Cleft Lip & Palate
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Welcome

Welcome to the Children’s Healthcare of Atlanta Center for Craniofacial Disorders. Our Center is a recognized leader in pediatric craniofacial care. We evaluate and treat the full range of craniofacial conditions for children from birth to age 21.

Our comprehensive services include:

– Pediatric dentistry services
– Oral and maxillofacial surgery
– Orthodontic services
– Plastic surgery
– Speech pathology laboratory
– Neuropsychological screenings and evaluations
– Feeding and lactation services

The Children’s Center for Craniofacial Disorders is located on the second floor of the Medical Professional Building at Children’s at Scottish Rite.

Our Promise to You

The Children’s Healthcare of Atlanta Craniofacial team wants to provide you and your child with quality, family-centered care. Our team can help support you during your child’s treatment. At each visit, you will encounter nurturing, caring people.

About the Handbook

We hope you find this handbook useful. Many parents of children with cleft lips and cleft palates say that they have many questions, concerns and fears about caring for their child. Sometimes, your child’s care will be the same as other children’s; at other times, it may be unique.

This handbook has been prepared by the Children’s Center for Craniofacial Disorders to answer your many questions. We hope you keep this handbook and refer to it often. It can help you learn more about your child’s cleft lip and palate.

You will notice that some of the words in this handbook are in italics. These words are found in the glossary at the back of the handbook. Other words may be followed by phonetic spellings to help you learn how to pronounce them.

Please note, this handbook should NOT replace instruction given to you by your child’s healthcare team. It is not meant to be medical advice or a complete resource for all information on this subject. Your child’s doctor is the best resource of information about what is right for your child’s treatment. If you have any questions about this handbook, please contact the Children’s Center for Craniofacial Disorders and a nurse will help you.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.
<table>
<thead>
<tr>
<th>Child’s name</th>
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<td>Medical Condition(s)</td>
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**Emergency Numbers**

- Closest Emergency Room: ______________________________________________
- Children’s Healthcare of Atlanta Emergency Department: **404-250-KIDS**
- Ambulance: __________________________________________________________
- Georgia Poison Center: **404-616-9000 or 800-222-1222**

**Craniofacial Team**

- The Children’s Center for Craniofacial Disorders: **404-785-2239 or 800-848-9049**
- Craniofacial Surgeon: _________________________________________________
- Craniofacial Nurse Practitioner: _______________________________________
- Speech Pathologist: ___________________________________________________
- Audiologist: __________________________________________________________
- Occupational Therapist: _______________________________________________
- Nutritionist: _________________________________________________________
- Lactation Consultant: _________________________________________________
- Pediatric Dentist: ____________________________________________________
- Orthodontist: _________________________________________________________
- Geneticist: __________________________________________________________
- Psychologist: _________________________________________________________
- Neuropsychologist: _________________________________________________
- Social Worker: _______________________________________________________
- Insurance Company: _________________________________________________
- Medicaid Number: ________________________________________________

**In the Hospital**

- Chaplain: ____________________________________________________________
- Child Life Specialist: _______________________________________________
- School Teacher: _____________________________________________________
- Primary Nurse (inpatient): ___________________________________________

**Other Numbers**

- Pharmacy: ____________________________________________________________
- Closest Relative or Neighbor: __________________________________________
Dear Parent,

Congratulations on the birth of your child. Your new baby wasted no time giving you your first surprise: your child has been born with a cleft lip and/or cleft palate. As you and your family welcome your new bundle of joy into the world, we encourage you to celebrate the things that make your child unique and special, including his or her strengths, weaknesses, beauty and imperfections.

Having a child born with a cleft can seem like a major crisis. Most parents go through pregnancy looking forward to the delivery of the “perfect child.” When this is not the case, it can at first feel like a major loss, bringing with it many emotions: fear, guilt, happiness, sadness, anxiety, uncertainty and hope. These feelings are normal. In fact, you share the feelings of many new parents—of not knowing enough, of doing the wrong thing, of making mistakes. You can’t know everything, and no one expects you to.

Right now you are the most important person in your child’s life. The craniofacial team at Children’s Healthcare of Atlanta is here to support and help you and your baby. This manual is the first tool in your journey. As you learn more about your baby’s condition, you will find ways to cope with your feelings of uncertainty and feel good about your child’s future.

Thank you for entrusting your child’s care to us.

Sincerely,

The Center for Craniofacial Disorders
Children’s Healthcare of Atlanta
Having a child with a cleft lip or palate can stir many emotions. At first, it may be hard to accept that years of treatment and progress lie ahead.

Keep this in mind: The outlook is good. Advances continue to be made in the treatment of people with clefts. Your child can reach adulthood with a good sense of self, an acceptable appearance and healthy social skills.

Your ability to deal with your feelings is vital to your child’s health. Your child will look to you for hope and strength. Your reaction will also set an example for other family members.

**Tips to Help You Prepare for Caring for Your Child:**

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**Take Care of Yourself**

Parents are the most important people in a child’s life, so you must stay healthy and strong. Maintain a healthy diet and exercise often. Take time to rest and relax each day. When you are relaxed, it is easier for your child to relax.

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**Ask for Help When You Need It**

You can’t do it all. Ask family members and friends to lend a hand when they can. If you feel scared or unsure about your feelings, ask to speak to one of our staff at Children’s right away. We can help you feel better about caring for your child.

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**Beware of Burnout**

Sometimes you might not know when your “battery” needs to charge. Watch for these signs in your life:

- Constant fatigue
- Constant depression
- Desire to avoid others
- Family arguments
- Increased use of alcohol or drugs

If you notice any of these signs, you may need to get some rest and ask for help.

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**Play With Your Baby**

You and your baby can still enjoy the pleasures of cuddling, rocking, talking and playing. Babies (and parents) need these kinds of things to help form bonds. They also provide for our need for love, closeness and nurturing. Set aside time to enjoy your baby after feedings, baths and naps. Your smile, voice and touch are vital to your child.

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**Set a Positive Example for Your Child**

Children can sense the feelings of the adults around them. Your child will form his feelings about the cleft from your feelings and actions. If you dwell on problems and act ashamed, so will your child. But if you treat your child as a whole person with many positive features, he will have more self-confidence.

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**Be Prepared for Teasing and Other Social Problems**

Do not shelter your child from other children to protect him. The more time he spends with other children, the sooner your child will learn to manage social situations. There are three points in time when this may be extra hard:

- The first year in school, when a child goes outside the home and loses some “special” status
- The early teen years, when a child is very aware of changes in his body and feels an increased need to fit in socially
- The later teens, when young people begin to desire closer relationships and to be seen as “special” by someone else
It may be helpful to role-play a teasing event at home to help a young child rehearse new ways to manage these events.

- **Use Your Craniofacial Team as a Resource**

Your craniofacial team at Children’s can help you prepare for and deal with many of the problems you may face. Our team members can help provide:

- A plan of care that is tailored for your child over time
- Education and updates on your child’s condition and treatment schedule
- Financial guidance
- Emotional counseling and support

The craniofacial team at Children’s is always available to you. You may speak with us during your visits or call us from home. Do not be afraid to ask for any type of help you need. We want to help.

- **Communicate With Your Partner**

The birth of a baby can cause stress for a couple. It is easy for your relationship to become strained while you are both focused on your child. Parents need to talk and offer support to each other as much as possible. Share your feelings and listen to those of your partner; you can be each other’s most valuable resource.

- **Siblings**

Your child’s care will affect every member of your family. At first, young siblings may be scared by the cleft. They may become jealous because they don’t understand why you need to spend extra time with their new sibling. This is natural.

Brothers and sisters need to be assured that they are also important to you. Remember to hold, comfort and love all your children—including your child with a cleft. Find time each day to spend with them.

As you learn about clefts and your child’s treatment plan, make sure that your other children learn, too. Give them plenty of chances to ask questions, and let them help as much as they can. Older siblings may be able to help by baby-sitting. All children can help by doing small chores around the house.

Offer lots of praise when your children help you. Let them know that they are a special part of a team effort. This can help them feel more important and independent. When you learn more about caring for your child, you may even include siblings in some care tasks.
What is Cleft Lip and Palate?

As a baby’s face forms in the womb, a space remains between the nose and mouth. This occurs in the eighth to twelfth week of the pregnancy. As the face nears its final form, this space is closed by the joining of the left and right halves of the upper lip and palate (the roof of the mouth). When this space does not fully close, a baby may be born with a cleft lip and/or a cleft palate. (“Cleft” means a split or separation)

- A cleft lip is a split in the upper lip and base of the nose. (See Figure 1a)

![Figure 1a: Unilateral complete cleft lip](image)

- A cleft palate is a split in the roof of the mouth and back of the nose. (See Figure 1b)

![Figure 1b: Unilateral complete cleft lip and palate](image)

A cleft is not usually dangerous or a medical emergency. It causes no pain for your child. About one of every 700 babies has a cleft lip or palate. (These numbers vary with race.)
A cleft lip or palate may be on one side of a baby’s face (unilateral) or on both sides (bilateral). (See Figures 2a - 2f) Both types can be repaired. But, treatment for a cleft is a gradual process. There are many steps that may need to be taken during the next few years or more.

Figure 2a: Unilateral incomplete cleft lip

Figure 2b: Bilateral complete cleft lip

Figure 2c: Bilateral incomplete cleft lip
Figure 2d: Bilateral complete cleft lip and palate

Figure 2e: Incomplete cleft palate

Figure 2f: Complete cleft palate
What Causes Cleft Lip and Palate?

Your child may have “inherited” his cleft from one or both parents. But other factors can also occur during pregnancy to cause it. The exact cause of a cleft is often unknown.

Genetic Inheritance

Genes are the smallest unit of heredity. Heredity is the passing of genes from one generation to the next. Each cell in the human body contains genes. Genes contain the “blueprint” for everything in our bodies, such as our height, hair color, skin color and eye color.

Genetic inheritance means that a child’s features are “inherited” (passed from parent to child) from both parents. There are two types of inheritance:

– In single gene inheritance, a feature appears as a result of a single gene carried by one parent.
– In multifactorial inheritance, a feature appears as a result of a number of genetic and non-genetic factors.

Your Geneticist

Genetics is the study of genes; a geneticist is a doctor who studies genes. The geneticist or genetic counselor on your craniofacial team can help you try to find the reason for your child’s cleft. Your geneticist may need to:

– Examine you and your family members
– Take X-rays and conduct genetic tests—these are usually blood tests
– Ask you for a detailed family medical history
– Ask you for a detailed pregnancy history

After your geneticist completes these studies, he will talk to you about the possible cause(s) of the cleft. Your geneticist will also discuss your risk of having another child with a cleft.

 Syndromes

Sometimes, groups of problems appear together in newborn babies. These groups are called syndromes. A cleft lip or palate may be only one part of a larger syndrome. Like clefts, syndromes may be the result of single gene or multifactorial inheritance.

Your geneticist will consult other members of your craniofacial team at Children’s to learn if your child has other problems that point to a syndrome. This will help the geneticist tell you more about the risk of clefts in children you may have in the future.

Notes From the Geneticist
Who Treats Cleft Lip and Palate?

Your child needs a treatment plan that is made just for him. The plan requires a team of people who play different roles in your child’s care. This team is called the craniofacial team. The craniofacial team at Children’s includes the following professionals:

**Audiologist (aw dee ah’ lah jist):** A person who studies and tests sound and hearing

**Craniofacial Surgeon (cray’ nee o fay shul/sur’ jen):** The doctor who performs many of your child’s facial surgeries

**Dental Hygienist (hi jen’ ist) and Assistants:** People who provide many types of dental care and education for parents

**Geneticist (jen et’ ah sist):** A doctor who studies genetics (the study of genes)

**Lactation (lack tay’ shun) Consultant:** A person who helps with breastfeeding and pumping breastmilk

**Neuropsychologist (ner o sy call’ a jist):** A person who tests children to find out about and help with cognitive (mental skills) problems

**Nurse:** Someone who coordinates care and provides education

**Nutritionist (new trish’ on ist):** A person who plans healthy diets and helps with feedings

**Occupational (oc you pay’ shun ul) Therapist:** A person who helps children with daily care activities like feeding and bathing

**Orthodontist (orth ah don’ tist):** A dentist who uses braces and other devices to correct problems in the teeth and jaws

**Otolaryngologist (o to lair in gol’ ah jist):** An ear, nose and throat (ENT) doctor

**Pediatric (pee dee at’ rick) Dentist:** A dentist with advanced training to help children with special dental problems

**Prosthodontist (pros thah don’ tist):** A dentist who makes and fits appliances and artificial teeth

**Psychologist (sy call’ a jist):** A person with special training to help people with emotional or behavioral needs

**Social Worker:** A person who provides counseling and resources to people

**Speech/Language Pathologist (path ah’ lah jist):** A therapist who helps children improve their speech
Like all babies, most infants with clefts are born ready to eat by mouth, but they may need special care during feedings. Due to the size and place of your baby’s cleft, he may not have enough suction and strength to draw milk from the breast or bottle. For that reason, there are special nipples that can be used to help with your baby’s feeding. Breastfeeding babies may refuse to nurse when they find they are unable to get much milk. Or, they may be unable to stay latched to the breast.

Babies with clefts tend to tire quickly, because they use more energy trying to eat. Our staff can assess your child’s feeding skills and decide on the most useful feeding method for your child’s needs. Feeding can be frustrating the first few weeks, but this will pass with training and support.

- Feedings should last no more than 30 minutes, whether breast or bottle feeding.
- Feedings should be pleasant for both you and your baby. This can help your child gain weight.
- You may need to use special feeding bottles, even if you are giving breastmilk to your baby.

**Tips for Feeding Your Child**

- Keep your child in a good position for feeding
  - Keep your baby upright at an angle between 45 and 90 degrees. This will help prevent milk from running out his nose.
  - Try to keep his chin tucked toward the chest. This improves the suck and reduces the amount of swallowed air.

- Point the nipple away from the cleft
  - If possible, angle the nipple away from the side of the mouth with the cleft. This will help your child gag less.
  - Do not place the nipple inside the cleft. Let the tongue reach for it and begin the sucking motion.

- Be ready for nasal regurgitation
  - Nasal regurgitation is when food comes back out of your baby’s nose during a feeding. When this happens, do not panic. Pause to let your child sneeze or cough, wipe his nose and resume feeding.
  - If this happens often, try holding your baby more upright during feedings.
  - Keep your baby’s mouth and nose area clean. Use a bulb syringe as needed. If the area around the nose or lip is crusty, clean it gently with sterile water and a cotton swab.
  - Let the feeding therapist know if this continues. She may be able to find a better bottle match.

- Ask about special bottles and nipples
  - A bottle or nipple made for children with clefts can make feedings easier for you and your child.
  - Ask the nurse, occupational therapist, nutritionist, lactation consultant or speech pathologist on your child’s craniofacial team about such products.

- Stick to a feeding schedule
  - Place your baby on a feeding schedule. Within the first two weeks of life, a newborn may need to feed every two to three hours. Missed feedings might mean your baby is not taking enough volume at feedings.
  - Limit feeding sessions to 20 to 30 minutes. Infants with clefts often work hard during feedings and tire easily. If allowed to feed longer, they may burn more calories than they take in from the bottle or breast.
• Ask your child’s craniofacial team for help in preparing a feeding schedule for your child.

**Burp your baby often**
• Burp your baby about every 15 minutes during and after feedings.
• Infants with clefts take in a lot of air when they swallow. This can cause painful gas buildup if they do not burp often.

**Keep your baby upright after feedings**
• Wait 30 minutes after feeding before you let your baby lie down. This can reduce the chances of food being spit up.
• Use an infant seat, baby sling, bouncy seat or car seat to help keep your baby upright.

Follow these tips, and watch your baby closely for any problems:
• To make sure your baby is gaining weight as fast as he should, record his weight every week for four to six weeks. He should gain about one ounce per day after 2 weeks of age.
• Have regular checkups with your child’s primary care doctor; share your child’s records with his craniofacial team.

Ask your child’s craniofacial team for help with any feeding problems. We have a special Craniofacial and Lactation Infant Feeding Clinic to help with your child’s feeding problems.

**Breastfeeding**
The goal of breastfeeding is for your baby to gain weight and enjoy feeding. A few babies with clefts can get all of their food by nursing. Most can nurse a bit, but also need supplemental (extra) feeding.
• Babies with just a cleft of the lip are better at nursing.
• Your baby’s success depends on the type of cleft and your milk supply.
• It is often not clear if a baby with a cleft palate can nurse well at the breast until your milk has “come in.” We advise putting your baby to breast several times and follow-up with supplements of pumped milk (or formula if needed). This helps to ensure that your baby gets enough food in the beginning.

Even if your baby is not nursing at the breast, breastmilk is still the best feeding choice for babies with clefts. Breastmilk:
• Helps your baby prepare for and recover from surgery and provides protection against infection
• Is easily digested and contains growth hormone
• Breastfeeding or just spending “skin-to-skin” time with your baby helps with other things as well—mother and baby both benefit from the comfort and time getting to know each other

If you pump for several feedings or more a day, it is best to use a double electric breastpump. Contact a local pump rental company or lactation consultant for more information.
• Your lactation consultant can help you set a pumping schedule that matches your baby’s needs. She can also teach you about milk storage and give you other support when you need it.
• Accept help from family and friends to free your time to pump and rest.
• Spend more “skin-to-skin” time with your baby to improve your let-down before pumping.
Pumping is not as pleasant as breastfeeding; accept this and continue so long as you feel it is of value to you and your family. Your baby will benefit from mother’s milk so long as you are able to provide it. Some families prefer to freeze some milk to use before surgery since hospitals often allow breastmilk as a “clear liquid.” Clear liquids can be given closer to the time of surgery than formula.

*Skin-to-skin time tip: practice feeding at the breast without expecting feeding.*

**Choosing a Nipple**

Once your child’s feeding skills are assessed, the feeding team can talk with you about a nipple and bottle for your baby. The feeding team is made up of a nutritionist, lactation consultant, occupational therapist and speech pathologist. Depending on the size and type of the cleft, your baby may need a special bottle or nipple. There is no “perfect” nipple. The best nipple is the one that works best for your child.

Some of the nipples commonly used by the feeding team at Children’s include:

- The Mead Johnson Cleft Palate Nurser has a cross-cut nipple so parents can control the flow of food by squeezing the bottle.
- The Pigeon nipple has a hard side that is placed at the roof of the mouth and a soft side placed on top of the tongue. No suction is needed to express formula, just compression of the tongue.
- The Haberman Feeder has a silicone nipple with varied flow rate. The baby may be able to feed by himself once he learns how to use it. This nipple does allow for squeezing by parents to help your baby’s sucking if needed.

The feeding team may suggest other nipples and bottles. In most cases, a bottle will work for your baby. In a few cases, a baby may be unable to take full feedings by mouth or be unsafe to feed by mouth. A feeding tube may be needed. The feeding team will then work with you to move toward all feedings by mouth when your child is ready.

**Feeding After Surgery**

After surgery, your child’s feeding schedule may need to be changed for a day or two. Your child can usually resume feeding with the same nipple and bottle after surgery. In some cases, you may also need to use a syringe or other method for a while. Your doctor and craniofacial team can explain any feeding changes to you and teach you what you need to know to feed your baby.

**Tips for Feeding Solid Foods**

Solid foods should be given by spoon—not in a bottle. Here are some guidelines to help you with feeding:

- Keep your child upright in an infant seat or high chair.
- Offer one spoonful at a time. Offer small amounts at your child’s own pace. Do not rush. Your child will let you know when he is ready for his next bite.
- Let your child use his lips to clear food from the spoon.
- Do not panic if food escapes through your baby’s nose. This will continue to happen until the palate is closed. Pause to let your child sneeze or cough, wipe his nose and resume feeding. If this happens often, try a more upright feeding position. Use a bulb syringe if needed to help clean the area.
- Avoid acidic and spicy foods. They can irritate the inside of your child’s mouth and nose.
- Start with purees and infant foods when advised by your child’s doctor. You can start purees before the palate is closed.
All babies with cleft lip and palate can have surgery to restore function and a more normal appearance. Surgical repair is most often done in stages. Some of the surgeries will be done when your child is very young and some when your child is older and more developed. Some surgeries may not be done until he is a teenager. Surgeries are planned to occur with your child’s facial growth.

Your child’s craniofacial surgeon at Children’s will explain what types of surgery your child may need and when they may occur.

**First Surgery**

The first surgery your child will have is to repair the cleft lip and rebuild muscles and tissues around his mouth and nose. This will be done while your child is still a baby.

– Cleft lip repair is most often done when your baby is 2 to 3 months old.

– Cleft palate repair is most often done when your baby is about 6 months old.

Each surgery takes about an hour and a half, and your child may need to stay in the hospital overnight. Your child’s doctor will tell you whether your child needs one or both types of surgery. (See Figure 4)

**Figure 4: Unilateral cleft lip repair**

**After Surgery**

You may stay in your baby’s room after surgery and help care for him. We will show how to care for your baby at home.

Here are some tips to help you prepare for caring for your baby right after surgery.

In the hospital:

– Your child will have a few tubes and wires attached to him. These may include:
  - A pulse oximeter. This is a monitor that measures the oxygen in your child’s blood. A soft, plastic wire leads from the monitor and is attached to your child’s finger with a bandage. The wire will not hurt or shock your child.
  - An I.V. (Intravenous) line. This is a thin, soft, plastic tube that goes into your child’s veins. It lets us give your child food, fluids and medicines that can’t be taken by mouth.

– Your child may have some discomfort from the cleft area after surgery. We can give him pain medicine through the I.V. or by mouth. To help prevent falls, be sure to keep your child’s side rails up and watch him carefully if he tries to stand or walk. Pain medicines can make him unsteady on his feet. (Falls after medication have been identified as a problem by our patient safety team)
- We may also give your child other medicines (antibiotics) to help prevent infection.
- You may notice some bloody drainage from the surgical site. Do not be alarmed; this is normal for a day or so.
- Your child may be extra fussy for a while after surgery. This is also quite normal for three to five days.
- Your child may need arm immobilizers (welcome sleeves) to help prevent him from touching his mouth area. If so, the restraints must be loosened a few times each day to check for skin problems. Loosen only one at a time, and do not let your child’s hand near his mouth. Arm immobilizers can make your child clumsy, so if your child is walking, watch for falls. Make sure his shoe strings are tied and pant cuffs are turned up.
- You will be able to begin oral feeding soon after surgery. You may need to use a special method for a few days. If so, we will teach you how to feed your child with a syringe or special bottle.

After you go home:
- Your child will return to the doctor’s office in a week or so for a checkup. Any sutures that won’t dissolve will be removed at this time. (Most sutures used for cleft repairs dissolve in three to six weeks.) At this visit, you may be taught how to help reduce the scar on the lip.
- Your child’s next visit will be four to six weeks later to make sure everything is healing well. If your child had a cleft palate repair, your doctor will see if any openings have formed in the new palate. If so, they will need to be repaired at a later date.
- Every six months or so at first, your child will be checked by the craniofacial team. They will see how your child’s facial growth, hearing, speech and mental and motor development are doing and provide treatment as needed. You will need to make clinic visits less often with time.

**Future Surgeries**

As your child grows, he may need more surgeries at different ages. Whether your child needs more surgeries depends on his treatment plan and any problems that might arise.

- Your child will be screened regularly by a speech and language pathologist to monitor his progress with speech. If air is escaping from your child’s nose, this may need to be repaired in surgery.
- Before your child reaches school age, he may have a nasal tip reconstruction (repair of the end of the nose) and a revision of the lip scar.
- When your child is 6 to 11 years old, the cleft in his upper gum will be repaired using a bone graft.
- During your child’s mid-teens, he will have the final repairs to the lip or palate and a last repair of scar tissue. He may also need surgery to advance the upper jaw.
- Regular hearing checkups can tell if a visit to an ear, nose and throat doctor is needed. Children with chronic ear infections may need ear tubes.
Hospital Visits
Most of your child’s surgeries at Children’s will be done as an outpatient. This means he may be sent home on the same day. At other times, he may need to stay in the hospital overnight. Your child’s doctor will tell you as soon as possible if your child needs to spend the night. Just in case, we suggest that you always pack a bag.

If your child stays overnight, you are welcome to stay also. Having a parent or family member nearby is important for your child. He will be less fearful and more secure with you nearby. Each of our hospital rooms at Children’s at Scottish Rite is private and includes a:
- Hide-a-bed sofa
- Full bathroom
- Television
- Telephone

When you stay overnight at the hospital, you may not get a lot of sleep. We must check your child often during the night, and you may wake up during our nurses’ visits.

We have a cafeteria for you to eat in or you may order meals to be delivered to your child’s room. You may also bring food and snacks from home. A refrigerator, microwave and coffee maker for parent use are provided on each floor of the hospital.

Visitation Guidelines
We want to provide you with quality family-centered care. Please follow these guidelines to help us keep your child safe and provide the best possible care and service.

- Visiting hours are from 8:30 a.m. to 8:30 p.m. We may need to limit the number of visitors in your child’s room to two at a time. Your nurse will let you know if a limit is needed.

- It is best for your child if one parent spends the night. Other family members may use the Ronald McDonald House, located at 5420 Peachtree-Dunwoody Road, Atlanta, GA 30342. The number of rooms available may be limited. Getting a room depends on such factors as how far away your home is from the hospital and family need. Call for information about reservations and house rules (office: 404-847-0760; weekends: 404-250-4994; night (emergencies only): 404-250-4993). A shuttle can take you to and from the Ronald McDonald House and the hospital at all hours.

- All visitors under 12 years of age must stop at the nurse’s station for screening before entering your child’s room. The nurse will ask questions about any possible illness. This includes brothers and sisters and is done with each visit. The visiting child will receive a special sticker to wear during the visit.

- Brothers, sisters and other visitors under 12 years of age must be with a parent and remain in the room at all times, unless they are taking part in activity center or family activities.

- Because of the risk of illness to our patients, we ask that infants, toddlers and young school-aged children keep visits brief.

- Siblings are not allowed in the play room until after 3:30 p.m., unless approved by the Child Life Specialist.

- Children under 12 years of age must be with a parent, volunteer or Child Life Specialist while in the playroom or on the playground.

At times, it may be necessary to alter these guidelines for the patient’s safety and health.
Notes About Surgery

Date of surgery:

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Type of surgery:

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Doctor:

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The person on your craniofacial team at Children’s who works with your child’s speech and language is the speech and language pathologist (SLP). Your SLP will conduct regular checkups as your child grows to see how his speech is developing. Based on these checkups, the SLP may advise treatment. Your child’s treatment may include speech therapy and surgery. Your child can be ready to speak at a normal level for his age by the first year in school.

Requirements for Normal Speech Development

1. **Your child must hear spoken words clearly.**
   We all must hear clearly before we can speak. The audiologist will test your child’s hearing and talk with you about any needed treatments.

2. **Your child must have a proper mouth structure.**
   Most children with clefts can speak normally once their palates are repaired. But some children still have very nasal voices because of air escaping from the nose. These children may need more surgery to close that opening in the future. Your SLP can perform many types of tests to check your child’s speech.

3. **Your child’s intelligence must grow for his or her speech to do the same.**
   Not all children with speech problems have cognitive (mental) and learning problems. But some children with cleft lip or palate do have developmental delays and cognitive problems. The neuropsychologist on your craniofacial team can help you monitor your child’s cognitive growth.

4. **Your child must have someone to teach him.**
   Children learn to speak by listening to the voices of others. You can help your child begin to link spoken words to objects and actions. Talk often to your child about the objects and actions in his world. This includes people, toys, food, playing, bathing and feeding.

Learning Speech and Language

Children begin practicing for speech during the first year of life. Speech begins with sounds that are easy to make (vowels such as a, e, i, o and u) and progresses to sounds that are harder such as “th,” “st” and “str.” For children, learning speech happens like this:

- First they make general sounds, such as cooing and vowel sounds
- Then they make sounds that are like speech sounds, such as babbling and consonant sounds
- Then they make real speech sounds and words
- After putting some speech sounds together to form words, they begin to make sentences

For a child with a cleft, it may be hard to move through these steps because of an opening into the nose, missing teeth or teeth that are out of line.

How We Speak

In English, we use about 46 sounds to speak. Some of these are vowel sounds like “a,” “o” and “ow.” Other sounds are consonant sounds like “p” and “d.”

- Of these consonant sounds, three—“m,” “n” and “ng”—are spoken through the nose. These are the nasal sounds.
- To make the remaining 43 sounds, the soft palate must seal off the nose and force sound out the mouth. This is important for the vowel sounds.
- For the 16 pressure consonants sounds, such as “b,” “d,” “p” and “t,” this is vital because air pressure is needed for enunciation (clear pronunciation of words).
Children with cleft lip and palate often develop other ways to attempt speech sounds that are hard to make. Once bad habits are learned, they are very hard to “un-learn.” This is why it is important that early speech habits are learned correctly the first time.

**How Does the Soft Palate Work?**
The soft palate is a muscular door attached behind the hard palate in the roof of the mouth.

During speech, the soft palate opens and closes a doorway (the nasopharynx). This doorway is hidden and cannot be seen by looking in the mouth. It adjusts sounds and air flow from the throat to make speech sounds. If the soft palate doesn’t close the doorway when it should, a number of speech problems can result.

**Speech Problems**
There are three main types of speech problems: hypernasality, hyponasality and articulation.

– If the soft palate is too small (or the nasopharynx too big), speech may be hypernasal. This is when the soft palate allows sound to pass through the nose during words that should not be nasal. As a result, speech sounds too nasal.

– If the doorway is too small, speech may be hyponasal. This is when sound can’t pass into the nose when it should. As a result, it may be hard to make nasal speech sounds like “n” and “ing.” A small doorway can also cause breathing problems and snoring.

– Articulation means being able to make sounds correctly. Articulation problems are caused by air leaking out of the nose or by teeth that are out of line. Poor speech habits often result when a child tries to find other ways to make difficult sounds.

Many consonant sounds are hard to make if the sound passes through the nose.

**Speech and Language Modeling**
Your SLP and the rest of your craniofacial team at Children’s will do everything they can to make sure your child has the tools to build normal speech and language skills. But you and your family play the most vital roles in this process. Your child will pattern speech after the voices heard around him, so you and your family members are all “models.”

Children who do not hear enough spoken language may have problems with speech and language skills. They may not learn certain skills (such as vocabulary and grammar) simply because they are not exposed to them. This is why your role as a “model” is so important.

As a model, there are a few things you can do to help your child improve his skills:

– Speak clearly and pronounce words well
– Use short sentences when you speak to your child
– Avoid “baby talk,” as it does not help your child learn to speak properly

Children learn “object” words first, so teach your child the names of objects. This includes the names of people, toys, food, utensils and furniture. Name and talk about new objects during shopping trips and visits.

Between the first and second year, children often learn “action” (like walk, eat, and play) and “description” (like soft, wet and furry) words. When your child begins to show interest in books, begin by talking about the pictures. Take turns naming objects and talking about what is taking place in the pictures.
Surgery to Improve Speech

Surgeries to repair clefts are different for each child. Correcting a soft palate problem often involves the combined skills of your craniofacial surgeon, orthodontist and SLP.

Your craniofacial team will study your child and perform many tests to decide how surgery will be done. The structure and function of the soft palate are tested by:

- Visual exam
- Videofluoroscopy (motion X-ray pictures)
- Special fiber-optic scopes
- Computerized instruments

These studies help us decide how your child's problem will be treated. If these studies are needed, your SLP will teach you about the tests.

Most children need only one surgery, but some need follow-up work as well. Your craniofacial surgeon, orthodontist and SLP will talk with you if your child needs further surgery.

After surgery, your SLP may give your child a set of sounds to practice. These speech exercises will most likely become much easier as your child heals. Follow your SLP's advice to help your child improve his speech as quickly as possible.

Notes About Speech and Language

Date: ____________________________________________________________________________

SLP: ____________________________________________________________________________

Practice sounds for your child:

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Notes: __________________________________________________________________________
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Infants and young children have more ear infections than adults because their ears are different. Infants’ eustachian tubes are shorter and straighter, so fluid cannot drain out as easily. When fluid builds up in the middle ear, it can cause an infection or a hearing loss.

A cleft palate may affect the structure of the upper throat and the eustachian tubes. So, children with cleft palates are more likely to have ear infections and other middle ear problems than most children.

Even very mild hearing losses can cause big problems for young children, as they are just starting to learn speech and language skills. Since children with clefts are at a higher risk, their hearing must be watched very closely for any problems. Some doctors prefer to insert tubes in the ears of children with clefts to prevent problems before they occur.

As a child with a cleft grows older, ear problems tend to occur less often and be less severe.

Tests

There are a number of tests that help us prevent, locate and treat your child’s ear problems. The audiologist on your craniofacial team at Children’s will discuss your child’s tests with you. She can also tell you how you can prepare your child for them.

Here are some of the most common tests:

– **Tympanometry Test**: measures pressure in the middle ear and how the eardrum reacts to pressure changes. It can also find holes in the eardrum and show if tubes are working well. This test may be done on newborns, but it works better for children who are at least 7 months old. It does not hurt.

– **Otoacoustic Emissions (OAEs) Test**: records how the inner ear responds to sound. A series of tones are played through a small tip that is placed in the ear. The inner ear responds by emitting tones of its own. The test takes only a few minutes, and your child must remain still. It does not hurt.

– **Auditory Brainstem Response (ABR) Test**: measures the response of the brainstem (the base of the brain) to sound. In an ABR, electrodes are placed on your child’s forehead and behind his ears.
  - Electrodes are soft pads that connect to the ABR machine by covered wires. They do not hurt or shock your child.
  - A clicking signal is made through the earphones, and a computer records the brainstem’s response. It measures the hearing level of each ear.
  - The test takes up to an hour, and your child must remain very still the whole time. Most children are given medicine to help them sleep during the test.

– **Behavioral Tests**: measure hearing by the way that a child responds to sound. They can be done with children as young as 6 to 7 months old. There are many types of behavioral tests. The test your child has depends mostly on his age:
  - Your child may sit on your lap while sounds are played through speakers. When your child turns toward the sound, a toy moves above the speaker that made the sound.
  - Your child may play a listening game such as dropping a block in a bucket when he hears a sound.
  - Older children may wear earphones and raise their hands when they hear tones.

A behavioral test requires your child’s interest. If your child is fussy or distracted, it may take several sessions to complete a test.
After your child’s hearing is tested, the audiologist will discuss the results with you. He will also discuss treatment options with you and your craniofacial team at Children’s.

If you have any questions about your child’s ears, hearing or hearing tests, please feel free to ask your audiologist.

Notes About Hearing Tests

Date of test:

Type of test:

Audiologist:

Notes:
Teeth and Other Dental Issues

A cleft lip and cleft palate often create problems with the upper jaw and teeth. These problems can almost always be solved over time by treatment from a skilled pediatric dental team.

Your child’s dental team is an important part of the craniofacial team at Children’s. Members of a dental team may include a pediatric dentist, an orthodontist, a prosthodontist, dental hygienists and assistants and a craniofacial surgeon.

Your child’s dental team can take a number of steps (which may be spaced over years) to correct problems with your child’s teeth and jaws.

Common Problems

- Poor occlusion
  Occlusion is the way the upper and lower teeth fit together when the mouth is closed. A cleft palate may affect the size and shape of the upper jaw and cause a poor fit.

- Altered facial appearance
  The shape of your child’s face may be affected by a cleft in his upper jaw. Such problems can be treated and corrected over time.

- Early or late appearance of teeth
  The teeth in the cleft area may appear earlier or later than the teeth around them. This is caused by their position in the jaw. These teeth may grow into a normal position. More often, they will need to be straightened.

- Missing, extra and poorly formed teeth
  Like any other child, a child with a cleft may have a number of problems as teeth grow into the mouth. Poorly formed teeth are more likely to develop tooth decay. Your pediatric dentist will discuss your child’s problems and review treatment options with you as needed.

Orthodontic Treatment

Your child’s orthodontist at Children’s will perform different types of treatment as your child grows older.

Newborns

A baby with a cleft may have trouble feeding. If the palate is split, food may escape through the nose. Also, an opening in the roof of the mouth can weaken a baby’s ability to suck.

To correct such problems, your pediatric dentist or orthodontist can insert an obturator in your child’s mouth. This is a plastic device that fits over the roof of the mouth and acts as a palate. It helps babies create suction for feeding and prevents most food from escaping through the nose. A special dental paste is sometimes used to hold it in place.

After an obturator is placed, your pediatric dentist or orthodontist will check it often and adjust it as needed. An obturator is worn until the cleft palate is surgically closed at about 6 to 9 months old.

Your child’s upper lip may need to be “molded” to reduce stress on it. This is often done by stretching a piece of foam tape over the lip. Other devices may also be used for this. Your craniofacial team will decide which type of molding is best for your child.
**Young Children**

Your dental team at Children's will watch your child’s teeth develop for several years until it is time for the bone graft.

– This is surgery to insert bone into the area of the cleft.
– To prepare for the bone graft, the craniofacial team will study X-rays, photographs and models of your child’s mouth.
– From these studies, the team will make a treatment plan that is best for your child’s needs.

Quite often, a child’s upper jaw must be expanded before a bone graft may be done. There are a number of devices for this. The dental team will explain the device that is best for your child.

– An expansion device is usually worn for several months before the bone graft is done.
– After the bone graft, the device is left in place as a “retainer” for several more months.
– Your child may need to wear a retainer until the final phase of treatment is done during his mid-teens.

Other treatments may also be needed at this time to correct your child’s teeth and jaws. This phase of treatment can take up to a year and a half.

**Teenagers**

The final phase of treatment is usually begun after all adult teeth appear. The orthodontist will study X-rays, photographs and models of your child’s mouth. From these studies, the orthodontist will make a treatment plan that is best for your child’s needs.

During this phase of treatment, your child will likely be fitted with braces. More expansion of the upper jaw may also be needed.

If your child needs surgery, it will occur about one to one and a half years after braces are fitted. Braces will remain in place after surgery.

If your child is missing teeth, the problem may be corrected with some type of implant. It depends on how many and which teeth are missing. Your dental team will discuss types of implants with you as needed.

This phase of treatment often takes two to three years.

**Oral Hygiene**

Teach your child about good oral hygiene as soon as possible. This means keeping the teeth and mouth clean. It begins when your child’s first baby tooth appears, and it includes:

– Brushing with a toothbrush and toothpaste at least twice each day
– Using dental floss after meals to clean between teeth
– Visiting the pediatric dentist twice each year for routine checkups and cleanings

Oral hygiene can help prevent many problems. It can also help your child achieve the best possible results from treatment.
Notes About Dental Care

Date of visit:

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Type of exam:

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Dentist:

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The person on your craniofacial team who can help check your child’s cognitive (mental) growth is the neuropsychologist. While not all children with cleft lip or palate have cognitive problems, some do experience developmental delays and learning problems.

**Screenings and Evaluations**

Your child may have a screening test to look for problems in mental, motor, social and behavioral growth. Screenings may begin when your child is a baby and continue into the teen years.

If any problems are found, formal testing can be done to help find the type and extent of the problems. Tests can also point to ways to help your child do better in many areas.

The test may look at how well your child:
- Thinks through problems
- Pays attention and finishes tasks
- Learns and remembers information
- Listens to speech sounds, identifies objects and uses words to communicate
- Copies shapes and writes letters
- Reads, writes and does math
- Copes with emotions and makes friends
- Follows directions and controls behavior
- Works quickly and efficiently on tasks

Formal testing is key to learning about your child’s cognitive strengths and weaknesses. It can also help your child do his best at home, at school and in the community.

**Notes About Neuropsychology**

Date of test:

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Type of test:

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Neuropsychologist:

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The Social Worker as a Family Resource

Having a child with a cleft lip or palate can be a scary, confusing time. You may have many questions about:

- What resources are available to your child and your family?
- What to expect during your hospital visits?
- How your child’s care will be paid for?

The social worker on your craniofacial team at Children’s can help you find the answers. The social worker’s role is to:

- Help you and your child deal with emotions
- Serve as a link between your family and the hospital
- Direct you to support groups and other sources of information
- Help you find and use any resources that are available to you

During your first meeting with your social worker, he may ask you many questions about your family, lifestyle, job and finances. This is to help the social worker understand your needs and direct you to resources. Your social worker may contact agencies for you or explain how you can contact agencies on your own.

Your social worker is always available to you. You may speak with him in person during your visits and call him between visits.

Financial Resources

Because each child’s needs are different, there is no way to know how much your child’s treatment will cost.

If your child is covered by private insurance, you must let them know about the cleft and your visits to the craniofacial clinic. Our staff and your child’s doctor’s office can help you arrange payment for surgeries and other treatments. You must stay in close contact with your insurance company and keep up with records and bills.

If your child is covered by Medicaid, you must stay in close contact with your caseworker. When your caseworker asks for information, provide it as soon as possible to prevent problems with your coverage.

If your child is not covered by private insurance or Medicaid, please tell our social worker so he can help you apply for other types of financial help.

Community Resources

There are many groups that can help you care for your child. Your social worker can discuss these groups with you and help you contact them. They include:

**About Face USA**

P.O. Box 969
Batavia, IL 60510-0969
Phone: 888-486-1209
[www.aboutfaceusa.org](http://www.aboutfaceusa.org)
e-mail: [info@aboutfaceusa.org](mailto:info@aboutfaceusa.org)

This group provides support and guidance to people with facial differences. They also publish a newsletter and sponsor support groups. Call to find a local chapter.
Children’s Craniofacial Association
13140 Coit Road, Suite 307
Dallas, TX 75240
Phone: 800-535-3643
Fax: 214-570-8811
www.ccakids.com
e-mail: contactCCA@ccakids.com

This group provides information, a newsletter, parents’ networks and an assistance fund for families who must travel for medical care.

Children’s Medical Services
Georgia Division of Public Health
2 Peachtree Street NW
Atlanta, GA 30303-3186
Phone: 404-657-2726
www.health.state.ga.us/programs/cms
e-mail: gdphinfo@dhr.state.ga.us

This agency can help with the cost of medical treatment and equipment for needy patients and families.

Families of Children Under Stress (FOCUS)
3050 Presidential Drive, Suite 114
Atlanta, GA 30340
Phone: 770-234-9111
www.focus.ga.org
e-mail: focus-ga@mindspring.com

This is a support group for parents of very ill children. They provide a newsletter, a hotline number, monthly support meetings, annual conferences and family get-togethers.

Cleft Palate Foundation
1504 East Franklin Street, Suite 102
Chapel Hill, NC 27514-2820
Phone: 919-933-9044
www.cleftline.org
e-mail: info@cleftline.org

This is a nonprofit agency that provides information and doctor referrals to families.

The Georgia Advocacy Office
150 East Ponce de Leon Avenue, Suite 430
Decatur, GA 30030
Phone: 404-885-1234 or 800-537-2329
www.thegao.org
e-mail: info@thegao.org

This group provides information, training, referrals and legal advice and representation to people in Georgia with disabilities and mental illnesses. They work with families having problems with public school systems.
Resources you may want to order

Resources for People with Facial Difference
Published by:
Let’s Face It
P.O. Box 29972
Bellingham, WA 98228-1972
Phone: 360-676-7325
www.faceit.org
e-mail: letsfaceit@faceit.org

This is a directory of reference materials. The resource list is now available through the Web site in Adobe Acrobat format (pdf). Let’s Face It is an information and support network for people with facial differences, their families and medical professionals.

Children With Facial Difference: A Parent’s Guide
Published by:
Woodbine House
6510 Bells Mill Road
Bethesda, MD 20817
Phone: 800-843-7323

(ask for the Special Needs Collection catalog)

This book is a very detailed resource for parents. It explains treatments, emotional issues, children’s self-esteem, speech, language, education issues and legal rights.

Children’s Healthcare of Atlanta has not reviewed all of the sites listed as resources and does not make any representations regarding their content or accuracy. Children’s Healthcare of Atlanta does not recommend or endorse any particular products or services or the content or use of any third-party Web sites, or make any determination that such products or services or Web sites are necessary or appropriate for you or for the use in rendering care to patients. Children’s Healthcare of Atlanta is not responsible for the content of any of the above-referenced sites or any sites linked to these sites. Use of the services referenced and/or links provided in this manual is at your sole risk.
Some of these terms are used in this manual. You may hear others used by your craniofacial team at Children’s.

**Acoustic Nerve**: a nerve in the inner ear that sends sound information to the brain.

**Alveolar Ridge**: the bony ridge where the teeth are held in the jaw.

**Anterior**: the front side.

**Antibiotics**: medicines to prevent or treat infections.

**Articulation**: the ability to use the mouth to make speech.

**Audiologist**: a person who studies sound and hearing.

**Audiology**: the study of sounds and hearing.

**Auditory Brainstem Response (ABR)**: a test that measures the response of the brainstem to sound.

**Bilateral Cleft**: a cleft on both sides of a lip or palate.

**Bilateral Myringotomy**: a surgery to implant tubes through the ear drum to allow fluid to drain from an ear infection.

**Bone Graft**: a surgery to insert bone into the area of a cleft lip or palate.

**Brainstem**: the base of the brain.

**Chromosome**: a part of a cell that carries genes and other information related to genetic inheritance.

**Cleft**: a split or separation.

**Cleft Lip**: a congenital split in the upper lip.

**Cleft Palate**: a congenital split in the roof of the mouth.

**Columella**: the front part of the tissue between the nostrils.

**Conductive Hearing Loss**: a hearing loss caused by a problem in the middle or outer ear. Common causes include fluid in the middle ear or wax blocking the ear canal. Conductive hearing losses can usually be corrected with medicine or surgery.

**Congenital**: this means “born with.”

**Craniofacial**: relating to the skull (cranio) and face (facial).

**Craniofacial Surgeon**: a surgeon who treats problems with the skull and facial bones.

**Craniofacial Team**: a group of medical professionals who work together to treat people with craniofacial anomalies.

**Cuspid Teeth**: the pointed “canine” teeth on either side of the front teeth.

**Dietitian**: a person who plans healthy diets for people.

**ENT**: an ear, nose and throat doctor.

**Electrodes**: soft pads that stick to parts of the body during some tests. Covered wires connect the electrodes to machines. Electrodes do not hurt or shock your child.

**Enamel**: the outer layer of a tooth.
**Eustachian Tube:** a tube that runs from the middle ear to the back of the throat. It allows air pressure on both sides of the ear drum to stay equal.

**Fistula:** an abnormal opening or gap.

**Functional:** an adjective meaning “working properly.”

**Gene:** the smallest unit of heredity. Genes contain the “blueprint” for everything in our bodies, such as our height, hair color, skin color and eye color.

**Genetic Counseling:** a study to help find issues of genetic inheritance. It includes physical exams, family histories, X-rays and chromosome testing.

**Genetic Inheritance:** the natural process by which children “inherit” their features from their parents.

**Geneticist:** a doctor who studies genetics (the study of genes).

**Genetics:** the study of genes and genetic inheritance.

**Gestation:** the amount of time a baby spends growing in the womb.

**Hard Palate:** the bony part of the roof of the mouth just behind the teeth.

**Hypernasality:** a speech problem in which a person’s voice sounds too nasal. It is often caused by an opening in (or behind) the palate that lets sound move through the nose.

**Hyponasality:** a speech problem in which a person has trouble producing nasal sounds because the voice sounds cannot move into the nose.

**I.V.:** a tube in a vein that allows food, fluids and medicines to be passed directly into the bloodstream.

**Inner Ear:** the innermost part of the ear where sound information is sent to the brain through the acoustic nerve.

**Larynx:** the area of the throat containing the vocal folds.

**Malocclusion:** a poor alignment of the upper and lower teeth.

**Mandible:** the lower jaw bone.

**Maxilla:** the upper jaw bone.

**Middle Ear:** the eardrum and the space just behind it.

**Mixed Hearing Loss:** a hearing loss that is partly conductive and partly sensorineural.

**Multifactorial Inheritance:** a type of genetic inheritance in which a feature appears as a result of a number of genetic and non-genetic factors.

**Nasal:** related to the nose.

**Nasal Air Escape:** The escape of air through the nose when pronouncing consonants.

**Nasal Ala:** the part of the nostril that joins the cheek.

**Nasal Regurgitation:** the escape of food through the nostrils during feedings.

**Nasal Septum:** the wall of tissue that divides the nostrils.

**Nasal Tip Reconstruction:** surgical repair of the end of the nose.
Nasendoscopy: a test that uses a small camera to record how the soft palate is working.

Obturator: a device that fits in the roof of the mouth to cover a cleft palate opening.

Occlusion: the way the upper and lower teeth fit together.

Occupational Therapist: a person who helps people with daily care activities like feeding and bathing.

Oral Hygiene: care and regular cleaning of the teeth and mouth.

Orthodontist: a dentist who uses braces and other devices to correct problems with teeth and jaws.

Otitis Media: a middle ear infection.

Otoacoustic Emissions (OAEs): a test that records how the inner ear responds to sound.

Otolaryngologist: an ear, nose and throat (ENT) doctor.

Outer Ear: the part of the ear you can see and the ear canal.

Occlusion: the way the upper and lower teeth fit together.

Primary Teeth: baby teeth. There are 20 of them.

Pre-Maxilla: the center of the bony ridge that holds the upper teeth.

Pressure Equalization (PE) Tubes: tubes that are inserted through the eardrum to allow fluid to drain from the middle ear.

Psychologist: a person with special training to help people with emotional or behavioral concerns.

Pulse Oximeter: a wire that attaches to a person’s finger and measures the oxygen in the blood.

Secondary Teeth: adult teeth. There are normally 32 of them.

Sensorineural Hearing Loss: a hearing loss caused by a problem in the inner ear or the acoustic nerve. Common causes include genetic inheritance, aging and constant loud noise. Sensorineural hearing losses usually cannot be repaired.

Single Gene Inheritance: a type of genetic inheritance in which a feature appears as a result of a single gene carried by one parent.

Social Worker: a person who provides counseling and resources to people.
**Soft Palate**: the movable part of the roof of the mouth behind the hard palate. It is critical for speech.

**Speech/Language Pathologist (SLP)**: a clinician who evaluates speech and helps people improve their speech.

**Speech Therapy**: treatment given by a speech therapist to help people with speech problems improve their speech. Speech therapy often involves practicing certain speech sounds and patterns.

**Sphincter Pharyngoplasty**: a type of surgery to improve the function of the palate. It places extra muscle on the back wall of the throat.

**Supernumerary Tooth**: an extra tooth.

**Sutures**: surgical stitches.

**Syndrome**: a group of congenital problems that appear together in newborn babies. Syndromes may be the result of single gene or multifactorial inheritance.

**Tympanic Membrane**: the eardrum.

**Tympanometry**: a test that measures pressure in the middle ear and how the eardrum reacts to pressure changes. It can also find holes in the eardrum and show if PE tubes are working properly.

**Unilateral Cleft**: a cleft on one side of the lip or face.
Illustrations: Types of Clefts and Repairs

Types of Cleft Lips

Unilateral incomplete cleft lip and palate

Unilateral complete cleft lip and palate

Types of Cleft Palates

Bilateral Incomplete

Bilateral Complete

Incomplete

Complete
Repaired Cleft Lips

Repaired Unilateral Cleft Lip

Repaired Bilateral Cleft Lip

Normal Anatomy of the Mouth

Ala (nose cartilage)

Piltrum (ridge of skin under nose)

Lip

Alveolus (gum)

Hard Palate (roof of mouth, front)

Soft Palate (roof of mouth, back)

Uvula

Tongue

Some physicians and affiliated healthcare professionals who perform services at Children’s Healthcare of Atlanta are independent providers and are not hospital employees.