



**Weill Cornell Medicine**  
Pediatrics

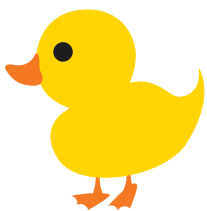
**NewYork-Presbyterian** Kids  
Komansky Children's Hospital

# A Parent's Guide to Cleft Lip and Palate

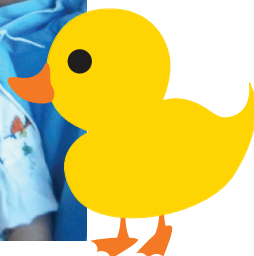
The Weill Cornell Pediatric  
Cleft and Craniofacial Team



Recognized and approved by the **American Cleft Palate-Craniofacial Association**



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THINGS  
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## We Are Here For You

The Weill Cornell Pediatric Cleft and Craniofacial Team takes a multidisciplinary approach to treating craniofacial disorders. Co-directed by Dr. Vikash Modi of Pediatric Otolaryngology and Dr. Caitlin Hoffman of Pediatric Neurological Surgery, the team is dedicated to ensuring a successful outcome for every child and family. This includes a thorough evaluation of the case, selecting the best option, and utilizing the most advanced technology. The team understands that the trust developed before surgery is equally important after surgery in order to support the child through a positive recovery.

Accredited by the America Cleft Palate Craniofacial Association, the team's goal is to provide coordination and facilitation of care for your family's comfort and convenience. When a family comes to the Cleft and Craniofacial Team, they will see all the specialists they need to see whether it's two or ten, in one place, in one session. After the visit, our experts meet to create a personalized treatment plan to meet each patient's needs, from the moment of initial consultation through treatment and beyond.

## How To Reach Us

**The Weill Cornell Cleft and Craniofacial Team**  
428 East 72<sup>nd</sup> Street, Suite 100, New York, NY 10021  
Phone: **646-962-4321** | Fax: **212-746-8124**

**[craniofacial@med.cornell.edu](mailto:craniofacial@med.cornell.edu)**

**<https://ent.weill.cornell.edu/patients/clinical-specialties/services/craniofacial-program>**

**Cleft Clinical Coordinator**  
**Kathlyne Purrini, CPNP**  
Phone: **646-962-5443**  
E-mail: **[kap9145@med.cornell.edu](mailto:kap9145@med.cornell.edu)**



## Team Members

### **Vikash Modi, MD**

Team Director, Pediatric Otolaryngology

### **Caitlin Hoffman, MD**

Team Director, Pediatric Neurosurgery

### **Kathlyne Purrini, CPNP**

Team Coordinator, Pediatric Otolaryngology

### **Michelle Buontempo, CPNP**

Team Coordinator, Pediatric Neurosurgery

### **Lilian Cohen, MD**

Genetics

### **Madeleine Drusin, MD, MSc**

Pediatric Otolaryngology, Microtia Specialist

### **Anthony Sciafani, MD**

Facial Plastic Surgery

### **Arron Cole, MD**

Facial Plastic Surgery

### **Thomas Imahiyero, MD**

Plastic Surgery

### **Naikhoba Munabi, MD, MPH**

Plastic Surgery, Microtia Specialist

### **Katharina Graw-Panzer, MD**

Pediatric Sleep Medicine

### **Jeremy Dixon, DDS**

Pediatric Dentistry

### **Robert Berg, DMD**

Prosthodontics

### **Jay Neugarten, DDS, MD**

Oral and Maxillofacial Surgery

### **Andrew Lemchen, DMD**

Orthodontics

### **Jordana M. Smith, MD, MPH**

Pediatric Ophthalmology

### **Yvonne Knapp, MS, CCC-SLP**

Speech and Language Pathology

### **Linzey Smith, MA, CCC-SLP**

Speech and Language Pathology

### **Michelle Kantor, MS**

Speech and Language Pathology, Feeding Specialist

### **Blakely Durham, CCLS**

Child Life Therapy

### **Jessica Spat-Lemus, PhD**

Neuropsychology

### **Elizabeth Poole-DiSalvo, MD**

Developmental Pediatrics

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# Important Phone Numbers

Cleft and Craniofacial Team .....	<b>646-962-4321</b>
Cleft Clinical Coordinator .....	<b>646-962-5443</b>
Audiology .....	<b>646-962-2231</b>
Billing Questions .....	<b>855-880-0343</b>
Child Life Services .....	<b>212-746-3516</b>
Financial Assistance .....	<b>866-252-0101</b>
Pediatric Otolaryngology .....	<b>646-962-2224</b>
Pediatric Neurosurgery .....	<b>212-746-2363</b>
Genetics .....	<b>646-962-2205</b>
Facial Plastic Surgery .....	<b>646-962-2285</b>
Medical Records .....	<b>212-746-0530</b>
Oral and Maxillofacial Surgery .....	<b>212-308-9200</b>
Orthodontics .....	<b>212-755-2333</b>
Pediatric Sleep Medicine .....	<b>646-962-3410</b>
Pediatric Dentistry .....	<b>212-477-7712</b>
Prosthodontics .....	<b>212-879-9292</b>
Radiology .....	<b>212-746-6000</b>
Social Work .....	<b>212-746-3042</b>
Speech and Language Pathology .....	<b>646-962-2231</b>
Feeding Therapy .....	<b>212-746-0258</b>
Pediatric Neuropsychology .....	<b>646-962-0118</b>
Developmental Pediatrics .....	<b>646-962-4303</b>

# Timeline

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- Before birth**
- Meet your Cleft and Craniofacial Team — prenatal consultation offered
  - Genetic counseling offered
- 

- At birth**
- Visit from Team Coordinator within 48 hours of birth
  - Feeding evaluation before hospital discharge
  - Newborn hearing test before hospital discharge
  - Assess the need for nasoalveolar molding (NAM)
  - Genetic counseling
- 

- 1–4 months**
- Cleft and Craniofacial Team clinic within 4 weeks of birth
  - Monitor feeding and growth
  - Monitor ears and hearing
  - Repair cleft lip and nasal deformity around 3 months of age
  - Possible insertion of ear tubes at the time of lip repair
- 

- 5–8 months**
- Monitor cleft lip healing
  - Monitor ears and hearing
  - First Speech and language evaluation
- 

- 9–12 months**
- Pre-operative feeding evaluation
  - Cleft palate repair
  - Insertion of ear tubes at the time of palate repair
- 

- 1–2 years**
- First dental evaluation
  - Speech and language assessment
- 

- 4–5 years**
- Consider lip/nose revision
  - Speech and language assessment
- 

- 6–11 years**
- Orthodontic evaluation
  - Assess the need for an alveolar bone graft
  - Monitor school and psychosocial needs
- 

- 12–21 years**
- Consider genetic counseling for the child
  - Consider nose revision
  - Orthodontic evaluation
  - Monitor school and psychosocial needs

# Common Questions

## Who is part of my child's treatment team?

A baby with a cleft lip and/or palate usually requires special care from a team of cleft specialists. The treatment team will support your family through childhood, adolescence and beyond.

- Surgeon (such as a plastic surgeon, oral maxillofacial surgeon or otolaryngologist)
- Speech pathologist who assesses speech problems
- Feeding specialist who assesses feeding problems
- Pediatric dentist who cares for teeth
- Pediatric orthodontist who prevents or corrects misaligned teeth and jaws
- Prosthodontist who specializes in nasoalveolar molding (NAM) devices and dental restoration
- Social worker, psychologist, and child life specialist who supports your child's emotional needs
- Team coordinator who is your point of contact and helps with education
- Geneticist who screens patients for genetic syndromes
- Audiologist who assesses hearing
- Other specialists as needed

## What is a cleft lip and palate?

A cleft lip and palate or cleft palate alone are very common birth defects. A cleft is an opening in the lip or the roof of the mouth (palate).

## How common are clefts?

Clefts are one of the most common problems found in newborn babies. In the U.S., 1 in 600 babies are born with a cleft. Clefts are twice as common in boys as in girls.

## What causes cleft lip and palate?

Babies' lips and palates develop during the first three months of pregnancy. Normally, the left and right sides of the lip and palate come together and fuse to form a normal upper lip and palate. Clefts are a result of incomplete development of the lip and palate while the baby is developing before birth.

We don't know why cleft lip and palate occur, but we know that it is usually not because you did something wrong. It was not your fault. Sometimes clefts occur in combination with other problems, known as a syndrome. Most children with clefts do not have a syndrome or any other genetic problems. An isolated cleft palate is associated with a syndrome in about 50% of patients, and cleft lip, with or without a cleft palate, in about 15% of patients.

# Common Questions *Continued*

## What are the types of clefts?

A cleft can be of the lip, the palate or both. Our team treats the following types of clefts:

### Cleft lip

A cleft lip occurs when the tissue that makes up the lip does not fuse during pregnancy, which results in an opening in the upper lip. A cleft lip can be a small slit or it can go through the lip and into the upper gum and nose. A cleft lip can be unilateral, involving only one side of the lip, or bilateral, involving both sides of the lip.

### Cleft palate

A cleft palate is an opening in the roof of the mouth in which the two sides of the palate do not fuse together during pregnancy. Sometimes the front and back parts of the palate are open, but for other babies only part of the palate is open.

### Submucous cleft palate

A submucous cleft palate occurs when the opening in the roof of the mouth is underneath the tissue (mucosa) of the palate. It is often associated with a split or "bifid" uvula, a notch in the palate bone that can be felt and a clear line in the middle of the palate that can be seen. About 50% of children with a submucous cleft palate do not need surgery. The other half of children need surgery to fix the muscles to achieve normal speech.

## How and when is my child's cleft repaired?

Cleft lips are usually repaired when your child is about three months old, as long as your baby is healthy, feeding and growing well. Cleft palates are usually repaired when your child is around 10 months old. Sometimes a procedure is not 100% successful the first time, so your child may need a revision surgery later in life to improve the appearance of the lip or nose or if there are speech problems. The Cleft and Craniofacial Team will monitor your child closely to assess for any problems that require follow up.

## How can I feed my child?

Babies with cleft lips alone can usually breastfeed or bottle feed normally. Babies with cleft palates have difficulty with breastfeeding and will require the use of special bottles and nipples. Our feeding specialist provides all the guidance you will need to feed your baby.

# Common Questions *Continued*

## Will this affect my child's hearing?

Children with cleft palates have an increased risk of ear infections and fluid buildup behind the eardrum. This is caused by dysfunction of the palatal muscles, which affects the Eustachian tubes (small tubes that connect the middle ears to the back of the nose). It is important that we test your child's hearing regularly as they age. Many children with cleft palates require ear tubes to help ventilate the middle ear to prevent fluid from accumulating and prevent hearing loss. Some children will need multiple sets of ear tubes through childhood.

## Will this affect my child's speech development?

A child with only a cleft lip typically does not have speech problems as long as their hearing is okay. Approximately 25% of children with a cleft palate develop speech problems once their palate is repaired. Some children require speech therapy while other may require further surgery to fix the problem. The Craniofacial Team will monitor your child frequently to assess their speech development.

## Will my child require special dental care?

Children with clefts should have routine dental care like any other child. They may have special dental problems, like missing teeth, extra teeth or incorrectly shaped teeth. Because of this, it is important to establish care with a dentist who has experience treating children with clefts.

## What is a nasoalveolar molding (NAM) device?

NAM is a non-surgical way to slowly mold the gums, lip and nostril with a plastic plate before cleft lip and palate surgery. Not all children will be candidates for NAM because it depends on the size of the cleft. Molding reduces the size of the cleft palate and/or lip so that the tissue is in a better position prior to surgery. Surgery is done after the molding is complete, when your child is around 3 to 6 months old. Molding may decrease the number of surgeries and revisions your child needs.



# What To Expect After Surgery

## Cleft lip repair

The cleft lip repair is usually performed when your child is around 3 months old. It is okay to continue regular feeding from the bottle or breast. Your child will wear arm restraints after surgery. Arm restraints are splints worn on the arm which prevent your child from bending their elbows and touching their lip.

## Cleft palate repair

The cleft palate repair is usually performed when your child is around 10 months old. Your child will spend 1–2 days in the hospital after surgery. Your child will use a sippy cup and eat soft solids for two weeks after surgery so that the palate can heal. Your child will also wear arm restraints during the healing process. Arm restraints are splints worn on the arm which prevent your child from bending their elbows and touching their lip.

## Lip and nose revision

Lip and nose revisions may be necessary as your child grows for functional or cosmetic reasons. Revisions usually take place when your child is between 3 to 18 years old.

## Velopharyngeal insufficiency (VPI) surgery

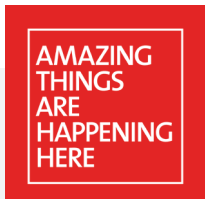
The Cleft and Craniofacial Team, in conjunction with the VPI Center, will periodically assess your child's speech development. Sometimes speech can be affected after cleft palate surgery. If surgery is needed to treat a speech problem, it is performed when your child is between 3 to 5 years old. Your child may resume speech therapy two weeks after surgery.

## Alveolar bone graft

An alveolar bone graft surgically closes the gum line and is needed for children with a cleft of the alveolus. It is performed when your child is between 6 to 10 years old. Your child will eat soft solids and should limit physical activity for two weeks after surgery.

## Jaw surgery

Jaw (orthognathic) surgery may be needed to align your child's teeth and improve their facial profile. It may be performed when your child is between 12 to 18 years old.



# NewYork-Presbyterian/Weill Cornell Komansky Children's Hospital Services



The NewYork-Presbyterian/Weill Cornell Komansky Children's Hospital is a state-of-the-art dedicated children's hospital. Our mission is to improve the health of infants, children and adolescents through high-quality and comprehensive programs in patient care, medical education, scientific research and child and family advocacy.

Our hospital has specialized units dedicated to the care of children including a Newborn Intensive Care Unit, Pediatric Intensive Care Unit and Pediatric Surgery Unit. All surgeries are performed by pediatric surgeons under the care of pediatric anesthesiologists. Child Life Specialists are available during our team evaluations, inpatient wards and surgical units. Child Life Specialists provide age appropriate educational materials so that our young patients can see, feel, hear and touch things with which they will come in contact during a procedure, test or their hospital stay. The goal of Child Life Services is to normalize the hospital environment for children and their families, as well as provide emotional support.

We perform specialized diagnostic tests including nasopharyngoscopy, speech video fluoroscopy, nasometry, and complex airway evaluations. Assessment of sleep problems is available through the Weill Cornell Pediatric Sleep Center.

# Notes

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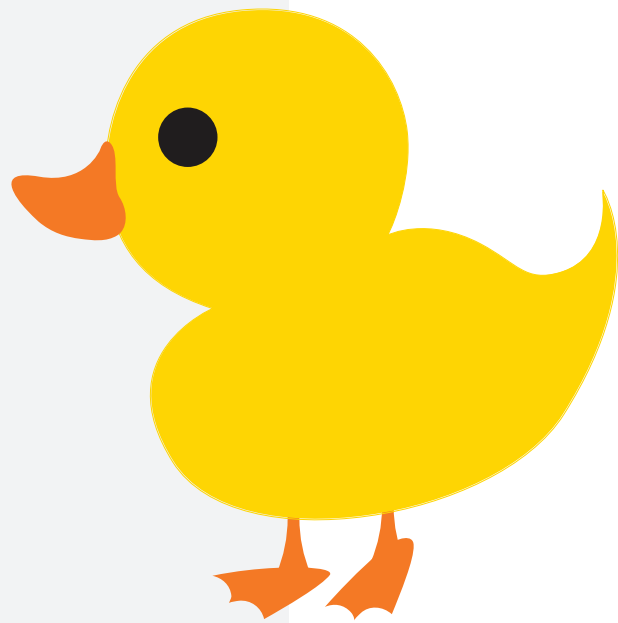
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