

## **July 2019- National Cleft and Craniofacial Awareness and Prevention Month**

*A note from the author—*

*Happy July NCP friends! This month, I am featuring an article about a very specific type of disorders: birth defects of the head and face. Many people have seen photos of children suffering from cleft lip/ palate and commonly associate such disorders with impoverished countries where access to medical and dental care is scarce. However, did you know that thousands of children born in the United States each year suffer from these same conditions? This month, celebrate with the NCP Health Ministry by reading more about Cleft and Craniofacial disorders below, which include information on risk factors, the impact on daily life, and treatment options.*

### **What is National Cleft and Craniofacial Awareness and Prevention Month?**

July is National Cleft and Craniofacial Awareness and Prevention Month, an effort to raise awareness and improve understanding of birth defects of the head and face, according to the Centers for Disease Control and Prevention.

**How common do you think cleft lip and palate are in the United States?**

The CDC estimates that about  
**7,000 BABIES**  
will be born with a cleft in the U.S. this year.  
Compare that to about 6,000 babies born with Down Syndrome

**JULY IS**  
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**ARE YOU AWARE?** [www.cleftline.org](http://www.cleftline.org)

### **The Prevalence of Cleft and Craniofacial Abnormalities**

Cleft and craniofacial conditions affect thousands of infants, children, teens and adults in the United States each year. Some are born with congenital anomalies like cleft lip and palate, others with more complex, life-threatening craniofacial conditions. Some are burned; others are injured in accidents and animal attacks, or diagnosed with various oral/head/neck and skin diseases.

## **The Impact of Cleft and Craniofacial Abnormalities**

Children with orofacial clefts and other craniofacial conditions often have impaired ability to feed and impaired language development, and might be at increased risk for a greater number of ear infections, hearing issues, and problems with their teeth. Because of the high prevalence of orofacial clefts and health care use and costs associated with treatment, improving the health of these children is an important public health goal (2). CDC and its partners are working to better understand the preventable causes of clefts and craniofacial defects, and how these conditions affect children and their families, by focusing on risk factors, health care—service use, access to care, quality of life, health outcomes, and management and treatment of these conditions.

## **What are Craniofacial Disorders?**

"Craniofacial disorder" is a broad term that describes malformations of the face and skull that may result from birth defect, disease or trauma. In the US, approximately 600,000 individuals have been diagnosed with a craniofacial condition.

Among the conditions seen most frequently:

- Cleft palate/Cleft lip — An abnormality in which the lip or mouth's palette doesn't close properly before birth and has to be fixed surgically.
- Misshapen heads — There are different disorders that can cause the skull to be misshapen. Among them:
  - Positional plagiocephaly
  - Simple craniosynostosis
  - Hemifacial microsomia
- Syndrome disorders — A syndrome is a disease or disorder that has more than one identifying feature or symptom. There are a number of syndromes specifically affecting head/facial disorders, including Crouzen, Apert, Pfeiffer, Saethre-Chotzen, Carpenter, and Cloverleaf syndromes.
- Trauma — The face or skull also can be damaged through accident and injury.

## **Crouzon Syndrome**



Midface (maxillary) hypoplasia  
Exophthalmos secondary to shallow orbits  
Ocular hypertelorism  
Nose: Beaked appearance  
Mouth: Mandibular prognathism  
Narrow, high, or cleft palate and bifid uvula



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## More Information about Craniofacial Birth Defects

Some of the most common craniofacial birth defects include orofacial clefts (cleft lip, cleft palate, or both). More detailed information about some of the most common types of craniofacial defects can be found below:

- **Cleft palate** is a birth abnormality that affects about one in every 2,000 newborns and is more common in boys. (A lesser-discussed but similar condition, cleft lip, affects about one in every 1,000 births). The palate is the inner, underside of the mouth. When the palate is cleft, it is because the roof of the mouth didn't close together properly during gestation. A newborn may have a large gap in the palate, which may affect the ability to nurse and eventually eat and talk. Most babies with a cleft palate or lip are otherwise healthy. They may experience some problems until the cleft is repaired like feeding difficulties and ear infections.
- A **cleft lip** is a birth defect in which the parts of the face that form the upper lip remain split, instead of sealing together before birth. Similar splits can occur in the roof of the mouth or palate. Both can present a variety of problems, including difficulty eating, speech difficulties, ear infections and misaligned teeth.



Baby with cleft lip



Baby with cleft palate

- **Positional plagiocephaly** is the most common of the head deformities called "positional" deformities. In positional plagiocephaly, the child's head often looks like a rectangle when viewed from above. Repeated pressure to the same area of a newborn's very pliable skull can cause the head to be deformed, sometimes with distinct differences between the right and left side of the face.
- **Simple craniosynostosis** – Natural sutures are joints between skull bones that hold the skull together, but that also grow as the skull grows. In children with normal development, the sutures eventually fuse together. Craniosynostosis occurs when the sutures fuse too soon before growth is complete. The result is a skull that is not normally shaped, with pressure on the growing brain that is trapped in a too-small structure.

- **Hemifacial microsomia (HFM)** is a condition in which the tissue on one side of the face is underdeveloped, affecting primarily the ear, mouth and jaw. Sometimes, both sides of the face can be affected and may involve the skull, as well as the face. HFM is the second most common birth defect after clefts.



- **Syndrome disorders** are complex congenital disorders that frequently result in multiple symptoms that require comprehensive care from an interdisciplinary team.

### **Craniofacial Birth Defects: Debunking the Myths**

Cleft and craniofacial conditions are commonly associated with other countries, though they also occur frequently in the U.S. Cleft lip, with or without a cleft palate, is one of the most common birth defects in the U.S., affecting about 7,000 babies annually according to the Centers for Disease Control and Prevention (CDC).

Here are five key facts about clefts and craniofacial conditions, their impact and treatments:

1. Clefts are usually repaired surgically in the first year of life, though many children require additional surgeries and treatments through adolescence to correct challenges to breathing, eating or speech development.
2. Individuals born with cleft lip or palate often need specialized dental or orthodontic care throughout their lives as well.
3. There is no single factor related to the cause of cleft. Sometimes clefts run in families and in some cases have been linked to environmental factors.

4. Despite unique health challenges, those born with cleft and craniofacial conditions lead fulfilling, successful and accomplished lives.
5. Coordinated care is the best approach for successful surgical repair. Multidisciplinary teams are located across the nation and are comprised of qualified professionals from medical, surgical, dental, speech and allied health disciplines.

### **What Causes Craniofacial Birth Defects?**

The defect may be genetic or the result of maternal environmental exposures during pregnancy. This year, the CDC is highlighting research on the association between smoking during early pregnancy and orofacial clefts.



### **The Effect of Cleft Palate**

Pregnancy can be a very trying process. There are many blood tests, screenings and ultrasounds to endure; each a milestone that brings you closer to holding your bundle of joy. But birth defects are a very real issue that can arise during pregnancy. Cleft palate is one type of birth defect that affects a baby's mouth. Learning about cleft palate symptoms will help you know what to look for if you think there's an issue with your baby.

### **Cleft Palate Symptoms**

A cleft palate is basically a split in the mouth's roof and is easily identifiable at birth. It can occur in combination with a cleft lip or as a stand-alone. One version of a cleft that might not be recognizable until later is a submucous cleft palate. Though the palate

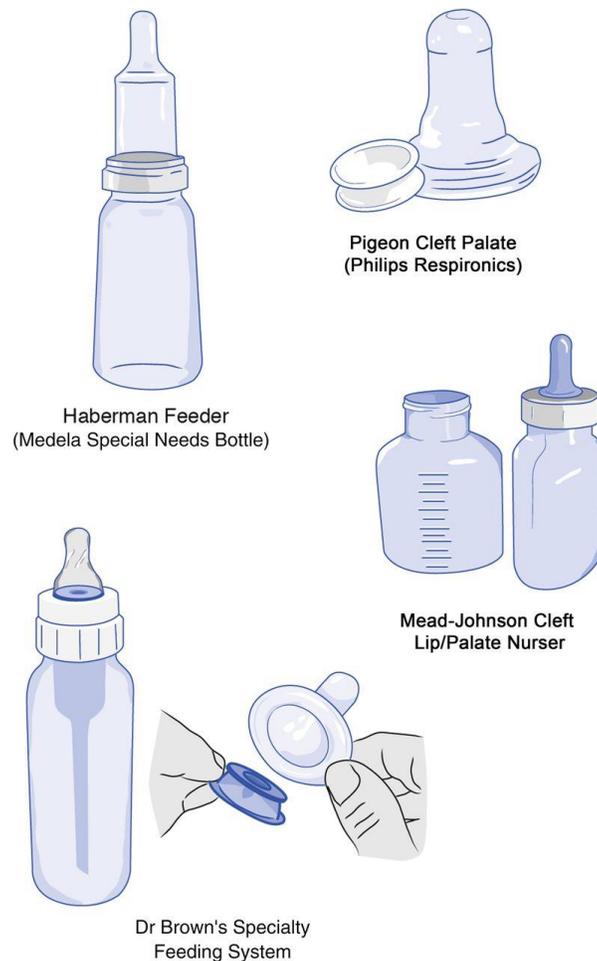
appears intact, below the mucous membrane resides a depression comprised of muscular and bone irregularities.

Symptoms to watch for that would indicate a submucous cleft are as follows:

- Nasally sounding speech due to air exiting through the nose
- Feeding and swallowing problems, including food and liquids entering the nose
- Ear infections caused by atypical muscle attachments

In patients with cleft palate, speech is affected in babies and children in multiple ways. Babies may be delayed in starting to babble while having a limited consonant range while babbling. They might be delayed in uttering their first words while learning additional words at a slower pace. As children age, they might be prone to articulation errors and a delay in expressive language abilities. They may have soft voice syndrome.

Feeding challenges occur in babies as they can't separate the nasal and oral cavities. This prevents them from sucking while affecting their ability to express breast milk from the nipple. Inadequate nutrition may lead to poor weight gain. They might take in too much air and experience fatigue as a result of working so hard to feed.

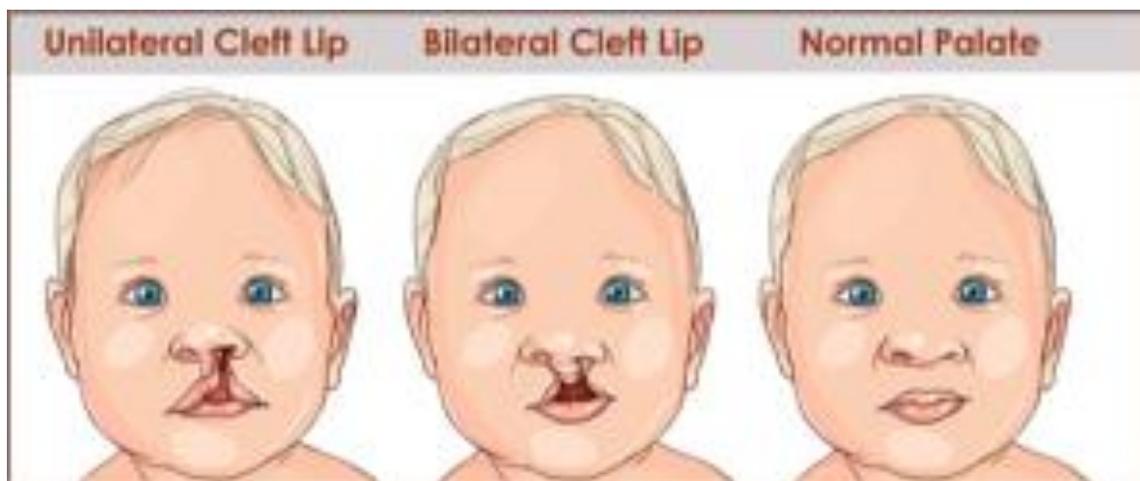


In addition to ear infections, conductive hearing loss is possible. Over 90 percent of children with a cleft palate will suffer from middle ear fluid buildup. Hearing loss may also cause socialization issues in older children due to an inability to keep up with conversations.



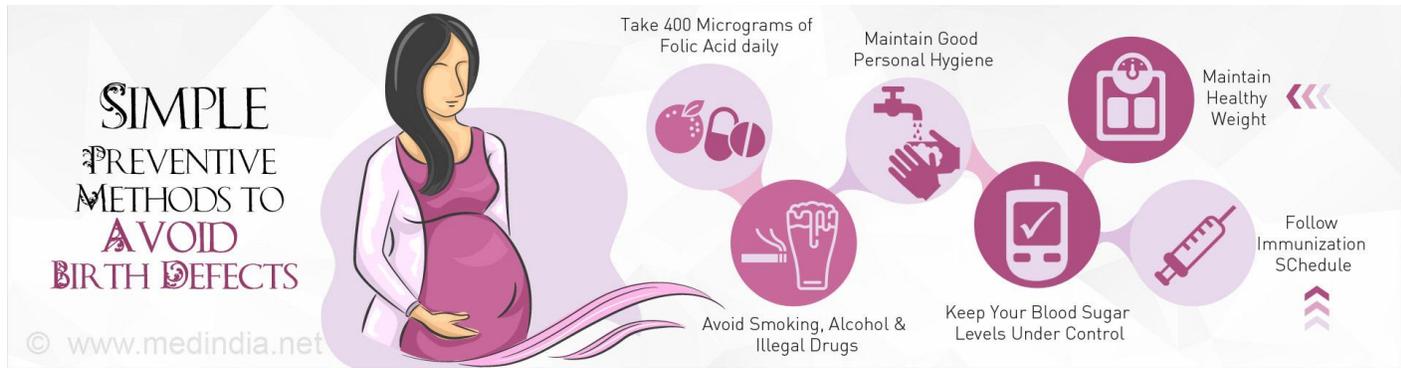
### **Oral Health Effects of Cleft Palate**

Oral issues that occur as a result of a cleft lip or palate can affect both baby and adult teeth, including the positioning, size, shape and number of teeth. Clefts can occur between the cuspid and lateral incisors.



### **Preventing Craniofacial Birth Defects**

The CDC said that although the causes of most lip and palate clefts are unknown, the 2014 Surgeon General's report confirmed that maternal smoking during early pregnancy can cause orofacial clefts in babies. In the U.S., about 7,000 babies are born with orofacial clefts each year. Women are encouraged who are thinking about becoming pregnant to quit smoking before pregnancy or as soon as they find out that they are pregnant.



### **Treating Craniofacial Birth Defects**

Treating each type of craniofacial birth defect is disease-specific. However, it is possible to correct both cleft lip and palate through surgery, which is usually performed between the ages of 3 to 6 months. Depending on the severity of the defect, more than one surgery may be necessary.



### **Advanced Surgical Repair Approach**

Children with deformities involving the growth of the head and face often have multiple problems that require the expertise of a multidisciplinary team. Hospitals that treat such conditions bring together a staff of pediatric experts from various disciplines, which allows the team to treat all aspects of the disorder. Examples of the disciplines that collaborate to provide integrated care include:

- Neurosurgery
- Oral surgery
- Audiology
- Dentistry
- Psychology
- Genetics
- Otolaryngology
- Speech pathology
- Orthodontics

- Ophthalmology

Centers that specialize in cleft lip and palate surgery provide the latest advances in craniofacial reconstruction. This includes:

- **Early intervention** - The earlier work begins on rebuilding any or all of a child's face, the more likely the changes will grow as the child grows.
- **Minimally invasive surgeries** – There is a recognized benefit of minimally invasive approaches which generally mean quicker healing; less risk of damage to surrounding tissue, nerves, arteries or veins; less physical pain and less emotional distress for patients and families.
- **Single-stage repairs** – Many craniofacial disorders require more than one surgery, which can be disruptive to families and budgets. Some hospitals have been working on single-stage surgeries—complex procedures completed during one surgery.
- **Continuity** – While patients generally prefer "single-stage" operations, the fact that children are constantly growing means some children will need multiple operations to correct their craniofacial disorders. Hospitals that perform these surgeries follow their patients for as long as needed, frequently into adulthood.

### Enhancing more than just appearance

It is not unusual for children who look different to be teased or bullied, or find social situations difficult. That means the cosmetic benefits of minimally invasive techniques and new materials that absorbable are important for their additional psychological benefits. This is why Cleft and Craniofacial Reconstruction Centers usually include professionals from a number of disciplines, including psychiatry, psychology, social work, speech and physical therapy to help children develop as normally as possible.



### Cleft Palate Surgery

Cleft palate is one of the most common types of birth defects and one that can be corrected with surgery. Ideally, cleft palate repair surgery is performed before a child reaches 18 months of age, though, it can be performed at 6 months of age. The child is put under general anesthesia. A surgeon closes the cleft by bringing together muscles and tissues after making incisions on both sides of the cleft. Dissolving stitches are used to seal the cleft. After surgery, a child typically spends a day or two in the hospital

recovering before being discharged. Parents should discourage a child from touching the surgically repaired area. Pacifiers and sippy cups with spouts shouldn't be used soon after surgery. Foods such as yogurt, ice cream and purees are all that should be eaten for the first week post surgery. Hard foods shouldn't be consumed for six weeks. Helping your children develop a good oral care routine from a young age is one way to ensure they'll carry those habits throughout their lives. Good habits include brushing at least twice a day and flossing regularly. Regular dental checkups will not only keep their teeth in good working order, but also dispel any fears they might have about the dentist. Be sure to practice what you preach and your kids will be more apt to take care of their teeth, if you're doing the same.



## Resources

<https://www.colgate.com/en-us/oral-health/conditions/cleft-lip-palate/ada-07-july-national-cleft-craniofacial-awareness-prevention-month>

<http://www.nccapm.org/>

<https://acpa-cpf.org/2017/07/06/july-is-national-cleft-and-craniofacial-awareness-month/>

[https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6425a5.htm?s\\_cid=mm6425a5\\_w](https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6425a5.htm?s_cid=mm6425a5_w)

<https://www.smiletrain.org/media/press/smile-train-celebrates-national-cleft-and-craniofacial-awareness-and-prevention-month-nccapm-around-world>

<http://americanhealthcouncil.org/national-cleft-craniofacial-awareness-prevention-month/>

<https://childrensnational.org/visit/conditions-and-treatments/genetic-disorders-and-birth-defects/craniofacial-disorder>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3942043/>

<https://medlineplus.gov/craniofacialabnormalities.html>

<https://www.nemours.org/services/cleftandcraniofacial.html>