Phoenix Children's®
Center for Cleft and Craniofacial Care



Cleft Lip and Palate Treatment Guide

Read more about Theo, our cover model, on page 5.



Photo taken by Ace Fanning Photography

Cover image taken by Vienna Glenn Photography

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Phoenix Children's®
Center for Cleft and Craniofacial Care

Welcome

Phoenix Children's Center for Cleft and Craniofacial Care was established more than 30 years ago as the Barrow Cleft and Craniofacial Center. Here, we help patients with facial differences navigate their care experiences successfully. Our multidisciplinary team of experts offers the highest level of quality and compassionate care, and we are accredited by the American Cleft Palate Craniofacial Association (ACPA).

Our caring team of experts includes:

Orthodontists

Our orthodontists provide orthodontic evaluations and treatments for patients with facial differences from birth into adulthood. In their role, the orthodontists are involved in preparing your child for surgeries such as cleft lip/nasal repair, bone grafting and jaw surgery. They also guide you and your child through phases of orthodontic treatment, as needed. Your child will likely meet with the orthodontist at birth and again around five or six years of age. The orthodontists will continue to be involved in your child's treatment until your child is fully grown.

Speech and Language/Feeding Therapists (SLP)

The role of the speech and language pathologist (SLP) is to provide initial evaluations and ongoing therapy for your child's feeding and speech development. In the first year of your child's life, our goal is to ensure your child is feeding effectively and gaining weight. As your child continues to grow, we will provide ongoing speech and language evaluations and treatment as necessary. Our SLPs also play a key role in determining whether surgery would benefit your child's speech and helping your child develop effective communication skills.

Behavioral Health Specialists

Our team of psychologists and social workers specialize in counseling parents, patients and siblings affected by a cleft or craniofacial diagnosis. These specialists provide support and education to families to help them adapt and adjust to having a child with a facial difference. The behavioral health team is available as a resource throughout your child's life to address behavior, emotions, social issues and even academic concerns. Our behavioral health specialists provide developmental evaluations periodically throughout your child's care and help prepare patients emotionally for surgery.

Plastic Surgeons

Our plastic surgeons evaluate your child and perform surgery when needed. The surgeon may meet with you and your child at birth and will continue to monitor them until they are fully grown. The surgeon will guide your child's care and coordinate treatments and therapies with our multidisciplinary team. The surgeons also work with a team of physician assistants, nurses, and medical assistants to provide the best possible care for your child.

We feel strongly about using a team approach when it comes to providing the best care for your child. Working with a group of providers specializing in facial differences allows us to provide a comprehensive evaluation and plan at each stage of your child's growth and development. We look forward to continuing to care for you and your child.

The Emotional Experience of Parenting a Child Born with a Facial Difference

You probably started your parenting journey assuming your baby would be born without a medical condition. Receiving the diagnosis was likely shocking, as it is for most parents in this situation.

If you are like many other parents facing this diagnosis, you may not know much about cleft lip and/or cleft palate. Our team is here to help educate and support you on this journey.

Following are some common questions and feelings we often hear parents express:

- "Why us?" or "Why me?"
- "What did I do wrong?"
- "How will I cope with this?"
- "How will this affect our lives?"
- "How will I care for my child?"
- "How will this affect my child's life?"
- "How will my child handle surgery and other medical procedures?"
- "How will my child be treated?"
- "How will my child feel about himself/herself?"

The initial time of diagnosis can often feel overwhelming and confusing. How the diagnosis is presented to you is something that can feel comforting or distressing, depending on your specific experience. If you received the diagnosis prenatally, you may find it especially difficult to cope with the "unknown." In our experience, this anxiety often decreases once you get to see and hold your baby.

It's natural to seek out information, especially online, to try to educate yourself and be proactive for your child. If searching the web increases your distress or anxiety, know that we are also here as a resource to empower and educate you.

Thoughts from Fellow Parents

"Enjoy the pregnancy. Don't stress about your baby and how he or she may look. Enjoy the wonderful journey you are about to embark upon. Enjoy feeling the kicks and movements."

"When I first saw Gabrielle, 20 weeks of worry and sadness melted away, and I instantly fell into the deepest love I have ever felt. I knew we could do anything, and we would do anything for her."

"She was born with a hole in her lip, but it's okay because the doctors can fix it. You should see her smile: It's beautiful."

"I would encourage someone with a new baby to look people in the eyes, and show them how proud you are of your child. I wasn't able to do that the first time I went into public with my sweet baby, but it got easier every time. I found that as my courage grew – that people were very supportive of me and my baby."

"In my experience, rude comments are few and far between! However, rude comments happen, and I always tell myself that they are just ignorant, and they don't know how to express their curiosity. Most of the time it's kids. It helped me to have a 'go to' response for any awkward encounter, and t hat way my emotions wouldn't get the best of me.

"I wish I had taken the advice of others to enjoy my pregnancy more."

What Is a Cleft Lip and Cleft Palate?

A cleft lip and a cleft palate are gaps or openings of the lip and roof of the mouth. They occur when the lip and mouth fail to form properly in the first trimester of pregnancy. A child can be born with a cleft lip, cleft palate or a variation of both.

Cleft lip and palate is the second most common congenital diagnosis with about 7,000 babies born in the United States with a cleft lip and/or palate each year. While receiving this diagnosis can be difficult, it is important to know that these conditions can be corrected with surgery. Most children born with a cleft lip and/or palate develop typically along with their peers.

Cleft Lip

A cleft lip occurs when the tissue of the lip does not fuse during the early stages of fetal development. There are many variations of a cleft lip, ranging from a small notch to a large opening that extends through the nose. Understanding these terms will help you when discussing treatment with your child's care team.

A cleft lip can be:



Unilateral, involving only one side of the lip

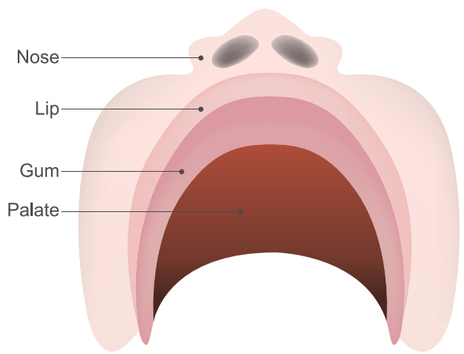
Bilateral, involving both sides of the lip

Incomplete, meaning it does not reach the nose

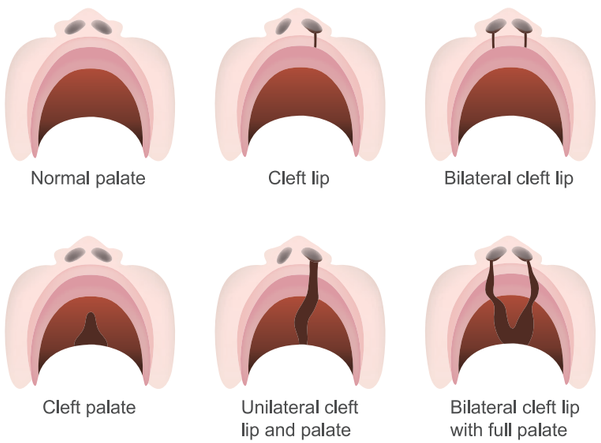
Complete, meaning it extends through the nostril

Cleft Palate

A cleft palate occurs when the roof of the mouth fails to fuse properly during early fetal development. This leaves an opening in the roof of the mouth. The opening can involve the hard palate in the front of the mouth, the soft palate in the back of the mouth or both. A cleft palate can occur with a cleft lip extending through the gumline or in isolation.



Oral Upper, Six-month-old (baby)





What Causes a Cleft Lip and Cleft Palate?

We do not fully understand what causes a cleft. Some clefts may be caused by genetic differences, while others may be caused by environmental factors such as alcohol or certain prescription medications. Many clefts seem to occur spontaneously and are not related to any genetic or environmental factors.

Most clefts are isolated and not associated with any physical or developmental differences. About 10 to 20 percent of clefts are related to a syndrome and associated with a group of symptoms that may impact physical or intellectual development. Your doctor will determine if a genetic evaluation is needed once your baby is born.

When Is a Cleft Lip and Cleft Palate Diagnosed?

A cleft lip can be detected on the fetal anatomy ultrasound in the second trimester of pregnancy. A cleft palate is sometimes detected at the same time but often hard to see on an ultrasound. If a cleft is not diagnosed via ultrasound, it is usually visible at birth or noted during the pediatrician's first examination. When a cleft is seen on prenatal ultrasound, expecting families have a chance to meet with our cleft team to discuss the diagnosis and treatment timeline to help prepare for the child's birth.

What Complications Are Associated with a Cleft Lip and/or Palate?

- **Feeding difficulties**

  A cleft may prevent your baby from forming proper suction, making breastfeeding or feeding through a regular bottle difficult. Babies born with a cleft palate (and some types of cleft lip) will need to use a special bottle to feed.

- **Ear infections and hearing loss**

  A cleft palate may increase your child's risk for ear infections. Repeated infections left untreated can lead to hearing loss. Your child's pediatrician will monitor your child's ears at each well check. An ear, nose and throat (ENT) specialist may need to see your child if they fail multiple hearing tests or have recurring ear infections.

- **Speech difficulties**

  Some children with a cleft palate have trouble with speech. A cleft can affect the length of the tissue of the palate and the way the muscle in the palate functions causing nasal sounding speech. (This is called velopharyngeal insufficiency or VPI.)

- **Dental complications**

  Children born with a cleft can have missing teeth, extra teeth or teeth that are in poor position.

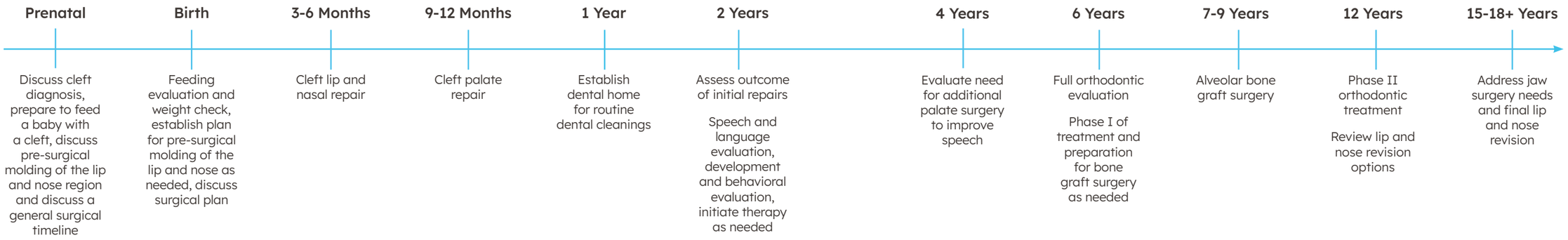
Treatment Timeline

At Phoenix Children's Center for Cleft and Craniofacial Care, your child's care team will develop a treatment timeline shortly after birth. We take the physical, social and emotional needs of you and your child into consideration when creating this plan. As your child grows, we will modify the timeline if needed.

This timeline is a general guideline for treatment. Your care team will customize it to meet your child's individual needs.

Your child will meet with our cleft multidisciplinary team at different points throughout their childhood and adolescent years. The team can also see your child in their adult years as needed. Team visits will occur at key times – for planning a surgery or evaluating speech, development and dental health. Each member of the multidisciplinary team will evaluate your child and participate in the discussion of their treatment plan.

CLEFT TREATMENT TIMELINE



Fearless Theo



Theo Forrest, age 4, is fearless and a bit of a daredevil, according to his parents, Erik and Emily. Anyone who's witnessed Theo's rambunctious energy and joyful personality might find it hard to believe his life has been marked by frequent doctors' appointments, regular blood draws and multiple surgeries for bilateral cleft lip and palate. He's taking it all in stride.

Early diagnosis sets the stage for effective treatment
Erik and Emily went to her routine 20-week prenatal ultrasound excited to learn the gender of their baby. But they left shocked, anxious and upset after the procedure revealed that Theo would be born with a cleft lip and cleft palate. The couple turned their fear into action, researching baby Theo's condition and learning what kind of care he would need.

Three months before Theo's birth, Emily and Erik met with plastic surgeon Davinder Singh, MD. The pre-birth consultation included meetings with other specialists who would be involved in Theo's care, including a speech and feeding therapist, an orthodontist and a psychologist.

After Theo's birth, he had weekly appointments at the center for several months. We monitored his feeding ability and weight gain and assessed him for upcoming surgeries.

Initial treatments lay the foundation
To prepare Theo for his lip repair procedure, Patricia Beals, DMD, began nasolabial molding when he was just a few weeks old. This nonsurgical technique reduces the cleft size and improves alignment of the lip and nose, ensuring better long-term results.

When Theo was about 4 months old, Dr. Singh performed surgery to repair his lip and nasal region.

When Theo was 10 months old, Dr. Singh performed surgery to close the roof of his mouth. And last August, at age 4, he underwent a second palate procedure to improve his speech. This involved taking a small amount of tissue from the inside of Theo's cheeks to extend his soft palate. Theo also works with speech therapists at Phoenix Children's and at his preschool.

Facing future treatments
Like most children with cleft lip and cleft palate, Theo will need additional surgeries as he gets older. The next planned procedure, alveolar bone grafting, will take place when he is around 8 years old. Dr. Singh will take a small piece of bone from another part of his body to build a stronger gum line around the repaired cleft lip. This will help support his permanent teeth.

Dr. Beals will closely monitor the growth of Theo's jaws and teeth. If his upper and lower jaws don't grow at the same pace, he may need surgery during his late teens – once his growth stops – to realign them.

Theo continues to thrive
Despite the challenges he's faced, Theo is thriving. Emily is grateful for the Phoenix Children's community, which includes Theo's medical team, as well as other families whose children have craniofacial differences. The Center for Cleft and Craniofacial Care hosts social activities, allowing families to meet and share their experiences.

"It's been wonderful getting to know other families going through many of the same issues we've dealt with," said Emily, who serves on the CCBD Family Advisory Board. "The team at Phoenix Children's does an incredible job."

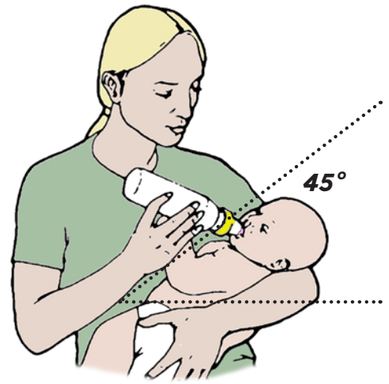
Feeding Your Baby

Except in rare cases, the opening in the palate makes it impossible for babies to seal their mouths and create the suction required for breastfeeding or feeding with a regular bottle. Almost all babies with a cleft palate and many babies with a cleft lip will need to use an adaptive bottle to get enough milk or formula.

Learning to feed a baby with a cleft lip and/or cleft palate takes practice. Our speech and language pathologist (SLP) will help you master this new skill.

Guidelines for Feeding Success:

1. Use an adaptive bottle.
2. Hold your baby in a semi-upright position – 45 degrees is ideal. Do not lay your baby on their back for feedings. If there are respiratory concerns, your SLP will show you how to use a side-lying position for your baby.
3. Place the bottle:
   a. On the non-cleft side of the mouth for babies with a unilateral cleft lip and palate (not inside the cleft area)
   b. At the midline in babies with a cleft palate only
   c. At the site of the mouth with the most tissue in babies with bilateral cleft lip and palate (This is usually at the midline.)
4. Burp your baby whenever they give you cues or halfway through feeding and at the end of feeding.



After the initial evaluation, your SLP will continue to monitor your baby's feeding, volume intake and weight gain. The SLP will send these feeding evaluations directly to your baby's plastic surgeon and other medical providers to coordinate care.

Adaptive Bottles

Your SLP will educate you on adaptive bottle options and help you choose the best one for your child. When feeding is going well with an adaptive bottle, it should take less than 30 minutes.

While there are many options available, we primarily recommend these two:

Dr. Brown's® Zero-Resistance™ Specialty Feeding System

How it works:
The baby directs the feeding by squeezing the nipple with their lips, gums or tongue.

You can learn more at:
drbrownsmedical.com/products/specialty-feeding/



Medela Special Needs Feeder

How it works:
The caregiver directs the feeding by squeezing the nipple to release liquid while the baby is sucking.

You can learn more at:
medela.com/breastfeeding-professionals/products/feeding/special-needs-feeder



What about Breastfeeding?

Even with professional support, exclusively breastfeeding is a difficult goal for babies with an uncorrected cleft palate or lip. However, you can still share many benefits of breastfeeding with your baby if you choose.

What you can do:

- Express breast milk with a pump, and feed your baby with an adaptive bottle.
  - You may find that a hospital-grade breast pump is helpful in meeting your feeding goals. Our team can give you information on where to rent or buy one if that is of interest.
- Enjoy eye-to-eye and skin-to-skin contact with your baby during feedings whenever possible.
- Put your baby to the breast for non-nutritive sucking **after** your baby has become successful at bottle feeding.
  - Non-nutritive sucking at the breast can be a satisfying bonding experience for both moms and babies.
  - Non-nutritive sucking exercises and stimulates important muscles in your baby's mouth and tongue.
  - It also helps stimulate milk production for moms who continue to pump breast milk.

If you decide that pumping does not work for you or your family's situation, you may choose to switch to formula. Please feel confident that your baby will receive excellent nutrition from formula.

Having a good support system in place for you and your family is important during this time. Ask your partner, family members or friends for help while you are learning to feed your baby. In addition, remember that you have resources through our team.



When Can My Baby Begin Solid Foods?

Each child's readiness to eat solid foods depends on their development. These guidelines, from *Nutrition: What Every Parent Needs to Know*, are recommended by the American Academy of Pediatrics (AAP) and will help you know when your child is ready.

- **Can your child hold their head up?** Your baby should be able to sit in a highchair, a feeding seat or an infant seat with good head control.
- **Does your child open their mouth when food comes their way?** Your child may be ready for solid food if they watch you eating, reach for your food and seem eager to be fed.
- **Can your child move food from a spoon into their throat?** If you offer your child a spoon of rice cereal:
  - Do they swallow it without problem? If so, your child is likely ready for solid food.
  - Do they push it back out of their mouth where it dribbles down their chin? Your child may not yet be able to move food to the back of their mouth to swallow it. That's normal. Remember, they never had anything thicker than breast milk or formula before. This may take some getting used to. Try diluting the rice cereal the first few times you offer it. Then, gradually thicken the texture. You may also want to wait a week or two and try again.
- **Is your child big enough?** Generally, when infants double their birth weight (typically at about four months of age) and weigh about 13 pounds or more, they may be ready for solid foods.

NOTE: Breastmilk and/or formula will be your baby's sole source of nutrition for about six months. When you add solid foods to your baby's diet, continue bottle feeding until at least 12 months. You can continue to breastfeed after 12 months if you and your baby desire. Check with your child's doctor about the recommendations for vitamin D and iron supplements during the first year if using breast milk.

Which food should I give my baby first?

For most babies, it does not matter what the first solid foods are. By tradition, single-grain cereals are usually introduced first, though you may choose to start with purees instead.

There is no medical evidence that introducing solid foods in any particular order has an advantage for your baby. In addition, while many pediatricians recommend starting vegetables before fruits, there is no evidence that your baby will develop a dislike for vegetables if fruit is given first.

When you introduce purees, we recommend using a shallow or flat spoon at first. Your baby will not have any other restrictions because of the cleft.

If your child has an unrepaired cleft palate, food may enter their nasal cavity. This can cause watery eyes and/or sneezing, and food may come through their nose. This is okay. Simply wipe the cereal or puree away if needed, and continue feeding. You can wipe away most of the puree, or it will clear when your child swallows.

If you have concerns after wiping and swallowing, give your child a drink of breastmilk/formula or suction out their mouth/nose, if desired. Although unexpected, if you see any signs of coughing or choking, stop feeding your baby, and consult your SLP. Remember to follow your surgeon's guidelines regarding purees after any surgical intervention.

Big Smile, Bright Future



Two-year-old Dylan Perez has kept his parents busy (and smiling) since day one. When he was born, he immediately had the whole room laughing as he stuck his booty straight in the air while being weighed. And since then, he's continued to be a bundle of fun energy. You would never believe that he's already had two surgeries, one for a cleft lip and one for a cleft palate.

Early feeding challenges were met with support
Dylan was born with a right unilateral complete cleft lip and palate, the most common type. One challenge Dylan's parents noticed right away was his inability to breastfeed or take a bottle. Arthur remembers being able to see inside Dylan's nose every time he opened his mouth.

"He wasn't able to suck because of the palate being open," he said. "Every time he would eat, he would choke because it would go down his breathing tube."

Dylan's family received support from the beginning. They met with our feeding therapist, who spoke to them in Spanish and helped them learn how to feed Dylan at home.

Surgery preparation and teamwork
The only treatment for a cleft lip and palate is surgery, so the family scheduled Dylan's cleft lip surgery first. Dylan's family also met with one of our orthodontists. The orthodontist showed them how to use a special type of tape to pull the two sides of the lip closer together. They also used a plastic stent to improve the shape of Dylan's nose.



"The cleft and craniofacial team guided us through the whole thing, and they were awesome," said Arthur. "They showed us exactly what we needed to do."

After cleft lip and palate surgery
Because of Dylan's cleft lip and palate, he'll always be at risk for speech differences. His feeding therapist will transition into offering speech therapy. They'll follow him as his speech develops and provide treatment if needed. Dylan also will continue working with an orthodontist throughout his adolescence.

It's possible that Dylan will benefit from a touch up surgery either before kindergarten or in his teenage years. But otherwise, Dylan is growing up and on the move.

Early Speech and Language Development

What can you do to help your child's speech development before palate repair?

- Continue to treat, play, talk and interact with your child just as you would if they did not have a cleft palate.
- You will hear the following sounds: "m," "n," "w," "y" and sometimes "h." You should also hear many vowel sounds like: "ah," "oh" and "ay." The sounds "ee" and "oo" can be more difficult for children with clefts, though some children produce them easily.
- Words to model prior to cleft palate repair (and continue to address after repair) include:
  - **M, N:** "mom," "me," "mine," "my," "more," "moo," "no," "nana," "now," "in," "on," "none"
  - **W:** "whoa," "wow," "wee," "want," "water," "one," "win"
  - **Y:** "yay," "yeah," "yum," "yummy"
  - **H:** "who," "how," "hey," "hi," "he," "hello," "home," "him"



Suggestions to increase early language skill development:

- Label items at the store, at home and in books. Read aloud with your child as often as you can.
- Hold items up beside your mouth, and verbally model the word (For example, hold an apple by your mouth, and say, "apple." Then give your child the apple.) Encourage any sound made by your child.
- Begin to model, and implement "baby signs" such as the words: "all done," "car," "eat," "drink," "please," "ball," "shoes," etc. Say the word, and make the sign at the same time for your child.
- Talk while doing things and going places. When taking a walk in the stroller, for example, point to familiar objects (e.g., cars, trees and birds), and say their names. Examples: "I see a dog." "The dog says, 'woof.'" "This is a big dog." "This dog is brown."
- Use simple but grammatically correct speech that is easy for your child to imitate.

How does speech change after palate repair?

- You will hear fewer "m" and "n" sounds because your child will increase production of "b," "p," "d," "t" and possibly "k" and "g." Ideally, you will hear these sounds and not sounds that are made in the throat.
- Sounds produced in the throat are one type of compensatory speech error children learn due to lack of palate closure (oral pressure). Our goal is to prevent and minimize the development of these errors.
  - An example of a throat sound is the "uh" in the word "uh-oh." Although this word may sound clear when your child says it, it is more helpful to teach them to say, "wow," "oh no" or other sounds produced in the mouth using the lips or tongue to avoid developing throat sounds. Otherwise, your child may overuse the "uh" sound for all stop/pressure sounds – like "b," "p," "d," "k" and "g" – making it difficult to understand your child's speech.

How can you help stimulate sound development?

- Early developing sounds include “b,” “p,” “t,” “d,” “y” “w,” “m,” “n” and “h.” Often “m,” “b” and “p” are good starting sounds since they are easy for your child to see you produce with your lips closed. Whenever possible, have your child watch your mouth when you make speech sounds.
- If you continue to hear an “m” sound when you child makes a “p” or “b” sound, or an “n” sound when you child says a “t” or “d” sound, you can plug their nose to demonstrate the sound. This does not change how their palate works, but it allows your child to have the feeling of saying a sound not coming out of their nose. You can also model keeping your lips closed when making these sounds for your child. This helps your child learn to make the sound in their mouth instead of their throat.
- You can introduce sounds during daily activities:
    - Make bath time “sound play time.” During bath, you are eye-level with your child. Play with Peter Tugboat, who says, “p-p-p-p.” Let your child feel the air of sounds as you make them.
    - Blow bubbles, and make the sound “b-b-b-b.”
    - Sound-walk around your house or in your child’s room. Introduce them to Timmy Clock, who says, “t-t-t-t.” Listen to the clock as it ticks.
- Words that may be helpful to model include:
    - **B:** “bye,” “bee,” “boy,” “ball,” “baby,” “bubble,” “beep,” “boo”
    - **P:** “papa,” “pop,” “pie,” “puppy,” “up,” “hop,” “happy”
    - **T:** “two,” “tie,” “tea,” “top,” “it,” “hot,” “hat”
    - **D:** “do,” “did,” (all) “done,” “dad,” “daddy,” “hide,” “had,” “head”
- When your child is two to three years old, try to stimulate sounds that have airflow in the mouth like “s,” “f” or “sh.” The “sss” for a snake sound and “shh” for “baby is sleeping” work well to practice. The word “off” is often a good way to try and start the “f.” If air is coming out of your child’s nose, you can also plug their nose on these sounds. Note: You do not need to plug their nose tightly – just make sure their nostrils are closed.
- Words that may be helpful to model include:
    - **F:** “full,” “fun,” “four,” “five,” “foot,” “off,” “if,” “woof,” “fee-fi-fo-fum” (from “Jack and the Beanstalk”)
    - **S:** “see,” “so,” “saw,” “say,” “sun,” “sign,” “some,” “ice,” “yes,” “house,” “miss,” “mess”
    - **SH:** “she,” “shoe,” “show,” “wash,” “wish”
- To show the difference between nose and mouth air, you can show how you blow your nose with nose air and bubbles with mouth air, and have your child try it. Blowing exercises do not directly help speech sound development.

You should be listening for nasal resonance and nasal emission in your child’s speech. What is that?

Resonance describes how sound comes through the mouth and the nose for all speech sounds with voicing.

- All sounds in English and Spanish are produced through the mouth (oral resonance) except “n,” “m,” “ng” (English) and “ñ” (Spanish). These are the only sounds that should be made through the nose as nasals.
- When the palate cannot separate the nose from the mouth, oral sounds (all sounds except “n” and “m”) have too much nasal resonance or nasality, and this is considered hyper-nasality. Too much nasal air flow is called nasal emission.
- When nasal sounds “n,” “m,” “ng” and “ñ” are produced with limited nasal resonance (e.g., when someone is congested and sounds “plugged up”), this is considered hypo-nasality.

Speak to your SLP at any time if you have concerns about your child’s speech skills.



Craniofacial Orthodontics

Your child’s craniofacial orthodontist will guide you through the specific stages of craniofacial (cleft) orthodontics required for your child’s care. Typically, more than one phase of orthodontic treatment is needed. As your child grows to the age of five or six, the orthodontist will assess and provide ongoing orthodontic treatment as needed.

All children born with a cleft lip benefit from orthodontic treatment to improve their function and appearance, and most children require orthodontics in conjunction with bone grafting. Your child’s specific orthodontic needs cannot be predicted in infancy, so we will continue to partner with you as they grow.

Before surgery, we will begin the nasolabial molding process – also known as “taping” and “stenting” – to improve your child’s lip and nasal form and position. This will ensure the best surgery results for your child.

Nasolabial Molding

Molding of the lip and nose is called nasolabial molding (or NLM). The NLM process molds the lip and nose using tape, elastic and acrylic. It is done while your baby is awake, and it does not hurt. Whenever possible, we will coordinate your NLM appointments with your feeding appointments.

Taping of the lip starts soon after your baby is born. The goal of taping is to decrease the width of the cleft and move the sides of the lip closer together. We will place the tape and teach you how to continue taping at home. We will also provide the supplies you need. In some cases, taping can help with feeding your baby.

We use an acrylic nasal stent to improve the shape of your child’s nose. The purpose of the stent is to make your baby’s nostril round on the side with the cleft and to create better projection of the nose. We will secure the stent to your child’s forehead with tape. It is removable and will not hurt your baby.

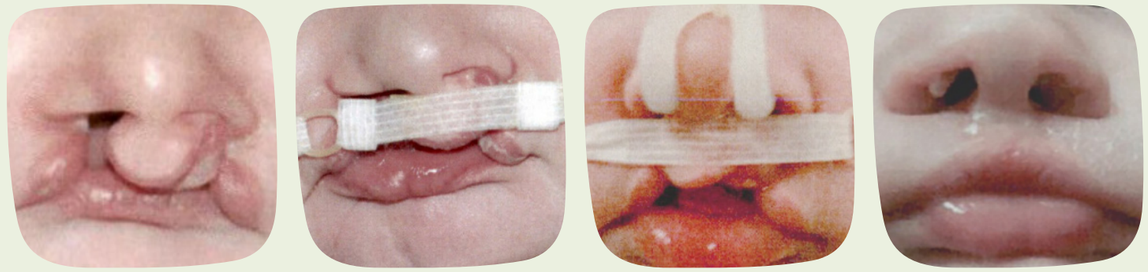
The combined goals of taping and stenting are to create symmetry, balance and better form of the face. Faithful taping and stenting will improve the evenness of your child’s lip and nose.

Unilateral Nasolabial Molding



Before taping *After taping* *After lip repair surgery*

Bilateral Nasolabial Molding



Before taping *During taping* *During stenting* *After lip repair surgery*

Behavioral Health Services

It is very normal to feel overwhelmed and anxious about the birth of a child with a facial difference, as well as the parenting journey ahead of you. Please know that if you are having these feelings, you are in good company! We have heard from many parents that it is helpful to speak with a mental health specialist during the adjustment process.

Our **clinical psychology team** is available to provide counseling to parents, children and siblings who are affected by a facial difference diagnosis. Counseling can provide support and education to your family to help improve overall family adjustment. At different times in your child's development, you may want to consult with our psychologist regarding issues such as behavior, emotions, social issues or academic concerns.

Our **clinical social workers** also provide resources to help you understand, navigate and engage in your child's medical care. Understanding treatment plans can be a challenge for anyone. Our social work staff can provide you with the support needed to feel empowered and capable to advocate for your child. You will encounter challenges along this journey. Our social workers will support you in your ability to face each challenge as it comes.

When children come into our lives, they have a powerful impact on us. They change us in ways that we never imagined. Use this experience as a positive one! Parents who embrace the whole experience – the challenging moments as well as the magical ones – tend to cope the best.

Parents who "roll up their sleeves" and do the necessary work ensure the best possible outcome for their child. This includes working on your own mental resilience, and we are here to support you in this effort. It will be important to find the strength within you that allows you to guide your child through life. You can do it!
We are here to help.

Surgical Repairs

Our team performs many different types of surgeries, including:

Cleft lip and nasal repair - Surgery to repair cleft lip is done around 3 to 6 months of age. Most babies will go home the same day and return to their previous method of feeding immediately after surgery. You can expect a one-week recovery from this procedure.

Cleft palate repair - Surgery to repair the palate, or roof of the mouth, is done between 9 to 15 months of age. Your child will stay at least one night in the hospital to ensure they are able to get enough to eat and drink by mouth, and to make sure their swelling and pain are well controlled.

Speech surgery – Secondary palate surgery, sometimes called VPI surgery, may be done to improve your child's speech. Evaluation for this process begins around age four, but a child can have surgery at any point after age four, even into adulthood. Not all children will need speech surgery.

Alveolar bone graft surgery – Bone graft surgery is done around ages seven and nine. During this procedure, bone marrow will be taken from your child's hip and placed into their gumline where the cleft once was. This will allow the adult teeth to come down properly. Your child will likely need bone graft surgery if they have a cleft that affected their gumline.

Jaw surgery – Jaw surgery is done once your child is done growing. For girls, this is usually around 15 to 16 years of age, while for boys it is closer to 18 to 20 years of age. This surgery is done to move the upper or lower jawbone to improve the way the teeth fit together ("the bite") and improve the facial profile. Your child's surgical and orthodontic team will determine if your child needs jaw surgery closer to their teenage years.

Lip and nasal revision surgery – This surgery can be done to improve the appearance of the lip and nose after the initial repairs in infancy. Lip and nasal revision can be done at any time, but we usually wait until your child is done growing. Waiting prevents the need for multiple surgeries and the formation of scar tissue. Your child's surgeon and behavioral health team will discuss options with them at each visit, considering your child's thoughts, their feelings about their appearance and their desire for surgery.

Preparing for surgery

You and your child will meet with the surgeon and team before the day of surgery. This is called a pre-surgical appointment. At this visit, we will talk about:

- Any testing needed before surgery
- When to stop feeding your child the morning of surgery
- When and where to arrive the day of surgery
- How the surgery will be performed
- How long you will need to stay at the hospital
- How to feed your child after surgery
- Activity restrictions
- When to call your child's surgeon
- When to follow up with the surgeon and cleft team



Scars

Each child heals differently. Your child's surgical site will change and mature over the course of an entire year as their body forms scar tissue and new blood vessels around the site to promote healing.

Right after surgery, you may notice a red, firm scar. It may become more noticeable up to three to six months after surgery. After this time, the scar will begin to mature and become lighter in appearance and softer to the touch.

You can help manage scar healing by:

- Massaging the scar several times per day. This helps break down scar tissue formation and achieve a flat, soft scar. Massaging with Vaseline®, Aquaphor® or a silicone-based gel to provide moisture can also help. Your child's surgical team will provide guidance on what will work best for your child.
- Protecting the scar from the sun, especially in the first year after surgery. Your child's surgical team will let you know when you can begin using sunscreen on your child's scar. Until then, you should keep the scar out of the sun as much as possible by using hats, umbrellas, etc.

Most scars will eventually become a soft, flat line and be much less noticeable once healed. Your child's surgical team will monitor the healing of their scar and provide recommendations to achieve the best, least noticeable scar possible.

Follow-up care

Your child will be followed by their surgeon and the cleft team until they are fully grown. They can also be seen as adults at any age, if needed.

Following is a timeline of when your child will be seen for a multidisciplinary team evaluation. This timeline is a general guideline for team care and can be modified based on your child's individual needs.

CLEFT TEAM TIMELINE

Prenatal Visit
- Surgeon
- Feeding
- Behavioral Health
- Orthodontics

Birth
- Surgeon
- Feeding
- Behavioral Health
- Orthodontics

2 Years Old
- Surgeon
- Speech
- Behavioral Health

4 Years Old
- Surgeon
- Speech
- Behavioral Health
- Orthodontics

6 Years Old
- Surgeon
- Speech
- Behavioral Health
- Orthodontics

8 Years Old
- Surgeon
- Speech
- Behavioral Health
- Orthodontics

12 Years Old
- Surgeon
- Speech
- Behavioral Health
- Orthodontics

15 Years Old
- Surgeon
- Speech
- Behavioral Health
- Orthodontics

18 Years Old
- Surgeon
- Speech
- Behavioral Health
- Orthodontics

Resources

American Cleft Palate-Craniofacial Association: ACPA-CPF.org
The American Cleft Palate-Craniofacial Association (ACPA) is a nonprofit association of individuals and healthcare professionals who are interested in clinical care and research advancements for those with cleft and craniofacial conditions. ACPA is unique – it is a multidisciplinary organization of more than 2,500 members who represent more than 30 disciplines in 60 countries and support patients and families to ensure the best outcomes.

American Speech-Language-Hearing Association: ASHA/public.org
The American Speech-Language-Hearing Association (ASHA) is committed to ensuring that all people with speech, language and hearing disorders receive services to help them communicate effectively. Their website offers resources to help you understand communication and communication disorders.

Emily Center Family Health Library: phoenixchildrens.org/the-emily-center
The Emily Center is a free, open to the public, health information library located at Phoenix Children's. The library is staffed with highly skilled nurses to conduct individualized research for any family member.

Raising Special Kids: raisingspecialkids.org
Raising Special Kids exists to improve the lives of children with the full range of disabilities, from birth to age 26, providing training, information and individual assistance so families can become effective advocates for their children.

Notes:

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Phoenix Children's®
Center for Cleft and Craniofacial Care

124 W. Thomas Rd., Phoenix, AZ 85013
phoenixchildrens.org/cleft-craniofacial
602-933-1050