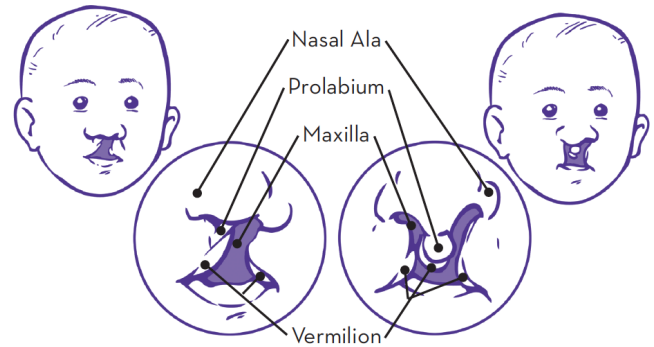


Figure 2A: The Unilateral Cleft Lip and Nose

Figure 2B: The Bilateral Cleft Lip and Nose

Cleft Palate

Cleft palates can extend from the front of the mouth (hard palate) to the throat (soft palate). Because the palate is inside the mouth, cleft palates are less noticeable than cleft lips on prenatal ultrasounds and after the child is born. Often, however, a cleft lip accompanies a cleft palate.

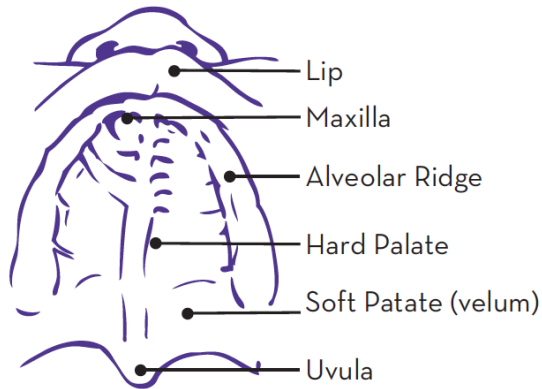


Figure 3: The Typical Palate

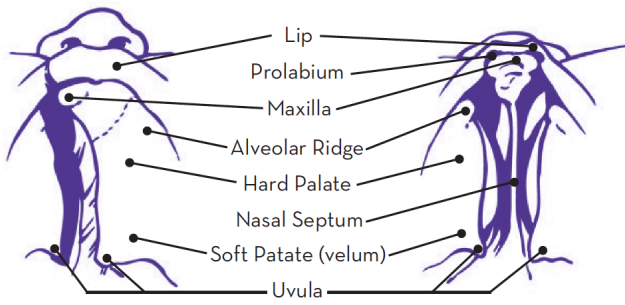


Figure 4A: Unilateral Cleft Palate

Figure 4B: Bilateral Cleft Palate

Illustrations used with permission from the Cleft Palate Foundation. cleftline.org

Associated Problems

Beyond cosmetic differences, clefts might cause other complications, including:

Feeding Difficulties. Infants with cleft lips usually have few, if any feeding problems. Infants with cleft palates, however, might be unable to suck properly. The severity of a cleft affects an infant's ability to suck and obtain nourishment. Babies with cleft palates might gag, choke or aspirate while feeding.

Ear Infections and Hearing Loss. Babies with cleft palates are especially susceptible to middle-ear disease; including infection and hearing impairment. Cleft palates affect the function of the ear canal/eustachian tubes and can cause fluid to build up in the middle ear, leading to moderate hearing loss. Children who receive proper treatment in infancy and childhood, however, can avoid permanent hearing loss.

Speech and Language Delays. Children with cleft lips generally develop typical or near-typical socially accepted speech by kindergarten or early elementary school years. It is common for children with cleft palate to have speech problems. A cleft palate impacts speech because the palate may not function properly to touch the back of the throat when speaking; therefore, air escapes and the voice sounds nasally. Their words might sound nasal, and they might have difficulty producing some consonant sounds. After cleft-palate repair, most children eventually develop typical speech, although some need speech therapy or additional surgery.

Dental Problems. Children whose clefts extend into the upper gums (which contain the teeth) have special dental problems. Some primary and permanent teeth might be missing, abnormally shaped or out of position. Some children with cleft lip or palate might also have extra teeth. Fortunately, our team of experts can generally treat such complications with ongoing care.

Definition of Repair

Cleft lip and/or cleft palate repair is surgery to fix the upper lip and palate (roof of the mouth). Clefts can be repaired through specialized plastic surgery techniques. The surgeries improve a patient's ability to eat, speak and hear, and they restore a more typical appearance and function of facial and dental structures.

Goals of Cleft Lip and Palate Repair

The goal of surgery is to close the cleft and repair associated problems. Ultimately, we seek to improve each patient's health, function, physical appearance and self-esteem.

Cleft Lip Repair

Cleft lip repair typically requires only one reconstructive surgery to restore the mouth's shape and muscle function. This surgery typically occurs when babies are approximately 3-4 months old. In addition to improving appearance and function, goals of surgery include:

- Closing the cleft lip, which leaves a straight line scar within the normal structures of the upper lip.
- Forming a cupid's bow (the curve at the center of the upper lip).
- Creating adequate distance between the upper lip and nose.

Cleft Palate Repair

By closing the opening in the roof of the mouth, this repair creates the floor of the nasal cavity. The surgery improves a child's ability to speak, eat and possibly eliminates the need for modified bottles and feeding techniques. It typically occurs when a baby is 9 to 12 months old. Some children who have cleft palates will need additional surgeries as they develop—to help with speech, improve the appearance of the lip, close openings in the gum and/or add bone to the upper gum to allow for proper teeth development.

When the cleft also affects the shape of the nose, we might recommend additional procedures any time after 4 years of age to:

- Improve symmetry between the nostrils.
- Create an adequate length of tissue separating the nostrils.
- Minimize the appearance of a flattened tip of the nose or a nose that pulls downward.

The timing of cleft repairs depends on the individual circumstances of each patient.



Robert Wood, MD is the Medical Director for the Center for Craniofacial Services at Gillette.



Wood is an internationally recognized researcher and surgeon.

Gillette Children's Specialty Healthcare Craniofacial Team Approach

The craniofacial team at Gillette Children's Specialty Healthcare works to achieve the best possible outcomes for children who have cleft lip and/or cleft palate. Whether treatment begins in infancy or early childhood, our goal is to improve a child's physical appearance and promote self-confidence.

As one of the top craniofacial centers in the U.S., we provide surgical correction of cleft lip and palate, as well as comprehensive services for associated issues. The Gillette team collaborates to treat all problems associated with cleft lip or palate. Our specialists will guide you through the services as your child grows and develops.

The following specialties and services are most often involved in caring for infants and children who have cleft lip and/or palate.

- Audiologists
- Child life specialists
- Craniofacial and plastic surgeons
- Dentists and orthodontists
- Dietitians
- Ear, nose and throat (ENT)/otolaryngologists
- Nurse practitioners
- Speech and language pathologists

Child Life Specialists

At Gillette, child life specialists help children feel at ease before and during hospital stays and medical procedures. Through hospital tours, education, emotional support, play and relaxation techniques, we help children who have disabilities and complex conditions feel prepared for and comfortable during their visits.

Our child life specialists have extensive experience working with children who have cognitive (thinking and learning), behavioral and communication challenges. We also collaborate with other Gillette specialists to support comprehensive care. In addition, we provide play activities and emotional support to patients' siblings and families.

- Our child life specialists understand the unique needs of children who have disabilities and complex conditions.
- We are committed to helping your child, and your family, feel prepared for an upcoming procedure or hospital stay.
- Our specialists collaborate to provide comprehensive care.
- We believe that preparation, emotional support and relaxation promote healing.



The Gillette craniofacial team collaborates to treat all problems associated with cleft lip or palate.

Dietitians

The core feeding team at Gillette includes registered dietitians, nurse practitioners, speech and language pathologists, and occupational therapists. We refer patients to other Gillette specialists, when needed, to help maintain proper nutrition and support health. Our team approach ensures comprehensive care for every patient.

Ear Nose and Throat (ENT)/Otolaryngologists

At Gillette, pediatric ENT (otolaryngologists) providers care for children and teens who have complex conditions that affect the head and neck, including the ears, nose and throat.

Our pediatric ENT providers collaborate with pediatric craniofacial and plastic surgeons as part of our integrated care model.

Nurse Practitioners—Feeding Specialists

Families of patients who have cleft lip and/or palate work closely with the nurse practitioners prenatally and/or after birth to assure proper growth and development. Nurse practitioners meet with families early on to discuss feeding methods, monitor weight and growth, and coordinate care with other services provided by the team. As the child gets older, the nurse practitioner continues to assess if the child is developing appropriately and provides additional resources (i.e. social work, psychology) as needed.

Craniofacial and Plastic Surgeon

Gillette is a leading provider of craniofacial and plastic surgery for patients who have complex conditions. We are committed to superb outcomes in patients who have conditions such as cleft lip and palate, craniosynostosis, deformational plagiocephaly, birth marks and skin anomalies.



*Robert Wood, MD, FACS, FAAP
Pediatric Craniofacial and Plastic Surgeon
Medical Director, Center for Craniofacial Services*

Our surgeons and nurse practitioners also collaborate with experts in speech and language pathology, neurosurgery, ENT, dentistry and orthodontics, and other specialties. Through Gillette Lifetime Specialty Healthcare, we serve patients whose needs continue into adulthood.

- Our pediatric craniofacial and plastic surgeons understand the unique needs of people who have conditions that began in childhood and affect their appearance and function.
- Our experts collaborate to provide comprehensive treatments that both minimize the need for surgery and maximize results.
- We pride ourselves on achieving the best possible outcomes in appearance and function.
- Our state-of-the-art technology and facilities are designed specifically for your needs.
- We believe that people who have disabilities deserve a lifetime of excellent health care — from birth through adulthood.

Speech and Language Pathologists

The speech and language pathologists at Gillette help patients who have conditions that affect speech, language, feeding and swallowing abilities. This team collaborates with providers across many specialties and services to provide comprehensive medical and rehabilitation care for every patient.

Our speech and language pathologists use the latest technology, tests and techniques to support patients who have disabilities, complex conditions, injuries, or delayed speech and language development.

We provide outpatient therapy sessions and support comprehensive inpatient rehabilitation care for patients who have a wide variety of conditions. Our goal is to help people achieve the highest levels of independence and function.

Audiologists

Our audiologists are experts in working with people who have physical disabilities as well as cognitive (thinking and learning), behavioral and communication challenges. We specialize in understanding how complex conditions, such as genetic syndromes, craniofacial conditions and neurodevelopment delays, relate to hearing challenges.

- We provide audiology care from experts who understand the unique needs of children, teens and adults who have disabilities and complex conditions.
- Our specialists collaborate to provide custom treatment plans.
- We provide facilities and technology designed specifically for your needs.



Gillette audiologists and speech language pathologists use the latest technology to assess your child's hearing and speech.

Dentists and Orthodontists

For children, teens and adults who have disabilities, finding appropriate dental and orthodontic care can be challenging. That's why Gillette offers dentists and orthodontists who understand the unique needs of people who have disabilities and complex conditions.

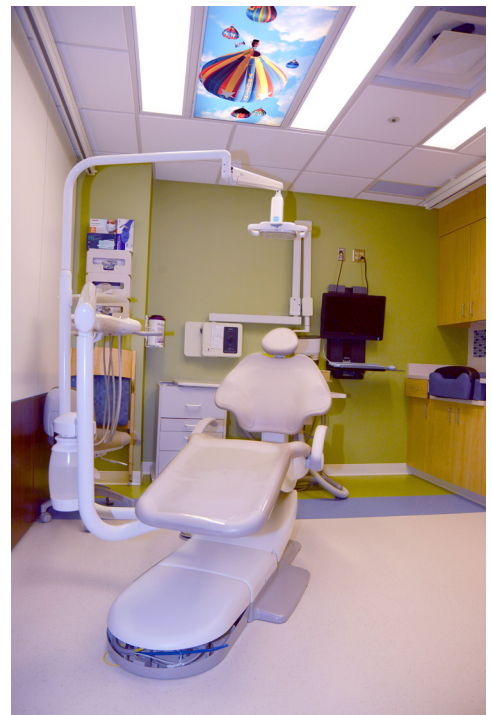
In addition to providing general dentistry and orthodontics for people who have complex conditions like cerebral palsy, our experts treat cleft lip and palate, hemifacial microsomia, and other disorders that affect the mouth and teeth. From sedation services to custom equipment, we have dental and orthodontic services designed to meet the needs of your child. Our dentistry and orthodontic services are primarily available to patients already receiving inpatient or outpatient medical care at Gillette.

- Our dentists and orthodontists understand the unique needs of people who have conditions that make routine dental care challenging.
- We provide dentistry and orthodontic care as part of a comprehensive treatment plan.
- Our features include sedated dentistry and specially designed equipment for people who have disabilities.
- We offer orthodontic care in a way that improves outcomes for children who have craniofacial conditions like cleft lip and palate.
- Our patients have access to a broad spectrum of services during a single visit.



Cheryl Anderson-Cermin, DDS, offers orthodontic care in a way that improves outcomes for children who have cleft lip and palate.

The Gillette dental and orthodontics team uses techniques such as visual distraction to make patients comfortable during their visit.



Presurgical Treatment

Before surgery, our surgeons often recommend that infants who have cleft lip or cleft lip and palate wear a presurgical OrthoCleft® appliance—an oral presurgical orthodontic device (PSO) that results in improved outcomes. The PSO appliance takes advantage of the fact that cartilage molds easily during the first six weeks after birth.

The PSO is custom molded to the baby's mouth and looks similar to an orthodontic retainer. The baby wears the device 24 hours a day (except for cleaning twice daily) until lip repair surgery. Many babies can feed better from a bottle once they begin wearing it. We gradually adjust the appliance to help change the shape of the mouth, nose and lip. When babies wear the PSO it can be painful for mothers during breast feeding. Mothers might find it more comfortable to use a pump to express their breast milk and then use a feeding system recommended by a Gillette provider.



The OrthoCleft® retainer results in better surgical outcomes.

The OrthoCleft helps:

- Bring the gum segments together.
- Reduce the size of the gap in the mouth.
- Stretch the lip muscles.
- Give the nose a more even shape.

Like other oral retainers, the OrthoCleft retainer is made of acrylic and wires. We use soft acrylic for areas that touch the mouth or nose, making the appliance easier for a baby to tolerate. Our orthodontists customize and fit the appliance when a baby is about a week old. Once a month—until the first surgery takes place, at about 3 months—we make a new appliance to ensure a good fit as your child grows. In the meantime, we typically adjust the PSO on a weekly basis.

Early use of the OrthoCleft retainer results in better surgical outcomes. In fact, estimates show that children who use presurgical appliances need 20 to 30 percent fewer reconstructive surgeries than those who don't.

In most cases, proper presurgical treatment by a craniofacial surgeon and an orthodontist results in correction with a single surgery (rather than requiring multiple procedures over time). Undergoing fewer surgeries reduces risks and complications, such as those associated with anesthesia.

Surgical Treatment

The goal of repair surgery is to close the cleft and repair associated anomalies. Ultimately, we seek to improve the child's health and physical appearance, thereby promoting self-esteem.

- **Cleft Lip Repair:** Cleft lip repair normally requires only one reconstructive surgery to restore the mouth's normal shape and muscle function. This surgery typically occurs when babies are about 3-4 months old. We modify the procedure for children who need bilateral cleft lip repair. Surgery to repair the nostrils takes place during the surgery, with later revisions, if needed.
- **Cleft Palate Repair:** In cleft palate surgery, the goal is to close the opening in the roof of the mouth, enabling a child to eat solid foods and learn to speak properly. This surgery is more extensive than cleft lip surgery and typically occurs when a child is between 9 and 12 months old. Some children with cleft palates will need additional surgeries as they grow and develop to help with speech, improve the appearance of the lip and nose, close openings between the mouth and nose, and assist breathing.

Hospital Stay for Cleft Lip Repair and Cleft Palate Repair

The day of surgery please **arrive at the Gillette 3rd floor registration check in** for surgery **1.5 hours before your surgery time.**

You and your child will then go to the pre-operative area where you will meet your nurse, nursing assistant, surgeon, anesthesiologist and child life specialist. When it is time for surgery, your child will be brought to the operating room for the procedure. After surgery your child will recover in the post anesthesia care unit (PACU) and you will be able to see your child. Once your child is awake, he or she will be transferred to the nursing unit and continue to be cared for until they are discharged to home.

Cleft Lip Repair

Estimated Time Duration of Surgery: One hour (this time is an approximation and subject to change).

Length of Hospitalization: Typically a 1-2 night stay. Your child is able to go home when they tolerate an oral diet, are comfortable on oral pain medications, have no signs or symptoms of infection, and when vital signs (i.e. temperature, blood pressure) are stable.

Diet: Same diet as before surgery (i.e. formula, breastmilk) using the same bottle. We discourage use of pacifiers for two weeks.

Activity: Activities of daily living as tolerated while no soaking or submerging incision for two weeks. Your child can be held as they are normally held. Your child will wear “No-No” sleeves that prevent bending of the arms so they cannot put their hands in their mouth or disrupt the incision.

Wound Care: Allow steri-strip to fall off on its own. Sutures are absorbable and do not need removal. Monitor for signs/symptoms of infection (redness, swelling, drainage, warmth, fever >101.5, uncontrollable pain).

Pain Management: In order to keep your child comfortable, they might receive IV pain medications (i.e. morphine, tylenol) and oral pain medications (i.e. tylenol, oxycodone). By the time your child goes home, they should be comfortable with oral pain medications.

Follow-up: Typically 1-2 weeks with surgeon. May follow up with audiology or ear nose and throat physician as needed for evaluation of pressure equalizing tube function or placement to promote healthy hearing.

Cleft Palate Repair

Estimated Time Duration of Surgery: One hour (this time is an approximation and subject to change).

Length of Hospitalization: Typically a 1-2 night stay. Your child is able to go home when they tolerate an oral diet, are comfortable on oral pain medications, have no signs or symptoms of infection, and when vital signs (i.e. temperature, blood pressure) are stable.

Diet: Full liquid or pureed consistency diet with no chunks for two weeks, then a soft diet (i.e. breads, pasta, scrambled eggs) for one week, then advance as tolerates and as age-appropriate. Avoid pacifiers for two weeks. Soft tip sippy cups or open cups are preferred for fluids. OK to use soft tip spoons for solid foods

Activity: Activities of daily living as tolerates while no soaking or submerging incision for two weeks. Your child can be held as they are normally held. Your child will wear “No-No” sleeves that prevent bending of the arms so they cannot put their hands in their mouth or disrupt the incision.

Wound Care: Monitor for signs/symptoms of infection (redness, swelling, uncontrollable pain, drainage, excessive swallowing or fever >101.5F). Might wear “No-No” sleeves to protect incision for 2 weeks, may brush lower teeth with assistance and keep toothbrush out of palatal area, normal saline drops as needed to nose but NO bulb suction.

Pain Management: In order to keep your child comfortable, they might receive IV pain medications (i.e. morphine, tylenol) and oral pain medications (i.e. tylenol, oxycodone). By the time your child goes home, they should be comfortable with oral pain medications.

Follow-up: Typically 1-2 weeks with surgeon.

Pharyngeal Flap Procedure

Estimated Time Duration of Surgery: 45 minutes (this time is an approximation and subject to change).

Length of Hospitalization: Typically a 1-2 night stay. Your child is able to go home when they tolerate an oral diet, are comfortable on oral pain medications, have no signs or symptoms of infection, and when vital signs (i.e. temperature, blood pressure) are stable.

Diet: Full liquid or pureed consistency diet with no chunks for two weeks, then advance to soft diet (soft breads, pastas) for one week, then advance diet as tolerates with age-appropriate foods.

Activity: Activities of daily living as tolerated while no soaking or submerging incision for two weeks. No contact sports for two weeks.

Wound Care: Monitor for signs/symptoms of infection (redness, swelling, uncontrollable pain, drainage, excessive swallowing or fever >101.5F). Due to swelling and tissue flap location, your child's airway may become occluded and you may notice snoring when your child sleeps. It is important to notify your surgeon if your child is excessively tired during the day, taking more naps, has changes in school performance or decrease in overall energy levels. These are symptoms of obstructive sleep apnea due to the swelling and tissue flap, which block your child's airway preventing them from taking full breaths.

Pain Management: In order to keep your child comfortable, they might receive IV pain medications (i.e. morphine, tylenol) and oral pain medications (i.e. tylenol, oxycodone) after surgery. By the time your child goes home, they should be comfortable with oral pain medications, but may have some remaining soreness and tenderness of the throat that will gradually get better.

Follow-up: Typically 1-2 weeks with surgeon.

Cleft Rhinoplasty

Estimated Time Duration of Surgery: One hour (this time is an approximation and subject to change).

Length of Hospitalization: Typically a 1 night stay. Your child is able to go home when they can tolerate an oral diet, are comfortable on oral pain medications, have no signs or symptoms of infection, and when vital signs (i.e. temperature, blood pressure) are stable.

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Cleft Rhinoplasty (continued)

Diet: May advance diet as tolerates. Avoid hard crusty foods that cause tension to lip/nose.

Activity: Activities of daily living as tolerates while no soaking or submerging incision. No contact sports for two weeks. Avoid blowing nose to prevent nasal stent from becoming dislodged.

Wound Care: Monitor for signs/symptoms of infection (redness, swelling, uncontrollable pain, drainage, excessive swallowing or fever >101.5F). May shower/bathe. DO NOT immerse or soak incision. If stints are present, these will be removed at post-op appointment. OK to apply gauze and tape dressing underneath nose if needed for drainage.

Pain Management: In order to keep your child comfortable, they might receive IV pain medications (i.e. morphine, tylenol) and oral pain medications (i.e. tylenol, oxycodone). By the time your child goes home, they should be comfortable with oral pain medications.

Follow-up: Typically in 2-3 weeks with surgeon. If a nasal stent is placed to maintain shape and provide support to your child's nose, it will be removed at the time of their follow-up appointment.

Alveolar Bone Graft

Length of Hospitalization (for each procedure): Typically a 1-night stay. Your child is able to go home when they tolerate an oral diet, are comfortable on oral pain medications, have no signs or symptoms of infection, and when vital signs (i.e. temperature, blood pressure) are stable.

Diet: Full liquid or pureed consistency diet with no chunks for two weeks, then advance to soft diet (soft breads, pastas) for one week, then advance diet as tolerates with age appropriate foods, while avoiding biting into hard apples, breadcrumb (i.e. pizza crust) for six weeks.

Activity: Activities of daily living as tolerates while no soaking or submerging incision or pin sites.

Wound Care: Monitor bone graft site and hip incision for signs/symptoms of infection (redness, swelling, uncontrollable pain, drainage, excessive swallowing or fever >101.5F). Keep toothbrush out of upper gums until directed by surgeon. May shower. DO NOT immerse or soak incision. Allow steri strip on incision to fall off on its own, do not remove. If present, stitches are absorbable and do not require removal.

Pain Management: In order to keep your child comfortable, they might receive IV pain medications (i.e. morphine, tylenol) and oral pain medications (i.e. tylenol, oxycodone). By the time your child goes home, they should be comfortable with oral pain medications.

Follow-up: Typically 1-2 weeks with surgeon.

Le Fort Procedure

Prior to Day of Surgery: If a rigid external distraction (R.E.D.) is needed, an orthodontic appliance must be made before surgery and then typically placed the day before surgery.

Length of Hospitalization: Typically a 1-2 night stay. Your child is able to go home when they tolerate oral diet, are comfortable on oral pain medications, have no signs or symptoms of infection, and when vital signs (i.e. temperature, blood pressure) are stable.

Diet: Full liquid or pureed consistency diet with no chunks for two weeks.

Activity: Activities of daily living as tolerates while no soaking or submerging the incision for two weeks. If your child has an R.E.D. no soaking or submerging of pin sites or incision until cleared by surgeon. No contact sports for two weeks or until cleared by surgeon.

Wound Care: Monitor incision for signs and symptoms of infection (redness, swelling, drainage, uncontrollable pain, fever >101.5F). Swish and spit mouth wash twice a day for 10 days total. OK to brush lower teeth and tongue. DO NOT brush upper teeth or gums. If R.E.D. present, clean head pin sites twice a day with sterile water and cotton tip applicator.

Pain Management: In order to keep your child comfortable, they might receive IV pain medications (i.e. morphine, tylenol) and oral pain medications (i.e. tylenol, oxycodone). By the time your child goes home, they should be comfortable with oral pain medications.

Follow-up: Typically in 1 week. If R.E.D. is placed, your child will also get a cephalogram, an x-ray of the craniofacial area, to evaluate advancement at a follow-up appointment.

Managing Pain and Incision Care

Generally children who have had a repair have some discomfort in the area of the incision. However, this usually lasts for only a few days and improves each day after surgery. Your child may want to be held more frequently after surgery. Holding and comforting your child might decrease the need for pain medication.

The incision inside the mouth is closed with absorbable sutures, which dissolve in 10-14 days. Do not rinse or rub the incision to clean it. The incision will heal best without any manipulation or handling. After cleft lip or palate repair, we will send your young child home with soft arm restraints called “No-No” sleeves. The sleeves keep your child from putting hands, toys or other objects in their mouth. You may remove the sleeves when you are holding and supervising your child. Your child will wear the sleeves until the follow-up appointment with the craniofacial team—usually in about 7-10 days.

Medicines for pain are provided during the hospital stay, and you will be sent home with a prescription and instructions for pain control. Many children do fine with children's acetaminophen.

Feeding babies is a special experience for parents and infants. Feeding provides babies with the nourishment they need to grow and provides parents a time to bond with their child. As infants eat, the sucking provides exercise to develop the tongue and oral muscles that are important in chewing and speech development.

An infant with a cleft lip usually has few, if any, feeding problems. Feeding a healthy baby with a cleft palate or cleft lip and palate can be more challenging. To suck, a baby must be able to compress a nipple between the tongue and the roof of the mouth. The lips complete the seal, creating negative pressure that allows the infant to draw milk from the nipple. The severity of the cleft lip or palate (or both) affects an infant's ability to suck and obtain enough nourishment for growth and development. With a little help you will successfully feed your baby.

Your Child's Nutritional Needs

When feeding infants, it helps to understand their nutritional needs.

A full-term, healthy newborn generally needs two to three ounces of breast milk or formula per pound of body weight per day. A newborn infant normally can lose up to 10 percent of birth weight in the first weeks of life. Following this initial weight loss, the baby will gain approximately three-fourths to one ounce per day, returning to birth weight by two weeks of life. Average weight gain in the first three months of life is four to seven ounces a week.

Once feeding patterns are established, most babies can complete a bottle feeding in 20 to 30 minutes. Breast-feeding may initially take a little longer, as mom and baby learn which feeding position works best for them. Feedings are usually one and a half to three hours apart for a breastfed baby (8 to 12 feedings in 24 hours) and two-and-a-half to four hours apart for a formula fed baby. A newborn may occasionally take a single four-hour rest period within a 24 hour period in the first three to four weeks.

A child with a cleft palate or both a cleft lip and palate often takes longer to feed and feedings may be more frequent. If your baby is taking more than 30 to 40 minutes to feed, or if feedings are consistently less than two hours apart, your baby may be using too much energy to obtain nourishment and calories for growth.

If your child is excessively sleepy, it can be a warning sign of poor nourishment. Poor urine and stool output and inadequate

weight gain signal a reduced intake of calories. Logging your baby's feedings, along with urine and stool output, is a good way to tell if your infant is getting enough to eat. Days 1-6, the number of wet diapers should be equal to the day of life. After six days of life, babies should have 6-8 wet diapers per day. For example, by the fourth or fifth day of life, a baby should urinate at least 4 to 5 times in 24 hours. Infant stools should change to a yellow color by the fourth day of life. An infant may have only one stool per day or up to four stools per day, depending on if they are breastfed or bottle fed. If your baby isn't meeting these guidelines, please contact your baby's health care provider or the Gillette craniofacial team feeding specialist.

Good nutrition is especially important in infants with cleft lip and palate. These children need to build up resistance to infection to be strong for surgery, and to have the nutrients needed to heal after surgery. For infants with poor weight gain, breast milk can be fortified, or higher calorie formulas can be used to meet nutrition requirements. You can also contact our craniofacial team feeding specialists with questions. A clinic visit will reassure you that your child is receiving enough nourishment. It will also let you ask questions and obtain further support, if needed.



The craniofacial team feeding specialists will help you select a feeding system for your child.

Overcoming Feeding Challenges

Infants with a cleft palate lack the normal bone and soft tissue separation between the nose and mouth. As a result, the baby may get milk into the nose. This is called nasal regurgitation. Nasal regurgitation can be upsetting, but there's no need to be alarmed if milk slowly runs out of your baby's nose or if your baby sneezes or coughs clearing milk from the nostrils. Have a soft cloth readily available to wipe the baby's nose and mouth and to allow the baby to rest a few moments before resuming feeding.

Cleft palate babies feed better when positioned upright (at a 60- to 80-degree angle) with the chin tilted up, so there's less of a chance of milk getting into the nose. As with all infants, rather than propping your child up, it's best to hold your baby during feedings. Frequent burping (approximately every 5 to 7 minutes) is important since infants with cleft lip and/or palate tend to swallow a lot of air. You'll know your baby needs to burp when the sucking rhythm slows or your child wiggles and appears uncomfortable.

Many babies with cleft palate cannot create enough suction to successfully draw milk from a breast or an ordinary bottle nipple to maintain adequate nourishment. Therefore, specialized bottles and nipples are needed for children with cleft palate. These are needed until the palate is surgically corrected, and at times for a short period of time after surgery. Techniques can help, such as directing the nipple back and slightly toward the more intact part of the palate. This avoids the cleft and allows the baby to compress the nipple between the remaining palate or upper gum, and the tongue.

Coordinating sucking and swallowing with breathing can be a problem for a child with cleft palate and/or lip, especially those infants who have associated neurological disorders. When using a specialized nipple or bottle, depending on the bottle, you can gently squeeze the bottle or nipple, allowing your baby to set the pace of sucking and swallowing. You'll probably need to adjust the pressure and direction/position/angle of the nipple as you're learning how your baby eats best. The bottle and nipple system used early on may need to be modified as your baby grows, while allowing for good use and development of the muscles of the face and mouth.



From left to right: Avent "My Natural Drinking Cup," The Cleft Palate Nipple, Special Needs Bottle by Medela, Dr. Brown's Specialty Feeding System, Mead-Johnson Cleft Palate Nurser, Nosey Cup

Feeding System Options

There are several bottle and nipple systems available for babies who have cleft lip and palate. You can go to [amazon.com](https://www.amazon.com) to purchase these systems. Here are several options to look for when choosing feeding supplies.

- **A soft nipple that allows the milk to flow moderately**—if the flow is too fast it can overwhelm your baby, if the flow is too slow it may cause exhaustion.
- **A squeezable, soft-sided bottle** or specialized nipple that allows you to gently compress the bottle in rhythm with your baby's sucking, swallowing and breathing cycles.

- **A nipple designed specifically for special feeding needs.**

Simply enlarging the hole in the tip of the nipple is not recommended. This will result in a steady flow of milk that may cause the baby to lose control of sucking, swallowing and breathing—possibly leading to choking and fatigue. It also increases the risk of aspirating part of the nipple as it wears out.

Nipples that are too short or too long may make it difficult for a baby with a cleft lip and palate to suck. Short nipples are not long enough to make good contact with the baby's hard palate and tongue. Nipples that are too long can gag the baby.

As babies grow and increase in strength, nipple requirements may change, so be prepared to adjust the bottle and/or nipple that you're using.

Four bottle and nipple systems are available for trial from the Gillette craniofacial team.

- **The Cleft Palate Nipple (aka the "Pigeon" nipple) by Children's Medical Ventures.**

This system has a firm bottle and a bulbous nipple with a Y-cut that is softer on the underside. It also has a one-way flow valve. This works well for infants who have good tongue extension and sucking coordination. It can also be used in conjunction with a Playtex Vent-Air bottle (nipple collar is interchangeable).

- **Special Needs Bottle By Medela** (formerly known as the Haberman Feeder) has a squeezable nipple with a slit, but the bottle is firm. Straight-line markings of different lengths are visible at the base of the nipple. The mark is "lined up" with the baby's nose. The longer the line, the faster the flow. The nipple may be squeezed gently which allows the baby to compress the nipple and control the flow of milk. The bottle also has a valve, which hinders excessive air from getting into the nipple and subsequently, into the baby's tummy.

- **Dr. Brown's Specialty Feeding System** has a unique bottle/nipple/valve system designed to assist infants and bottle-fed children with severe to profound difficulty in efficiently getting nutrition through a bottle. The unidirectional flow valve is known as the "Infant-Paced Feeding Valve."

- **The Mead-Johnson Cleft Palate Nurser** has a squeezable bottle and soft cross-cut nipple, which directs the milk flow beyond the cleft. This bottle should be gently squeezed, so the baby can compress the nipple and control the milk flow.

The Gillette craniofacial team is happy to help you choose and obtain a feeding system that is right for you and your baby. We will also answer any questions you have after you go home and at any time between follow-up appointments. Some children with cleft lip and or palate meet with the nurse practitioners (feeding specialists) on a weekly basis until feeding and weight gain are well established.

Special Tips for Breast-feeding Moms

The American Academy of Pediatrics recommends breast milk as the best form of nutrition for all babies. Children with cleft palate are more susceptible to ear infections as their eustachian tubes don't work as effectively. Breast milk, with its anti-infective properties, affords some protection for infants who have cleft lip and palate. Breast milk is easily digested and is, therefore, associated with fewer digestion problems such as colic and constipation.

A baby who has a cleft lip will most likely be able to breast-feed directly at the breast without difficulty. Often the breast tissue will fill the cleft to create a seal. You also may be able to seal the cleft with a finger while breast-feeding. If a pre-surgical oral appliance (PSO)/OrthoCleft® is used—breast-feeding directly at the breast may be painful for the mother. Most mothers prefer to pump and bottle feed when an oral appliance is used.

Breast-feeding a baby who has a cleft palate is more of a challenge. Early and frequent breast stimulation is extremely important when breastfeeding a child who has a cleft palate. Most babies with a cleft palate are not able to get enough nourishment at the breast alone. You may need to express additional breast milk or your child may need supplemental feedings. Some mothers pump breast milk and put the milk into one of the special bottles designed for children who have a cleft palate. You should start double pumping both breasts with a hospital-grade, electric breast pump within 6 to 8 hours following the delivery of your baby. Most hospitals have these pumps available for new mothers.

You should pump for 10-15 minutes, 6 to 8 times in 24 hours following breast-feeding attempts. If your baby is unable to nurse, pump at least eight or more times in a 24 hour period. This helps to establish and maintain your milk supply. Most breastfed babies will demand 8 to 12 feedings in 24 hours. By pumping after feedings, you stimulate the prolactin (milk making hormone) receptors in the breast during the “early calibration phase” of milk production.

A visit with a feeding specialist at the hospital where you delivered your baby will ensure you're off to a good start when it comes to feeding your infant. It's important to note that most breast pumps purchased over the counter at your local drugstore do not provide adequate stimulation to maintain your milk supply. If you require a pump at home, you should use a hospital-grade electric pump. A Gillette feeding specialist can help you obtain a hospital-grade electric pump.



Determining the Feeding Method

The feeding method you chose, in consultation with your health provider, must ensure your baby will gain enough weight to sustain appropriate growth and development. It should also foster bonding and promote good feeding skills.

The feeding schedule of infants with cleft lip and palate follow the American Academy of Pediatrics recommendations for all infants.

- **Infants up to 6 months**—breastmilk and/or formula.
- **4 to 6 months of age**—Introduction of cereal mixed with breastmilk and/or formula.
- **5 to 6 months**—Introduction of strained vegetables and fruits.

There are no restrictions from the normal pattern of introducing solid foods, except around the time of cleft lip and palate surgery.

Be aware that just as milk might initially come through your baby's nose, the same nasal regurgitation may occur when you introduce strained or soft-cooked foods. When this happens, your baby might clear the nose with a sneeze or cough. You can then wipe their nose and mouth with a clean, moist cloth and allow your baby to resume feeding. Normal saline drops can be used to help clear any residual material, as needed.

Feeding Before and After Surgery

The Gillette craniofacial team will advise you about feeding restrictions before and after your child's surgery. Cleft lip repair is normally done at 3 months of age. Most babies can resume breast or bottle-feeding immediately after the initial surgical recovery period.

To maximize good speech development and facial growth, cleft palate repair is usually done at 9 to 12 months of age. Introducing your baby to a sippy cup with a soft spout (such as the “Nuby” or “Avent”), spoutless sippy cup (Avent My Natural Drinking Cup by Philips), or “nosey” cup at 6 to 7 months of age is recommended (see photo of feeding systems). If your baby is used to using a cup with feedings, it'll be easier to feed your baby.

It's important for you to realize your child will be on a diet of full liquids, strained foods without “chunks” and pureed foods for about two weeks after cleft palate surgery. The use of a bottle or sippy cup with a firm spout is not recommended after your child's cleft palate surgery. The reason for these two restrictions is to keep the repaired cleft area free from food particles and disturbance. Foods with chunks may become lodged in the stitches near the repair area and could promote infection.

Gillette specialists will ensure your child is achieving good health and reaching growth benchmarks.



A Guide to Cleft Lip and Palate Repair

Prenatal
Consultation with a specialist



Birth to 4 Months

Presurgical orthopedics (if needed)

Feeding evaluations to ensure proper growth and weight gain, as needed.



3-4 Months

Cleft lip repair

9 to 12 Months

Cleft palate repair

In anticipation of speech and language development, or prior to learning many words.



18 to 24 Months

Begin to evaluate developing speech abilities

After 24 months, we'll evaluate speech regularly until skills reach typical range.

3 to 5 Years

Additional speech surgeries

In some cases, we might recommend surgery to correct velopharyngeal function for children who have hypernasality (too much sound or air through the nose for speech). Velopharyngeal function allows children to produce oral air pressure for accurate speech sounds.



Ongoing orthodontic evaluations

Until facial growth is complete.

4 to 6 Years

Follow-up nasal repair

This is the youngest a nasal repair would be considered for a patient. Nasal repairs are often performed later in life. The procedure might not be necessary, depending on the decision of the family and recommendation of the surgeon.



7 to 11 Years

Alveolar (gum line) bone graft

This might be necessary for teeth to grow properly, depending on the recommendations of the surgeon or orthodontist.



Teens

Le Fort procedure (if needed)

If the patient has misalignment or slowed growth of the teeth or jaw, this surgery repositions the upper jaw to a more optimal position.



Any Age

Cleft lip revisions

These can take place when needed, depending on the preference of the family and recommendation of the surgeon.



About Gillette

Gillette Children's Specialty Healthcare is an independent pediatric hospital specializing in treating children who have complex conditions, rare disorders and traumatic injuries that affect the musculoskeletal and neurological systems. Gillette providers treat patients—including adults who have conditions that began during childhood—who have complex medical needs.

In addition to our 60-bed hospital, we have eight primary clinics or hub locations, 11 outreach sites, and one adult clinic. We serve more than 25,000 patients each year, many of whom have rare or complex conditions. Our integrated care model means we organize care around a child's condition. Experts from multiple areas work together in highly coordinated teams, and patients can often see all of their providers on the same day.

Resources

For more information about the services and care at Gillette please go to gillettechildrens.org.

For more information about cleft lip and palate please go to the Cleft Palate Foundation website cleftline.org.

St. Paul (Main) Campus

200 University Ave. E.
St. Paul, MN 55101
651-291-2848
800-719-4040 (toll-free)

Gillette Children's Specialty Healthcare is named in honor of orthopedic surgeon Arthur Gillette, MD, who helped found the nation's first hospital for children who have disabilities. We are an independent, not-for-profit children's hospital, and our organization has no affiliation with the Gillette Company or the Gillette brand of personal care products.

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Contacts

Robert Wood, MD

Associate Medical Director
Pediatric Craniofacial and
Plastic Surgeon
651-602-3277

Paul Lim, MD

Pediatric Plastic Surgeon
651-578-5197

Martin Lacey, MD

Pediatric Craniofacial and
Plastic Surgeon
651-254-0883

Cheryl Anderson-Cermin, DDS

Orthodontist
651-312-3107

David Collier, DDS

Pediatric Dentist
651-229-3919

Micah Berman, MD

Pediatric Otolaryngologist/ENT
651-290-8707 (612-871-1144)

Benhour Soumekh, MD

Pediatric Otolaryngologist/ENT
651-290-8707 (612-871-1144)

Graham Schenck, PhD, CCC-SLP

Speech Language Pathologist
651-578-5256

Christina Kruse, MS, CCC-SLP

Speech Language Pathologist
651-578-5613

Martha McGrory, APRN, CNP

Pediatric Nurse Practitioner
651-312-3131

Katie Bucka, APRN, CNP

Pediatric Nurse Practitioner
651-578-5008

Analise Ludwig, AuD

Audiologist
651-578-5040

Stephanie Campbell, RD

Registered Dietitian
651-229-3933