

# KNOW BEFORE YOU KNOCK



## CLEFT PALATE

Every child and family has unique aspects of their situation, experience, and diagnosis. This page is intended to provide a general overview, but is not attempting to represent every situation or child you encounter. Every family deserves your expertise to assess and adapt your prior knowledge. This resource is best viewed electronically.

### DEFINITION

Cleft lip and cleft palate are openings or splits in the upper lip, the roof of the mouth (palate) or both. Cleft lip and cleft palate occur when an unborn baby's face and mouth are developing and the upper lip and palate don't close fully.

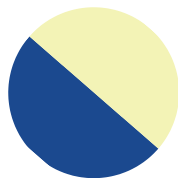
### NATIONAL/STATE ORGS

[American Cleft Palate Craniofacial Association](#) (ACPA) Leading Interdisciplinary Cleft and Craniofacial Care So Patients and Families Thrive.

[Face Equality International](#) Working together to ensure the global facial difference community is seen, protected and respected.

### PREVALENCE

Orofacial clefts are one of the most common congenital disorders in the United States, affecting one in every 1,032 births and resulting in 3,560 cases every year. [\(1\)](#)



### TOP RESOURCES

- [Cleft Lip and Palate](#)- Treatment tab in particular, American Speech and Language Association (ASHA)
- [Parents & Carers](#)- Cleft Lip and Palate Association (CLAPA)- Great resources for parents and providers!
- [ACPA Booklet to Support Baby's First Year](#)

### CONSIDERATIONS THAT MAY IMPACT SERVICES

- Important to collaborate with medical team (surgeon, audiology, otolaryngology, ophthalmology, dentistry, genetics, etc)
- Common with other genetic diagnoses such as Van der Woude, Pierre Robin's, Apert, and other syndromes. [\(5\)](#)

### LANGUAGE TO USE/AVOID

- Ok to Use: Cleft lip, cleft palate, lip affected, palate affected, visible difference
- Avoid: "Deformity", "defect", "hare lip" or making comments about the cleft difference being "only cosmetic"

### DIFFERENCES THAT MAY BE PRESENT

- Feeding and swallowing
- Hearing
- Resonance and airflow
- Speech and language
- Articulation
- Voice [\(2\)](#)
- Ear infections
- Family stress [\(3\)](#)
- Attachment differences [\(4\)](#)

### SPECIFIC SUPPORT THAT PARENTS MAY NEED

- Knowing how to deal with other people's reactions
- Coping with their child's change in appearance following surgery
- Knowing how to raise the topic of cleft with their child once their child is old enough to understand
- Getting access to genetic counselling and understanding the environmental and genetic contributors to cleft lip/palate. [6](#)

### SUPPLEMENTARY TESTS THAT COULD BE USED OR SEEN IN MEDICAL RECORDS

The "Rule of Ten": A guide for surgery readiness, often looking for a baby to be 10 weeks old, weigh 10 lbs, and have a hemoglobin of 10 g/dL

### REFERENCE LIST