Carolinias Center for Cleft Lip & Palate Surgery

Carolinias Center for Oral & Facial Surgery
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COORDINATORS
Clinical Coordinator – Abby Arthur, RN, BSN
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Please visit our website, mycenters.com, prior to your visit to familiarize yourself with our procedures and practice.
Welcome

Thank you for your interest in our center, we are pleased to be a part of your child's care. You and your child will be seen by our Cleft Lip & Palate Team, and the doctors and specialists who will see you will be evaluating your child's condition and be making recommendations regarding future care. After your initial visit, your child will be seen in increments determined by the team, usually every 6 months to a year. This is so we can evaluate and make necessary adjustments for your child's future treatment.

During your visit, you will have the opportunity to ask our doctors and specialists any questions you may have. To help guide you through all visits and treatment you will be in contact with our clinical coordinator, Abby Arthur, and our scheduling coordinator, Nikki McCullough.

During your visit, you and your child will meet with all present specialists who will evaluate your child. After your visit is complete all of our doctors and specialist meet in a team conference to discuss your child’s specific concerns.

The team members will agree upon recommendations for your child’s treatment and will decide on any necessary additional referrals to other specialists. In approximately 3-4 weeks, you will receive a letter from our team in the mail. This letter will summarize the team’s recommendations and referrals that have been made for your child. We suggest you keep this letter as your guide for your child’s treatment and file it with their medical records.

Finally, our team values parental input in all aspects of care and decisions regarding your child’s progress though out treatment. Please feel free to contact us at any time.
For Parents

Parent(s) Role:

1. Ask questions so you feel that you have a good understanding of what the doctors and specialist are telling you about your child’s needs. Please let us know if you do not understand something or if you feel you cannot carry out any of our recommendations.
2. Please open all mail from our team as soon as you receive it as it may have important information regarding your child enclosed.
3. Please notify our office of any change of address, phone number, or other pertinent information.
4. When seeing any of your child’s providers please ask them to send us a report regarding your child’s treatment. This will help to keep our records on your child up to date.

We understand this can all seem a bit overwhelming. We want to be a key resource and support for you and your child.

Resources

American Cleft Palate Association  [www.acpa-cpf.org](http://www.acpa-cpf.org)
Cleft Palate Foundation  [www.cleftline.org](http://www.cleftline.org)
Cleft Advocate  [www.cleftadvocate.com](http://www.cleftadvocate.com)
Cleft Kids, Inc.  [www.cleftkids.org](http://www.cleftkids.org)

Facebook Groups

NC Face to Face – A group for families living or seeking care for a cleft lip/palate or other craniofacial differences in the state of North Carolina.
Cleft & Craniofacial Connection – Community of families affected by cleft and craniofacial abnormalities.
Cleft Advocate – Family to Family Connection for all cleft lip and palate related questions.
Cleft Palate Foundation – The mission of CPF is to enhance the quality of life for individuals affected by cleft lip and palate and other craniofacial birth defects.
Cleft Kids, Inc. – Supporting families of children born with cleft lip/palate.

American Cleft Palate-Craniofacial Association – ACPA’s mission is to optimize interdisciplinary care of persons affected by cleft lip, cleft palate, and other craniofacial abnormalities.
Description of Specialties

PARENT: YOU are the most important members of our team. Your unique knowledge of your child is carefully considered in the treatment process. You are responsible for evaluating the team’s recommendations and following up on care that is in your child’s best interest. Our professional staff wants you to understand what is being done and why. You should ask questions until you receive answers you understand.

AUDIOLOGIST (Melissa Horning, Au.D): Audiologists do hearing tests to detect any hearing difficulties. The audiologist also makes recommendations for hearing aids when necessary and is involved in the fitting and monitoring of these devices.

PATIENT CARE COORDINATOR (Abby Arthur, RN, BSN): The patient care coordinator will be in touch about upcoming team meetings. The main goal of the coordinator is to keep you informed and guide you through the process of appointments and treatment. The Patient Care Coordinator will ask you a number of questions in order to obtain information that will help the team provide you or your child with the best possible treatment and care. You are encouraged to visit or call the Patient Care Coordinator if, at any time, you have questions about the scheduled appointments or any part of your diagnostic evaluation here at Carolinas Center for Cleft Lip & Palate Surgery.

ORAL AND MAXILLOFACIAL SURGEON/PLASTIC SURGEON (Richard Kapitan, DDS, MS; Daniel Cook, DDS, MD; Byron Henry, DDS; William Bicket, MD): The oral and maxillofacial surgeon examines your child’s face and mouth focusing on alignment of the jaws and dental arches. This specialist looks for misplaced or impacted teeth and irregularities of the jaw, face, and mouth. Both surgeons are concerned with your child’s appearance and ability to speak, chew and swallow normally. These team members may provide the surgical care required to correct these conditions and/or improve the appearance or function of the lips, palate, nose, and jaws. The oral surgeon and the orthodontist may develop a combined treatment approach when tooth movement and surgical treatment are appropriate.

ORTHODONTIST (Meredith Quimby, DDS, MS & Kelly Collins, DDS, MS): The orthodontist is concerned with growth and development of the jaws and teeth. Early recognition of problems is necessary so that orthodontic treatment can coincide with other procedures recommended by the team. Straightening your child’s teeth and monitoring the growth and development of the jaws should result in improved appearance and function.

SPEECH-LANGUAGE PATHOLOGIST (Brenley Ogden, CCC, SLP): The speech-language pathologist evaluates your child’s communication skills. During this evaluation, patient’s speech and language is tested and analyzed. The speech pathologist recommends speech and/or language therapy if needed. This therapy is usually provided in the area where you live or by our provider. The speech-language pathologist also encourages and demonstrates parent-infant stimulation for persons with children from three months to three years of age. Parent education is provided along with overall speech and language evaluations and treatment for the patient.
**NURSING** (Abby Arthur, RN, BSN):
The clinic nurse will measure your child’s height and weight and discuss overall questions or concerns you (the patient or parents) may have. The nurse will coordinate care between providers, is also available for counsel on surgical options or treatment plans, and can help you navigate the journey of cleft care.

**DENTIST** (Stephanie Chen, DDS, MS):
The dentist is concerned with primary dental care. The dentist will examine your child’s teeth at an early age to identify any growth or developmental problems. Your child should receive dental examinations and fluoride treatments every six months. If your child is using a nursing bottle, the dentist will tell you about early childhood decay and good feeding practices that can help prevent this condition.

*See Dental Specialties in the next section for Speech Appliances & Replacement of Missing Teeth

***As your child grows, many physical changes will take place, which is why your child should be seen by our team for follow-ups on a regular basis. Periodic team visits will ensure appropriate timing of any treatment needed and can help with planning future treatment.

**TEAM MEMBERS TO WHOM YOU MIGHT BE REFERRED

**PEDIATRIC GENETICIST** (Ed Spence, MD):
The team’s pediatric geneticist focuses attention to your child’s general health and development. Through a complete physical examination and review of the medical and developmental history, the pediatric geneticist determines if there are specific health factors the team should consider when preparing your child’s treatment plan. The pediatric geneticist determines the need for specific genetic testing and talks with you about the genetics of clefting as well as possible recurrence risks involved. He/she advises you about special health considerations and follow-up by your personal physician.

**PROSTODONTICS** (Mollie Griswold, DDS):
*Speech Appliances* – The dentist works together with the speech pathologist to determine if your child is a candidate for a prosthetic approach to improving speech (speech appliance) as an alternative to surgery. The dentist fabricates the appliance, fits it into the mouth and monitors how well it fits as your child grows.
*Replacement of Missing Teeth* – Removable dentures, fixed bridges, or implants are all options for replacing missing teeth. The dentist will plan treatment for you, which might include periodontal and/or restorative dentistry prior to the delivery of your dentures, bridge, or implants.

**EAR NOSE THROAT Otolaryngologist** (CEENTA):
Persons born with clefts or other craniofacial anomalies frequently have ear infections or middle ear fluid causing some degree of hearing loss. When necessary, an otolaryngologist, or an ear, nose, and throat (ENT) doctor will examine the ears and make recommendations to correct any problems that a patient may have. Early detection and periodic evaluations are important since hearing impairment can result in delayed speech-language development and poor performance in school.
INFANT FEEDING/NUTRITION (Megan Guthman, RN):
Feeding a child with a cleft or other craniofacial defect is often complicated and challenging. A feeding problem can be caused by a problem anywhere along the digestive tract, and may also involve breathing problems. For your child to maintain a healthy diet and develop good eating behaviors, feeding and nutrition are key.

PEDIATRIC NEUROSURGEON:
If your child has a disorder related to the brain, head, or spinal column, a consultation with a pediatric neurosurgeon will be recommended.

PEDIATRIC OPHTHALMOLOGIST (CEENTA):
An assessment of your child’s eyes and vision may be suggested

PSYCHOLOGIST/PSYCHIATRIST:
Acceptance by family members and friends is important to your child’s social adjustment. The psychologist plays a supportive role in dealing with possible psychological, social, and/or educational concerns. The team members evaluate your child’s self-concept, interpersonal skills, behavior, and learning to offer guidance to promote healthy psychosocial development for you and your child.

Map
Glossary of Terms

Here is a list of some of our most commonly used medical terms and their definitions.

A

Alveolar Ridge: The bony ridge of the gum line containing the teeth.

Anesthesia: Medications provided during a surgical or dental operation that put the patient to sleep.

Articulation: Movements of the mouth and airway that produce speech.

Articulation Test: An evaluation which provides information about how speech sounds are formed

Audiogram: A record of hearing levels or sensitivity

Audiologist: A person with a degree, license, and certification in audiology (science of hearing) who measures hearing, identifies hearing loss, and participates in rehabilitation of hearing impairment.

C

Cerumen: Earwax.

Columella: The central, lower portion of the nose which divides the nostrils into right and left.

Communication Disorder: An interference with a person’s ability to comprehend others or express themselves (usually in verbal form).

Congenital: A disease, deformity, or deficiency existing at the time of birth.

Craniofacial Anomaly: A visible, structural and/or functional difference affecting the head (cranium) and/or face.

Crossbite: A dental condition where the upper teeth are behind the lower teeth rather than in front of them.

Cupid’s Bow: The double curve of the upper lip is said to resemble the bow of Cupid.

D

Dental Arch: The curved structure formed by the teeth in their normal position.

Dental Extraction: Dental procedures performed to remove damaged, malformed, or malpositioned teeth.

Dental Restoration: Dental procedures performed to repair or correct damaged, malformed, or missing teeth.

E

Eardrum: Tympanic membrane which vibrates and transmits sound to the middle ear.
ENT: The abbreviation for ear, nose, and throat.

Eustachian Tube: The air duct which connects the nasopharynx (back of the throat) with the middle ear; usually closed at one end, opens with yawning and swallowing; allows ventilation of the middle ear cavity and equalization of pressure on two sides of the eardrum.

Evaluation: Assessment, test.

Expressive Language: Communication of one’s ideas, desires, or intentions to others, usually through speech or printed words.

F

Fistula: An abnormal opening, usually referring to a hole in the palate after repair.

G

Genetics: The science of heredity (how things pass from one generation to the next).

H

Hard Palate: The front part of the roof of the mouth containing bone covered by mucosa (pink “skin”).

Hearing Impairment: A loss in hearing which may range from mild loss to complete deafness.

Heredity: The total of the physical characteristics, abilities, and potentialities genetically derived from one’s ancestors.

Hyponasality: A lack of normal nasal resonance during speech.

Hypernasality: Speech that sounds overly “nasal,” as if the person is talking through his/her nose.

Hyponasality: Denasality. A lack of normal nasal resonance during speech.

L

Language Disorder or Impairment: Inability to communicate normally and effectively due to problems with comprehension or expression of language.

M

Malocclusion: A deviation from the normal occlusion, that is incorrect positioning of the upper teeth in relation to the lower teeth.

Mandible: The lower jaw.

Maxilla: The upper jaw.

Middle Ear: The portion of the ear behind the eardrum. It contains three small bones which transfer sound from the eardrum to the inner ear.

Myringotomy: A minor surgical procedure in which a small slit is made in the eardrum to allow fluid to drain from the middle ear.
**Multidisciplinary Team:** A group of professionals who work together to help plan and carry out treatment from patients, in our case, with cleft lip, cleft palate, and related disorders. The group usually includes surgeons, dental specialists, speech pathologists, orthodontists, and others who meet regularly to evaluate and discuss the patients under their care.

**N**

**Nasal Emission or Nasal Escape:** An abnormal flow of air through the nose during speech. Usually indicative of an incomplete seal between oral and nasal cavities.

**Nasal Septum:** The “wall” that divides the nose into right and left halves. It normally joins the roof of the hard palate like and “inverted 7.”

**Nasopharyngeal:** The part of the pharynx behind and above the soft palate, directly continuous with the nasal passages.

**Nasopharyngoscope:** A lighted telescopic instrument used for examining the passages in the back of the throat. Useful in assessing velopharyngeal function.

**O**

**Occlusion:** Relationship between upper and lower teeth when they are in contact. Refers to the alignment of teeth as well as relationship of dental arches.

**Oral Cavity:** The mouth bounded by the teeth in from and the soft palate at the back.

**Oral Hygiene:** Care of the teeth and gums which is performed at home on a daily basis. This is performed first by the child’s parent or guardian while the child is small and eventually by the child under continued supervision of the parent or guardian.

**Oral-Maxillofacial Surgery:** The specialty of surgery concerned with management of facial and skeletal deformities.

**Orofacial:** Relating to the mouth and face.

**Orthodontics:** The specialty of dentistry concerned with the correction and prevention of irregularities and malocclusion of the teeth and jaws.

**Orthodontic Care:** Dental visits designed to move teeth into better alignment with one another to improve chewing, oral hygiene, and appearance.

**Otitis Media:** Inflammation of the middle ear with accumulation of thick, mucous-like fluid – Ear infection.

**Otolaryngologist:** An “ear, nose and throat” physician specializing in the diagnosis and management of head and neck disorders.

**P**

**Palatal Insufficiency:** A lack or shortness of tissue preventing the soft palate from contacting the back of the throat (pharynx).
**Palate:** The roof of the mouth including the front portion, or hard palate, and the back portion, or the soft palate (also called the velum).

**Pansinusitis:** Inflammation involving the sinuses near the nose.

**Pediatrician:** A physician specializing in treatment of children.

**Pediatric Dentistry:** The specialty of dentistry concerned with the care of children's teeth.

**Pharyngeal Flap:** Surgical procedure designed to minimize hypernasality. A flap of skin creates a “bridge” between the soft palate and the back of the throat.

**Pharynx:** The tube or cavity, with its surrounding membrane and muscles, that connects the mouth and nasal passages with the esophagus.

**Philtral Columns:** Normal ridges in the skin of the central upper lip connecting the peaks of the Cupid’s bow to the back of the nose.

**Premaxilla:** The small bone in the upper jaw which contains the upper four front teeth. Normally connected with the side segments of the upper jaw (maxilla), but separate in some clefts.

**Preventative Dental Care:** Regular dental visits during which teeth are checked for cavities and cleaned.

**Prolabium:** The central area of the upper lip beneath the center of the nose (columella) and between the philtral columns.

**Prosthesis:** An artificial substitute for a missing body part.

**Prosthetic Speech Aid:** A removable plastic appliance which provides a structural means of achieving velopharyngeal closure (separating the nose from the mouth).

**Prosthodontist:** A dentist who specializes in providing prosthodontic appliances for oral structures.

**Psychologist:** An individual with the necessary academic training and experience to be licensed to practice psychology as a profession.

**Psychology** The science of the mind, of mental states and processes, and of human behavior.

**Radiography:** Photographic image depicting internal body parts. X-ray.

**Resonance:** Vocal quality associated with the vibration of the air in the oral and nasal cavities.

**Soft Palate:** The back part of the roof of the mouth containing muscles and mucosa (pink “skin”). The Latin name for the soft palate is “velum.”
Speech-Language Pathologist: An individual with the necessary academic training and experience to be certified or licensed to diagnose and treat disorders of speech, language, and communication.

Speech Defect: Deviation of speech from the range of normal.

Speech Video Fluoroscopy: A tape recorded x-ray examination of the speech mechanism during function, focusing on the soft palate (velum) and walls of the throat (pharynx). Useful in assessing velopharyngeal function.

Sphincter Pharyngoplasty: Surgical procedure designed to minimize hypernasality.

U

Uvula: Small, cone-shaped muscular process hanging at the back of the soft palate.

V

Velopharyngeal: Relating to the soft palate and the posterior nasopharyngeal wall.

Velopharyngeal Closure: The closing of the nasal cavity from the oral cavity which directs air used in speech through the mouth rather than the nose. It requires interaction of the muscles in the palate and the back of the throat.

Velopharyngeal Incompetence: Inability to achieve adequate velopharyngeal closure despite structures that may appear normal.

Velopharyngeal Insufficiency: A structure or functional disorder resulting in the inability to achieve adequate separation of the nasal and oral cavities.

Velum: The Latin name for soft palate.

Voice Disorder: Speech problems such as hoarseness, slow speaking volume, or strained voice quality.