

a guide to understanding
**cleft lip
and palate**

a publication of children's craniofacial association

a guide to understanding cleft lip and palate

This parent's guide to cleft lip and palate is designed to answer questions that are frequently asked by parents of a child with a cleft lip and palate. It is intended to provide a clearer understanding of the condition for patients, parents and others.

how can children's craniofacial association (cca) benefit my family?

CCA understands that when one family member has a craniofacial condition, each person in the family is affected. We provide programs and services designed to address these needs. A detailed list of CCA's programs and services may be found on our website at www.ccakids.org or call us at 800.535.3643.

The information provided here was written by Richard J. Redett, MD, FACS, FAAP

This booklet is intended for information purposes only. It is not a recommendation for treatment. Decisions for treatment should be based on mutual agreement with the craniofacial team. Possible complications should be discussed with the physician prior to and throughout treatment.

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what is a cleft lip and palate?

a cleft lip and palate is a gap, which occurs when the lip or roof of the mouth does not completely fuse during the first trimester of fetal development. The lip and palate

develop separately so it is possible for a child to have a cleft lip, a cleft palate or both. The size of the cleft lip may range from a small notch in the upper lip to an opening that extends into the base of the nostril (Diagram 1). The cleft may be single sided (unilateral, Diagram 2) or occur on both sides (bilateral, Diagram 3). A cleft palate may involve only the hard palate or soft palate or a combination of both (Diagrams 4-6).

CLEFT LIP

DIAGRAM 1

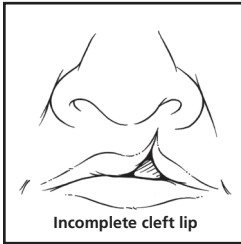


DIAGRAM 2

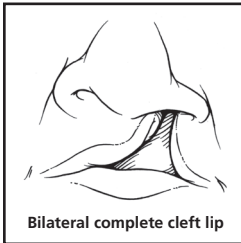
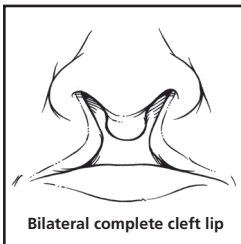


DIAGRAM 3



CLEFT PALATE

DIAGRAM 4

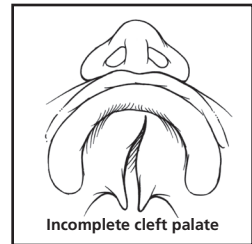


DIAGRAM 5

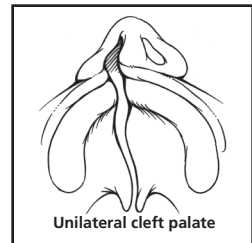
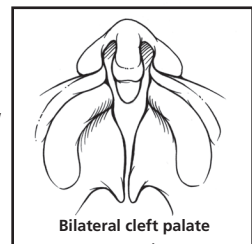


DIAGRAM 6



how often does clefting occur?

the incidence of cleft lip with or without cleft palate is estimated to be between 1/300 and 1/2500 births depending on the

patient's ethnic origin. It is most common in Native Americans and Asians and least common in African Americans. Cleft palate alone occurs in 1/1000 births. Cleft lip occurs more frequently in males and cleft palate occurs more frequently in females. The majority of children born with cleft lip and palate are otherwise normal with no associated syndromes.

what are the chances of my baby having a cleft lip and/or palate?

If two unaffected parents have a child with a cleft lip/palate or isolated cleft palate, their chance of having another child with a cleft is 3 to 5%. If either parent has a cleft lip/palate or isolated cleft palate, but no affected children, the risk of having any other children with a cleft is 5%. If more than one of the parents and/or children have a cleft, the risk for future offspring is greater.

Parents who have had a baby with a cleft lip/palate or who have a family history of clefts can consult a genetic counselor to discuss the risk of having future children with a cleft.

what causes clefting?

The cause of clefting is multifactorial and probably involves a combination of genetic and environmental factors, however, the cause of clefting is usually unknown. Environmental factors, which may increase the risk of clefting, are smoking and alcohol use during pregnancy, poor maternal nutrition and certain medications. Many mothers who have a baby born with a cleft have a normal pregnancy.

how is a cleft lip and/or palate diagnosed?

Acleft lip can sometimes be diagnosed on prenatal ultrasound. An examination of the nose, lip and mouth confirm the presence of a cleft lip or palate.

what other problems might we expect and how will they be treated?

Children with only a cleft lip and no cleft of the gum line or palate frequently have no other problems. Children with a cleft palate may have ear infections and hearing loss, dental problems and difficulty with feeding and speech. An experienced cleft lip and palate team has specialists to help with each of these potential problems.

Feeding difficulties

A child with a cleft palate can have difficulty sucking through a regular nipple due to the gap in the roof of the mouth. Most babies require a modified or special nipple to properly feed. It may take a couple of days for the baby and parents to adjust to using the nipple before going home. Most babies learn to feed normally with a cleft palate nipple. The pediatrician and cleft team will keep close track of the child's weight.

Most babies with a cleft palate cannot generate enough suck to breast-feed. To take advantage of the health benefits of breast milk, many mothers elect to feed their baby breast milk in a bottle with a cleft palate nipple. The hospital nursery and cleft team have feeding specialists available to evaluate the baby and meet with the parents before going home.

Speech issues

Children with an unrepaired cleft palate have a nasal quality to their speech because air escapes through the gap in the roof of the mouth and out the nose. These children may also have difficulty generating enough air pressure to produce certain sounds. After cleft palate repair, most children develop

near normal speech. Some children will require speech therapy or another surgery when they are older to improve persistent nasal speech.

Hearing and ear infections

Any child with a cleft palate is at risk of developing frequent ear infections. The Eustachian tube, which drains the middle ear, malfunctions, causing persistent fluid build up in the middle ear. A combination of fluid and repeat ear infections can cause scarring of the tympanic membrane (ear drum) and hearing loss. Pressure equalizing eardrum tubes can be inserted at the time of lip or palate repair to drain the middle ear and reduce the risk of ear infection and hearing loss.

Dental concerns

A child with a cleft palate or a cleft through the gum line may have missing or abnormally shaped baby and permanent teeth. In addition, the upper jaw may not grow as far forward as the lower jaw, necessitating corrective surgery later in life. Your cleft team will refer you and your child to a dental and orthodontic expert who can successfully treat these problems.

treatment

the care of an infant with cleft lip and/or palate begins at birth with accurate diagnosis, identification of the child's needs and the location of a proper treatment center. All children with cleft lip and palate should be followed by a cleft team. The cleft team consists of multiple specialists including a plastic surgeon, speech therapist, dentist, orthodontist, otolaryngologist, audiologist, geneticist, pediatrician and feeding specialist. Team members will work closely with you and your child to determine the best treatment plan.

The cleft lip is usually repaired between the ages of 3 to 6 months. The cleft palate is repaired between the ages of 9 to 12 months. Some children may require a two-stage lip repair or molding device if the cleft is wide. Ear tubes are often placed at the time of palate surgery if needed.

Your child's speech, hearing and dental development will be followed closely by the cleft team. Secondary surgeries such as pharyngeal flap, alveolar bone graft, rhinoplasty and upper jaw surgery may be recommended.



children's craniofacial association

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empowering and giving hope to individuals and families affected by facial differences