

Our team...
with you at every step



at St. Joseph's Regional Medical Center

**The Regional
Craniofacial Center**

St. Joseph's Regional Craniofacial Center

Each year, approximately 1 in 750 children is born with a cleft lip or palate which can have an impact on a child's speech, dental health, hearing, educational advancement and swallowing. The mission of the Regional Craniofacial Center at St. Joseph's Children's Hospital is to provide quality specialized team care to children and adolescents with clefts and other congenital and/or acquired craniofacial anomalies. At St. Joseph's Regional Craniofacial Center, a premier multidisciplinary team of pediatric specialists provides consultation, diagnosis and treatment for patients with craniofacial disorders as well as education and support for their family members.

An on-site, 24-hour consultation service is available for newborns with craniofacial, cleft, velopharyngeal, and feeding problems. A staff member will travel to the referring facility or to the newborn within hours of initial contact. Through an outreach program, parents of children whose craniofacial anomalies were treated at the Center are matched with parents of children born with similar conditions. This allows parents to share their experiences. An on-call system enables parents and referral sources to reach specialists 24 hours a day, seven days a week. The mobile number is 201-655-3895.

Our Team... Your Team

Craniofacial deformities are particularly difficult because of their immediate impact on function, appearance and parent-child bonding. Finding the right clinicians and getting them to communicate with each other and you is a fundamental goal. Team care is recognized as the standard for affected children and adults. A cleft palate/craniofacial team is a committed group of specialists who use open communication and their shared experience to make treatment timely, efficient and as comfortable as it can be. Each clinician has a role to play, but the major benefits of team care are realized when we all work together.

A premier
multidisciplinary team
of pediatric specialists



Questions & Answers

Q. *I read about clefts online and some of it was confusing. Is all that information accurate?*

A. That depends on the source of what you are reading. There are a number of websites that provide accurate information and that we feel are helpful for parents and others who want to learn more about clefts and other craniofacial anomalies. These include: www.cleftline.org, www.aboutfaceusa.org.

Q. *Why did this happen and can it happen again if we have another child?*


A. The majority of birth defects are sporadic in nature, meaning that they do not follow a clear pattern of inheritance. Fortunately, this means that most families will be at low risk to have another child with the same issue. Some clefts are related to factors that could impact on your future children and should also lead to genetic counseling.

Q. *Can I speak with other families who are having a similar experience?*

A. Yes, in fact, our “buddy system” is a very important part of how families educate each other. Our team encourages mutual support and sharing of information among our patients and their loved ones.

Q. *Do I have to come to your Center for every element of my child's care?*

A. Members of the team are able to provide all of the necessary services. Sometimes it is easier to continue treatment with your own orthodontist, speech pathologist or other specialist, especially for families who travel significant distances to get to St. Joseph's. In these cases, the team makes recommendations and provides guidance to the clinician as needed.



Surgical specialists including craniofacial, plastic and reconstructive, otolaryngology/ head and neck and oral and maxillofacial surgeons collaborate in an effort to produce the best functional and aesthetic outcomes.

Q. *Can we speak with team members between team appointments?*

A. Absolutely! You will have contact information for every clinician involved in your care or the care of your child. The clinical director will assist in facilitating your interactions with individual team members.

Q. *Will someone help me with insurance issues?*

A. Yes, there are members of the team who are responsible for helping to work through social, educational and financial issues.



Unique to this Center is a subgroup of team clinicians dedicated to prosthetic reconstruction of the ears and other parts of the face. Prosthetic reconstruction was chosen for this child, who was missing his right ear from birth. Titanium implants placed in the skull are used to support a silicone ear that is crafted to match the left ear and characterized to match skin tone. Some families chose biologic reconstruction involving the fabrication of an ear from rib cartilage and the use of local tissues and grafts.

Success Story

Cleft Lip and Palate

Prenatal counseling (before birth)

Ultrasound may detect the presence of a cleft or other craniofacial anomaly well before the birth of a child. Prenatal counseling affords parents the opportunity to learn, understand and prepare.

This may help parents adapt to a new set of expectations and priorities and may also include a visit with a genetic counselor who can address specific questions asked by many parents.

NAM (0-3 months)

A unique technique called nasoalveolar molding (or NAM) may be utilized to shape the mouth, lip and nose during the first few months of life in preparation for cleft repair.

An acrylic appliance is custom made to fit your infant and is adjusted weekly as the oral structures and bones are slowly molded and shaped to bring them in better alignment, improving the contours of the lips and nose. This creates a more aesthetic and natural appearance in children even before surgery and allows the surgeon to close the cleft with better functional and aesthetic outcomes. NAM also shapes the nose and allows for the cartilage to be molded naturally through growth, reducing the need for nasal surgery.

This technique is one that depends on the involvement of dedicated parents/caregivers supported by members of the team.

Cleft lip repair (3 months)

Lip repair is among the most dramatic and visible procedures done for children who are born with cleft lip and palate and is typically scheduled within a few months after your child is born. Often, surgery takes place after the structures around the cleft have been molded to improve the outcome of surgery.

Cleft palate repair (9 months)

Palate repair is generally performed before your child's first birthday although for some, it may be necessary to wait a little longer. When possible, the palate repair is completed before that structure is needed to participate in the development of speech.

Pharyngeal flap (5 years)

A pharyngeal flap may be recommended if your child has hypernasal speech.

This is much more likely in the cleft palate population than among unaffected children.

Speech and language pathologists, surgeons and other team members work together to develop the approach best suited for each child.

Orthodontics (6 years)

The orthodontist is one of the core specialists on any cleft lip and palate or craniofacial team. Every child with a cleft should have an orthodontic evaluation to monitor facial and dental growth and development and most of these children will benefit from treatment.

Early orthodontic intervention may improve positioning of the hard and soft tissues of the face. In children with clefts, the hard palate is narrowed and teeth are often missing or improperly positioned. Orthodontic appliances may widen and prepare the palate for necessary bone grafting, as well as align the teeth for improved speech, function, and aesthetics.

For patients who need surgery to reposition the jaws, the orthodontist will work with an oral and maxillofacial surgeon and other team members to produce a functional, aesthetically pleasing and stable outcome.

Alveolar bone grafting (7-10 years)

Even after lip and palate repair, many children have residual clefts of the alveolus, which is the tooth-bearing part of the upper jaw. Left untreated, there is inadequate bone support for the lip and nose as well as for teeth in the area. The alveolar cleft may also result in food and liquid escaping through the nose. By age 7 or 8, these children are ready to have the upper jaw expanded with an orthodontic device in preparation for bone grafting of the residual cleft. Once the bone graft heals, tooth eruption may proceed, and the opening between mouth and nose is eliminated.

Braces can then be used to straighten teeth.

Bone grafting also facilitates subsequent dental interventions and provides a good framework for lip and nose revision, if needed.

Orthognathic Surgery (16-18 years)

When growth is complete, orthognathic surgery may be necessary to properly align the upper and lower jaws, to produce a functional dental occlusion (bite) and to develop harmony among the different parts of the face.

Jaw surgery is a collaborative effort beginning with orthodontic preparation and careful surgical planning. Speech and swallowing are re-evaluated prior to jaw surgery to help reduce complications associated with moving the upper jaw forward.

We encourage teens to postpone cosmetic revisions of lip and nose until the teeth and bones are in their proper and final position.

Pregnancy

Birth

3 months

6 months

12 months

3 years

6 years

9 years

18 years

Geneticist

When a patient is born with a craniofacial birth defect, it is important to evaluate that child and determine whether the condition is isolated or if it occurred as part of a more complex genetic disorder. The genetics specialist reviews the family, medical and pregnancy histories and conducts a detailed physical examination. This allows the team to provide individualized education and support, an outline for future medical management and an assessment of recurrence risks for family members (risks for future children or other relatives).

Audiologist

Audiologists on the craniofacial team provide state-of-the-art hearing assessments and interventions for infants and children. We work closely with your family to help you understand how your baby or child hears. Parents of children with hearing loss will be offered all appropriate and available options along with the support and guidance of the team. From the assessment and fitting of conventional hearing aids to the use of bone-anchored devices, we follow a comprehensive team approach that allows for optimal care.

Maxillofacial Prosthodontist

While surgery is often a good choice for repair and reconstruction of parts of the face, prosthetics play a major role, particularly when replacement is superior to repair. The maxillofacial prosthesis specialist provides services including: pre-surgical orthopedics (NAM appliances for the unilateral and bilateral cases), palatal lifts and speech bulbs and artificial replacement of head and neck structures. Candidates for prosthetic rehabilitation include those who have had cancer or suffered traumatic injury as well as children with congenitally missing or deformed structures.

Prosthetist, specializing in artistic facial prostheses

An additional dimension unique to this team is the level of artistry that is applied to our maxillofacial prosthetics. Patients are able to appreciate the collaborative efforts of an artist with a maxillofacial prosthetist along with the support of surgeons who place implants in bone to anchor facial prostheses. The most compelling advantage of a prosthesis over surgical reconstruction using living tissues is the aesthetic outcome. The touches added by a trained artist/technician enhance the ability of our team to provide prostheses with superior aesthetics.



Feeding Specialist

Newborns with cleft lip/palate who are otherwise healthy make normal attempts to suck but may have difficulty coordinating breathing and sucking and may not be able to generate the necessary pressure. While feeding solutions for babies with cleft lip/palate or craniofacial disorders vary, nearly every baby will be able to feed successfully with the right technique. Some of the earliest and most important interventions by members of a craniofacial team involve counseling and guidance from a feeding specialist. This clinician will enable parents to find the method that provides both adequate nutrition and a comfortable feeding pattern.

Pediatric and Special Needs Dentist

While every child is special and has needs, children with cleft lip and palate and other craniofacial syndromes may develop aversions and/or anxieties and dentistry is often challenging for these children. Using behavioral, sensory and other anxiety-reducing approaches, we have been successful in treating their oral health needs.

Operating room and sedation services for children with extensive dental needs are available but it is our goal for these children to be comfortable with dental treatment in the usual office setting. We encourage parents to visit the pediatric dentist as early as the eruption of the first tooth and not later than 12 months of age.

Speech Pathologist

The ability to communicate is a fundamental skill that may be compromised by a delay in development, a cleft or an underlying palatal muscle dysfunction. Speech and language pathologists on the team are skilled in the diagnosis and treatment of both speech and language issues specific to children with a cleft or craniofacial disorder. Specialized speech, airflow, x-ray and scoping equipment allow staff members to visualize possible defects in the muscles of speech and provide data on how best to treat the issue.



Infant Head Shape

Babies are often born with misshapen heads and most of these will normalize during early infancy. Sometimes, head shape does not improve and for some babies, head shape becomes distorted during the first few months of life. A subgroup of team clinicians including a craniofacial surgeon, a pediatric neurosurgeon, a pediatric physical therapist and orthotist meet frequently to evaluate and manage head shape issues.

Plagiocephaly/Helmet Program

The condition known as plagiocephaly is a deformation of the skull often related to infant sleep positioning during the first few months of life. "Back to Sleep" recommendations designed to reduce the incidence of sudden infant death syndrome (SIDS) were very successful, but did result in an increase in plagiocephaly. When caught early, management may simply involve changing sleep positions and physical therapy. Sometimes, a helmet may be used to direct growth of the head during a baby's first year in an effort to improve head shape, reestablish symmetry and to support proper development of the head and face. It is only on very rare occasions that children with misshapen heads will become candidates for surgical treatment.

The helmet was worn for 3 months.



5-month old with significant right plagiocephaly, head tilt, asymmetries and torticollis.



8-month-old post helmet therapy.

Parents should feel comfortable in discussing their child's head shape with their pediatrician. While some infants may outgrow misshapen heads, referral to a craniofacial team during the first few months of life may result in more conservative treatment and better outcomes.

Success Story

Craniosynostosis

Craniosynostosis affects about 1 in 2,000 children. Although the cause is usually unknown, premature fusion of the suture prevents the bone of the skull from growing normally and results in stereotypical skull and facial deformity. This deformity tends to worsen with time over the first few years of life unless surgically treated. At the Regional Craniofacial Center at St. Joseph's Children's Hospital, recent advances have made surgery for children with craniosynostosis shorter and safer. Minimally invasive endoscopic-assisted craniosynostosis surgery utilizes a small camera to assist with removal of the abnormal bone that causes skull deformity through one or two one-inch incisions. The surgery is performed in one to two hours, children rarely need a blood transfusion, and they typically go home the next day. This is in striking contrast to the traditional approaches used to treat craniosynostosis at nearly all other centers in the Northeast. The key for success using the minimally invasive endoscopic-assisted approach is to intervene early, when the bone is thin. Removal of the prematurely closed suture (the abnormal bone) when the child is less than 6 months of age allows the skull to develop a more normal shape as the child grows. The use of a helmet for 6-12 months after surgery helps facilitate this bone remodeling.

Psychosocial and Family Issues

When a child is born with any type of medical concern, all members of the family are affected. Parents, siblings, grandparents, aunts, uncles and family friends all receive a quick education hearing unfamiliar words and feeling uncertain about the baby's future. Typical childhood development and memories are stolen from the family and replaced with medical appointments, surgeries and specialists. Families need support. One of the critical services provided by the team is family counseling. Among the many functions of the counselor is the task of connecting families when an issue is identified, prior to surgery or when a family needs peer support. Sometimes, the most helpful conversation for a parent is with another parent who has gone through a similar experience.



Our Mission

To provide a contemporary multidisciplinary team approach to the evaluation and treatment of children with cleft lip, cleft palate, velopharyngeal disorders and craniofacial anomalies.

The Regional Craniofacial Center at St. Joseph's Children's Hospital meets or exceeds standards set by the American Cleft Palate-Craniofacial Association for designation as a Craniofacial Team. The team is also a member of the New Jersey Federation of Cleft Palate-Craniofacial Teams and is funded in part by the Department of Health and Senior Services, Special Child Health and Early Intervention Services.



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The Regional Craniofacial Center is affiliated with the Alfiero and Lucia Palestroni Birth Defects Center

An acute care specialized state designated children's hospital at St. Joseph's Regional Medical Center
A member of St. Joseph's Healthcare System
Sponsored by the Sisters of Charity of Saint Elizabeth
The Craniofacial team is a member of the American Craniofacial Association and the
New Jersey Federation of Craniofacial Centers.