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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
- Oral and maxillofacial surgery
- Orthodontic services
- Plastic surgery
- Speech pathology laboratory
- Screenings and evaluations
- Feeding and lactation
- Genetics
- Ear, Nose and Throat (ENT)
- Audiology
- Psychological counseling and consultation

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

Our Promise to You

The 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 lip and cleft palate say that they have a lot of questions, concerns and fears about caring for their child. Sometimes, your child’s care will be the same as that for other children; 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.

Some of the terms used in this manual can be 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.

Many of the words and terms in this booklet may be new and confusing. Our craniofacial team can explain them to you and teach you what you need to know. For easier reading, we will use the words “he or him” when we talk about your child—even if your child is a girl.

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 for 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 at 404-785-2239 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.
Important information

Child’s name: ________________________________________________

Medical condition(s): _______________________________________

Primary care physician (PCP): _______________________________

PCP phone number: _______________________________________

Emergency numbers: _______________________________________

Closest emergency department: ______________________________

Georgia Poison Center: 404-616-9000 or 800-222-1222

Children’s Emergency Departments:
Egleston: 404-485-6400
Scottish Rite: 404-785-2273
Hughes Spalding: 404-785-9650

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: __________________________________________________________
Your child’s care timeline

Stage 1: Birth to 2 weeks of age
• Feeding team evaluation

Stage 2: 3 to 6 weeks of age
• Clinic visit with craniofacial surgeon
• Genetics evaluation
• Dentist or orthodontist visit for pre-surgical molding devices
• Referral to ear, nose and throat (ENT) doctor if needed or hearing (audiologist) screening

Stage 3: Weekly clinic visits for next 2-3 months
• Orthodontist visit to adjust Nasal Alveolar Molding (NAM) or with the dentist to adjust the Latham Appliance
• Feeding follow-up and weight check

Stage 4: Surgery 3-12 months
• Cleft lip closure 3-5 months of age
• Cleft palate closure 6-12 months of age

Stage 5: Toddler years
• Team visits including the craniofacial surgeon once a year
• First speech evaluation at 12-18 months of age
• First dental evaluation at 12-18 months of age
  NOTE: Speech and dental visits are often done together at this visit.
• Possible speech surgery, if needed
• Continued well-child exams with your child’s primary care provider

Stage 6: School-age years
• Team visit including the craniofacial surgeon every 1-2 years, based on need
• Possible cleft lip revision, cleft nasal (nose) revision at 5-6 years of age
• Speech therapy
• Possible speech surgery, if needed
• Dental and orthodontics surgery, if needed at 6-11 years of age
• Dental cleaning every six months until released to other dental care
• Audiologist or ENT screening
• Continued well child exams with your child’s primary care provider

Stage 7: Teenage Years
• Team visit including craniofacial surgeon
• Cleft lip and scar revision, cleft nasal (nose) surgery, if needed
• Jaw advancement, if needed
• Dental or orthodontics visit
• Braces, surgery, prosthetic dentistry, if needed
**Family reactions and emotions**

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**

**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.

**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.

**Beware of burnout.**
Sometimes you might not know when your “battery” needs to charge. Watch for these signs in your life:
- Constant fatigue (tiredness)
- Constant depression (feeling down)
- 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.

**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 satisfy 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.

**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 good features, he will feel better about himself.

**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 with others
- 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 the Children’s craniofacial team as a resource.**
The Children’s craniofacial team 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 made for your child over time
- Teaching and updates on your child’s status and treatment schedule
- Financial guidance
- Emotional counseling and support

The craniofacial team is always here for 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.

**Talk 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 best source of support and help.

**Remember siblings (brothers and sisters).**
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 know why you need to spend extra time with their new sibling. This is natural.
• Tell your other children that they are also important to you.
• 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 babysitting. All children can help by doing small chores around the house.
• Offer lots of praise when your children help you. Let them know 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 (Image 2). This occurs in weeks 8 to 12 during pregnancy. As the face nears its final form, this space closes as the left and right halves of the upper lip and palate (the roof of the mouth) join. When this space does not fully close, a baby may be born with a cleft lip or a cleft palate or both. (“Cleft” means a split or separation.)

• A cleft lip is a split in the upper lip and base of the nose. (Images 3, 4, 5 and 6)
• A cleft palate is a split in the roof of the mouth and back of the nose. (Images 7, 8 and 9)

A cleft is not usually dangerous or a medical emergency. It causes no pain for your child. A cleft lip or palate may be on one side of a baby’s face (unilateral) (Images 3 and 4) or on both sides (bilateral) (Images 5 and 6). 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.

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 parent to child. 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” or passed from parent to child through the genes. 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 nongenetic factors.

Your geneticist

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

• Check you and your family members
• Take X-rays and conduct genetic tests—usually blood tests
• Ask you for a detailed family medical history
• Ask you for a detailed pregnancy history

After completing these studies, the geneticist will talk to you about the possible cause 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 such as Pierre Robin Syndrome (Image 1). Like clefts, syndromes may be the result of single gene or multifactorial inheritance. Your geneticist will talk with other members of our craniofacial team 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.

Image 1: Pierre Robin Syndrome—Micrognathia (small jaw) and cleft palate
Image 2: Normal anatomy of the mouth

- Ala (nose cartilage)
- Philtrum (ridge of skin under nose)
- Lip
- Alveolus (gum)
- Hard palate (roof of mouth, front)
- Soft palate (roof of mouth, back)
- Uvula
- Tongue

Image 3: Unilateral (one-sided) complete cleft lip

Image 4: Unilateral incomplete cleft lip

Image 5: Bilateral (both sides) complete cleft lip

Image 6: Bilateral incomplete cleft lip
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. Our craniofacial team includes these 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 breast-feeding 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 artificial teeth and fits dental or surgical appliances (devices) to correct your child's condition
- 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
Feeding your baby

Our feeding team will check your baby to find out how well he feeds and what type of help he needs. Once this is done, a member of the team can talk with you about your baby’s special needs. The feeding team is made up of either an occupational therapist or a speech pathologist, a nutritionist and a lactation counselor. Please feel free to ask them any questions you may have.

Feedings should be pleasant for both you and your baby, but they can be frustrating the first few weeks. This will pass as you and your baby learn more about methods that can help. Our team is here to help and support you with feeding your baby.

Like all babies, most babies with clefts can bottle feed, but they may need special care during feedings.

- Babies with clefts can tire quickly since they use more energy to eat. Our staff can check your baby’s feeding skills and decide on the most useful feeding method.
- 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, you may need to use special nipples to help your baby feed.
- Feedings should last no more than 30 minutes, whether breast or bottle feeding.

Breast-feeding babies may:
- Refuse to nurse when they are not able to get enough milk.
- Be unable to stay latched or get milk from the breast.
- Need special bottles and nipples to supplement nursing so they can gain weight.

Tips for feeding your baby

During the feeding
- Keep your baby 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 head centered between his shoulders without tucking his chin down toward his chest or allowing the head to extend backwards.
- Point the nipple and angle it away from the cleft. This may help your baby gag less.
  - Offer the nipple to your baby, let him open his mouth and guide it to where he is most comfortable.
- 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 baby 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. Medicated saline spray can be used 20 to 30 minutes prior to the feeding to help clear any nasal congestion. If the area around the nose or lip is crusty, clean it gently with sterile water and a cotton swab.
  - If your baby has problems, your feeding therapist may be able to find a better bottle or nipple match.
  - Burp your baby often.
    - Burp your baby about every 15 minutes during and after feedings.
    - Babies with clefts swallow a lot of air when they suck. This can cause painful gas buildup if they do not burp often.

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

Other feeding tips
- Ask about special bottles and nipples.
  - A bottle or nipple made for babies with clefts can make feedings easier.
  - Talk with a member of our feeding team about them.
- Stick to a feeding schedule.
  - Place your baby on a feeding schedule. Within the first two weeks of life, your baby may need to feed every two to three hours. Missed feedings might mean your baby does not get enough nutrition each day.
  - Limit feeding sessions to 20 to 30 minutes. Babies 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 a member of your child’s feeding team for help preparing a schedule for your baby.
- Make sure your baby gains weight.
– To make sure your baby gains weight as fast as he should, record his weight every week for four to six weeks. He should be back to his birth weight by two weeks of age. He should gain about 1 ounce a day after two weeks of age.
– Have regular checkups with your baby's primary care doctor. Share your baby's records with his craniofacial team.

Ask the Children's craniofacial team for help with any feeding problems. We have a special Infant Feeding Clinic to help with your baby's feeding problems.

Breast-feeding

The goal of breast-feeding 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. Your baby's success depends on the type of cleft and your milk supply.

- Babies with just a cleft lip are better at nursing than those with a cleft palate.
- Sometimes nursing is easier than a bottle for babies with a cleft lip.
- It is often not clear if a baby with a cleft palate can nurse well at the breast until your milk "comes in."
- We advise putting your baby to breast several times and following up with extra pumped milk or formula if needed. This helps to ensure 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. Pumping often is important, even from the very beginning.
- Breastmilk:
  – Helps your baby prepare for and recover from surgery.
  – Provides protection against infection.
  – Is easily digested and contains growth hormone.

Breast-feeding or just spending “skin-to-skin” time with your baby helps with other things as well. It benefits both mother and baby from the comfort and time of getting to know each other. If you pump for several feedings or more a day, it is best to use a double electric breast pump. 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. Skin-to-skin time tip: practice feeding at the breast without expecting your baby to feed.

Pumping is not as pleasant as breast-feeding; accept this and continue as 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.

Choosing a nipple

Depending on the size and type of your baby’s cleft, he may need a special bottle or nipple to feed. There is no “perfect” nipple. The best nipple is the one that works best for your baby.

Some commonly used nipples include:

- **Pigeon Nipple**: This bottle system has a nipple with a hard side and a soft side.
  – Place the hard side with the notch on the rim at the roof of your baby’s mouth.
  – Place the soft side on the tongue.
  – There is a one-way valve between the bottle and nipple. It allows the milk to flow onto the tongue when your baby sucks.

- **Medela Special Needs Feeder** (formerly the Haberman Feeder): This bottle system has a silicone nipple with three different flow rates and a one-way valve between the bottle and nipple. The nipple allows you to squeeze it to help express milk if your therapist advises.

- **The Mead Johnson Cleft Palate Nurser**: This bottle has a cross-cut nipple and a squeezable bottle. You can squeeze the bottle to express milk into your baby’s mouth.

Our feeding team may suggest other nipples and bottles. In most cases, your baby will be able to feed from a bottle. In a few cases, a baby may be unable to take full feedings by mouth or be unsafe to feed by mouth. If so, a feeding tube may be needed. The feeding team will then work with you to move toward all feedings by mouth when your baby is ready.
Feeding after surgery

After surgery, your baby’s feeding schedule may need to be changed for one to two days. Your doctor and feeding team can explain any feeding changes to you and teach you what you need to know to feed your baby.

- Pain is the biggest factor that may hinder eating after the cleft lip repair.
- Pain and swelling are the biggest factors that may hinder eating after cleft palate repair.
- Be sure to talk with your baby’s nurse about your baby’s pain medicines. Let the nurse know that you would like your baby to have a dose before feeding time when possible.

Other things to know about feeding after surgery

- Babies are allowed to eat (bottle or spoon feeding) as soon as they show hunger after waking up from surgery.
- Your baby should use the same bottle after a lip or palate repair that he used before surgery.
- If your baby was using a special nipple before surgery, do not use a regular nipple until the repair heals.
- Babies will usually accept the nipple into the mouth, but may pull off due to pain.
- Parents usually have to feed the baby more frequently, but with smaller volume.
- It often takes babies 2-3 days after lip repair to begin feeding normally.
- It can take up to 7-10 days for babies to return to normal feeding after the repair of the palate.
- Talk with your surgeon at your post surgery appointment about when you can try a regular nipple. Use the special nipple until then.
- Do not be upset if your baby still prefers the special nipple after surgery. It is the only nipple that he knows and he may find it comforting.

Tips for feeding solid foods

Start pureed and table foods when your baby’s primary doctor advises. You should be able to begin feeding your baby foods with a spoon at normal eating times.

- For pureed baby foods, this is usually at four to six months of age.
- For beginning table foods, such as small pieces of soft well cooked vegetables (diced carrots, peas), soft breads and pasta, and small pieces of soft fruits (avocado, banana) this is usually at 9-10 months of age.

Here are some guidelines to help you with feeding:

- Keep your baby upright in an infant seat or high chair.
- Give pureed baby food with a spoon—not in a bottle.
  - Offer one spoonful at a time. Offer small amounts at your baby’s own pace.
  - Do not rush. Your baby will let you know when he is ready for his next bite.
  - It may be helpful to put the spoon in at the side of his mouth instead of in the center.
  - Let your baby use his lips to clear food from the spoon.
- If your baby has a cleft palate, stay calm if food escapes through his nose (regurgitation). This will happen until the palate is closed.
  - Pause to let your child sneeze or cough, wipe his nose and resume feeding.
  - If this happens often, sit him more upright to feed.
  - Try a slightly thicker puree.
- Use a bulb syringe if needed to help clean the area. Avoid excess use of the syringe as it may irritate the inside of the nose and cause swelling. You can use a saline spray to help decrease congestion in the nose due to regurgitation.
- Avoid acidic and spicy foods. They can irritate the inside of your baby’s mouth and nose.

If feeding continues to be a problem for you and your baby, ask to speak with one of our feeding therapists. They may be able to suggest other tips to help.
Treatment before surgery

Children’s Center for Craniofacial Disorders is one of the few centers in the U.S. that uses both the Latham Appliance and Nasal Alveolar Molding (NAM). Both devices are used before surgery to help bring a baby’s lips and gums together. They help ready the lips and palate for surgery. Your child’s doctors will help decide which device will work best for your child.

Latham appliance (pinned appliance)

What is a Latham appliance?
A Latham appliance is a plastic device used to bring a baby's lip and gum together. It helps to better align and shape the cleft area before surgery.

How does the Latham appliance work?
At one of your child’s first visit to the center, a dentist who treats gum problems (pediatric orthodontist) will make a mold of your baby’s mouth.

• It looks like the mold a dentist uses to make dentures.
• Using the mold, he will make a plastic and metal appliance to fit inside your baby's mouth.

During surgery, the orthodontist will attach the appliance to the roof of your baby's mouth using screws.

• This happens in the operating room while your baby is asleep under general anesthesia.
• It takes about 30 minutes to place the device.
• Your baby may need to stay in the hospital overnight.
• Your baby will need to wear the appliance for about four weeks.
• Your doctor will remove it when your baby has surgery to repair his cleft.

Why should my baby use a Latham appliance?
Children with cleft lip and palate may need five to seven surgeries. Sometimes, they even need surgery into their teen years. The Latham appliance can help:

• Improve how your baby looks after the cleft lip and palate surgery.
• Make the width of the cleft smaller, which helps in the first surgical repair.

When should my baby be fitted with a Latham appliance?
Your baby will be fitted before he is 6 months old. It is usually done when a baby is about 2 to 3 months old. It is used when your baby is young because:

• The tissues in the mouth are still flexible
• Your baby does not have any teeth yet

What do I need to do?
The appliance means that you will need to give your baby extra care and time. This is vital in order for it to work well. You will need to:

• Bring your baby to the center every one to two weeks.
• The dental team will check your baby and adjust the appliance as needed.
• You may need to adjust it at home as well. If so, we will teach you what you need to do.
Nasal Alveolar Molding (NAM)

What is Nasal Alveolar Molding (NAM)?

Nasal Alveolar Molding (NAM) is a way to treat cleft lip and palate.

- Nasal means that it fits up into the nose.
- Alveolar means that it fits around the gums.
- Molding means that it is a hard, plastic mold.

The NAM mold brings your baby’s lip and gum together by helping to move and reshape the cleft area as your baby grows. This is needed to prepare your baby for further cleft repair during surgery.

How does a NAM work?

At your child’s first visit to the center, a dentist who treats gum problems (pediatric orthodontist) will make a plastic mold of your baby’s mouth, lip and nostrils.

- The mold will be specially made just for your baby.
- Your baby will wear the mold 24 hours a day for about six months.
- The mold is held in the mouth by surgical skin tape. The tape will also help guide the growth of your baby’s face.
- Each week, the orthodontist will reshape the mold. This will help to make your baby’s cleft smaller and reshape his nose.

Why should my child use NAM?

Children with cleft lip and palate may need five to seven surgeries. Sometimes, they even need surgery into their teen years.

- It helps during the first surgery and helps mold the nose.
- NAM can help to reduce the number of surgeries your child needs during his life.
- Since the mold covers the roof of your baby’s mouth, it also helps with speech and feeding.
- NAM can also help to improve your child’s appearance.

When should my baby be fitted for a NAM mold?

Your baby will have the mold fitted before he turns 1 year of age.

- It is usually fitted when a baby is about 2 weeks old.
- It is worn 24 hours a day until his first surgery. This is usually when he is about 6 months old.
  - NAM is used when your baby is young because his tissues (cartilage) are flexible.
  - After 6 months of age, his cartilage is not as flexible, his teeth begin to come in and he is able to take out the mold himself.

What do I need to do?

The NAM device means that you will need to give your baby extra care and time. You will be caring for the NAM at home, so your help is vital in order for it to work. This means that you will need to:

- Bring your baby to the center each week. The center’s orthodontist and team will check your baby and adjust the NAM device as needed.
- Attach the tape to your child’s face as needed to keep the NAM device in place.
Surgery

All children with cleft lip and palate can have surgery to help:
• Restore function for feeding, eating and talking.
• Give them a more normal appearance.

Cleft lip and palate repair is most often done in stages.
• Surgeries are planned to occur with your child’s facial growth.
  – Some surgeries are done when your child is a baby and some when your child is older and more developed.
  – Some surgeries may not be done until he is a teenager.
• Your child’s craniofacial surgeon will explain what types of surgery your child may need and when surgery may occur.

First year surgeries

Your baby will have surgery done at an early age to rebuild the muscles and tissues around his mouth and nose. Surgery may include:
• A cleft lip repair at 3 to 4 months of age (Images 10 and 11)
• A cleft palate repair at 6 to 9 months of age (Image 12)
• A mandibular distraction (lengthening the jaw) surgery (Image 13)

Each surgery takes about one and a half hours and your baby may need to stay in the hospital overnight. Your child’s doctor will tell you what type of surgery your child needs.

Image 10: Bilateral (both sides) complete cleft lip repair

Image 11: Unilateral (one side) complete cleft lip repair

Image 12: Cleft palate repair surgery

Image 13: Mandibular distraction (lengthening the jaw) surgery
After surgery

It is best to stay in your baby’s room after surgery and help care for him. We will teach you 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 he cannot take by mouth.
- Your child may have some discomfort after surgery. We can give him pain medicine through the I.V. or by mouth.
  - Pain medicines can make him unsteady on his feet.
  - 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.
  - Also make sure his shoe strings are tied and pant cuffs are turned up.
- We may also give your child other medicines (antibiotics) to help prevent infections caused by germs or yeast.
- You may notice some bloody drainage from the surgery 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 to keep his arms straight. These help prevent him from touching his mouth area.
  - If so, loosen the restraints 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.
- Ask your child’s nurse how to work with the restraints. You will be able to begin to feed your baby by mouth soon after surgery. You may need to use a special method for a few days. If so, we will teach you how to use 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, we may teach you 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.
- At first, every six to 12 months, depending on needs, you will bring your child to be checked by our craniofacial team. They will check on your child’s facial growth, hearing, speech, and mental and motor development 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 (Images 14 and 15).

• 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 (Image 16).

• 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 midteens, he will have the final repairs to the lip or palate and a last repair of scar tissue. He may also need surgery to move the upper jaw forward (Image 17).

• 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 Scottish Rite hospital 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 bought to your child’s room for an additional cost. You may also bring food and snacks from home. There is a refrigerator, microwave and coffee maker for parent use on each floor of the hospital.

Visiting 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 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; contact hours: Monday to Friday, 8:30 a.m. to 8:30 p.m.; Saturday, 9 a.m. to 1 p.m.; and Sunday, 4 p.m. to 8 p.m.). A shuttle can take you to and from the Ronald McDonald House and the hospital at all hours.
• All visitors less than 12 years of age must stop at the nurses’ station for screening before they enter 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 less than 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 babies, 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 less than 12 years of age must be with a parent, volunteer or child life specialist while in the playroom or on the playground.

At times, we may need to alter these guidelines for our patients’ safety and health.
Notes about surgery

Date of surgery: _____________________________________________________________

Type of surgery: ____________________________________________________________

Doctor: _____________________________________________________________________

Notes: _____________________________________________________________________
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Speech and language

The person on the craniofacial team who works with your child’s speech and language is the speech and language pathologist (SLP). Your SLP will:

- Check your child as he grows to see how his speech develops.
- Advise treatment based on the check-ups.

Your child’s treatment may include speech therapy and surgery. A child can usually be ready to speak in a normal way for his age by the first year in school.

Needs for normal speech

In order for your child to speak well, certain things must be in place. A few of these things are listed below.

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 someone teach him to speak. Children learn to speak by listening to people speak. You can help your child begin to link spoken words to objects and actions.
   - Talk to your child about the objects and actions in his world often. This includes people, toys, food, playing, bathing and feeding.
   - Read two or three books each day to your child. Reading is a great way to help him learn to speak. Point to and talk about the names of characters and things in the book.

3. Your child must have a proper mouth structure. Most children with clefts can speak normally once their palates are repaired.
   - Some children still have a nasal voice due to air escaping from the nose.
   - These children may need more surgery to close the opening.
   - Your SLP can test your child to check on his speech.

4. Your child’s intelligence must grow in order for his speech to do the same. Not all children with speech problems have cognitive (thinking and learning) problems.
   - Some children with cleft lip or palate do have delays with thinking, learning and development.
   - A neuropsychologist can help you check on your child’s cognitive growth.

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. In time, speech moves onto 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 sound like speech, such as babbling and consonant sounds.
- Then they make real speech sounds and words.
- After putting 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 due to 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.”

- There are three consonant sounds that are spoken through the nose—“m,” “n” and “ng.” These are the nasal sounds.
- To make the other 43 sounds, the soft palate (the rear part of the upper mouth) must seal off the nose and force sound out the mouth.
- For the 16 pressure consonants sounds, this is vital because air pressure is needed to pronounce words clearly (enunciation). Pressure sounds include letters like “b,” “d,” “p” and “t.”

Children with cleft lip and palate often develop other ways to make speech sounds that are hard to do. Once they learn bad speech habits, they are very hard to “un-learn.” It is vital that you work with your child to make sure that early speech habits are learned correctly the first time.
How does the soft palate work?
The soft palate is a muscular door in the back of the mouth. It sits behind the hard palate in the roof of the mouth.
• During speech, the soft palate opens and closes a door called the nasopharynx. This doorway is hidden and you cannot see it 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, speech will be too nasal from too much air coming out of the nose.

Speech problems
There are many types of speech problems, but some are common when a child has a cleft palate: hypernasality, hyponasality and articulation.
• If the soft palate is too small or if the nasopharynx too big, speech may be hypernasal. This is when the soft palate allows sound to pass through the nose when making 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 sounds that are hard to make. Many consonant sounds are hard to make if the sound passes through the nose.

Speech and language modeling
Your SLP and the rest of the Children’s craniofacial team will do all 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 he hears around him each day, 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 using words and grammar because they do not hear them often enough. 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.

Repeat words and phrases after your child. Make the sounds clear and add other information. If your child points to a truck and says “ruck” you might say, “That is a red truck. Let’s make it go.”

Since children learn “object” words first, 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, walks and visits.

Between 12 to 18 months, children learn that some objects also have parts. Talk about your child’s eyes, nose and hair. A toy car also has parts. Talk about the wheels, doors and lights.

Between the first and second year, children often learn “action” words like walk, eat and play. They also learn words that describe an object like soft, wet and furry.

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. Our 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:
• Looking at and checking your child
• X-rays and videofluoroscopy (motion X-ray pictures)
• Special fiber-optic scopes
• Computerized instruments

These studies help us decide how to treat your child’s problem. If 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:

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SLP:

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Practice sounds for your child:

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Notes:

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Hearing and the ears

Babies and young children have more ear infections than adults because their ears are different. Babies’ eustachian (ear) 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 ear problems. The audiologist on the craniofacial team will discuss your child’s tests with you. The audiologist 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 children of all ages. 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 and quiet. It does not hurt.

- **Auditory Brainstem Response (ABR) test** measures how the hearing nerve and base of the brainstem respond to sound. In an ABR, electrodes are placed on your child’s forehead and behind his ears. ABR testing can tell how much hearing is in each ear.
   – Electrodes are soft pads that connect to the ABR machine by covered wires. They do not hurt or shock your child.
   – Various sounds are made through the earphones and a computer records the brainstem’s response.
   – The test takes up to one 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. If your child is fussy or distracted, it may take several sessions to complete a test. There are many types of behavioral tests and they all need your child to be involved during the test. 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 movie will play or a toy will move 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.

After your child’s hearing is tested, the audiologist will talk with you about the results. The audiologist will also discuss treatment options with you and the Children’s craniofacial team.

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:

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Type of test:

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Audiologist:

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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. Members of the 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 to correct problems with your child’s teeth and jaws. These steps may be spaced over years.

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**
  A cleft in the upper jaw can affect the shape of your child’s face. 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. Their position in the jaw causes this. 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 have tooth decay. Your pediatric dentist will talk with you about 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 treatments 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 six to nine 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 midteens.

Your child may also need other treatments at this time to correct his teeth and jaws. This phase of treatment can take up to a year and a half.
**Teenagers**

The final phase of treatment usually begins 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, we may correct the problem 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 2 times each day
- Using dental floss after meals to clean between teeth
- Visiting the pediatric dentist two times 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.

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**Notes about dental care**

Date of visit:

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Type of exam:

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Dentist:

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Notes:

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Neuropsychology services

A neuropsychologist can help check your child’s cognitive (thinking and learning) growth. While not all children with cleft lip or palate have cognitive problems, some do have delays in development and learning problems.

Screenings and evaluations

Your child may have a screening test to look for problems with thinking, movement, social and behavioral growth. Screenings may begin when your child is a baby and continue into the teen years. If we find any problems, we can complete more tests to help find the type and extent of the problems. These tests can also point to ways to help your child do better in many areas.

The tests may measure:
- Learning
- Attention
- Memory
- Ability to see and move well
- Problem solving
- Social and emotional function
- Effort and motivation (the desire to do something)

Before the evaluation, we will:
- Look at your child’s medical and school records.
- Ask about your child’s developmental, social and family histories.
- Ask you and your child’s teacher to fill out forms about his learning and behavior.

During the evaluation, we will:
- Use tests to check how your child thinks and behaves. The tests can take one to five hours. This might happen on more than one day.

After the evaluation, we will:
- Look at your child’s test results. We will talk to you about the results. We will make suggestions to help him at home and school.
- Make a plan to help your child. We will work with your child’s teachers and doctors.
- Help you start your child’s plan so he can reach his goals.

When is an evaluation needed?

If your child has problems with:
- Thinking and planning
- Paying attention, learning and remembering
- Doing well in school
- Controlling his negative emotions or reactions about medical treatment

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.

Contact our Neuropsychology Department at 404-785-2849 or visit choa.org/neuropsych for more information.
Resources

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 the Children’s craniofacial team 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 available resources

During your first meeting, the social worker may ask you many questions about your family, lifestyle, job and finances. This is to help the social worker learn about 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. You may speak with your social worker in person during your visits and call 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 Children’s Center for Craniofacial Disorders. Our staff and the staff of 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.
- Please tell your social worker if your child is not covered by private insurance or Medicaid, so your social worker 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
123 Edward St.
Suite 1003
Toronto ON Canada M5G 1E2
Phone: 800-665-FACE
aboutfaceusa.org
Email: info@aboutface.ca

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 517
Dallas, TX 75240
Phone: 800-535-3643
ccakids.com
Email: 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 Room 11-205
Atlanta, GA 30303
Phone: 404-657-4855
health.state.ga.us/programs/cms

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

Families of Children Under Stress (FOCUS)
3825 Presidential Parkway, Suite 103
Atlanta, GA 30340
Phone: 770-234-9111
focus-ga.org
Email: inquiry@focus-ga.org

This is a support group for parents of very ill children. It provides 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
Phone: 800-242-5338
cleftline.org
Email: info@cleftline.org

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

Georgia Advocacy Office
150 East Ponce de Leon Avenue, Suite 430
Decatur, GA 30030
Phone: 404-885-1234
thegao.org

This group provides information, training, referrals and legal advice and representation to people in Georgia with disabilities and mental illnesses. It works with families having problems with public school systems.

Resources you may want to order

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

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.

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GLOSSARY

Some of these terms are used in this manual. You may hear others used by the Children’s craniofacial team.

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.

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 nongenetic 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.

Palate: the roof of the mouth.

Pediatric dentist: a dentist who works on children’s teeth.

Pharyngeal flap repair: one type of surgery to improve the function of the palate.

Pharynx: the throat.

Plastic surgeon: a doctor who repairs the function and appearance of parts of the body.

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.

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

Prolabium: the central part of the upper lip between the mouth and the nose.

Prosthesis: a man-made replacement for a body part.

Prosthodontist: a dentist who makes and fits false teeth and other oral appliances.

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 (also called the “velum”)**: the movable part of the roof of the mouth behind the hard palate. It is needed 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.