

# WHY BABIES ARE BORN WITH CLEFTS

Approximately 1,000 babies are born with cleft lip and palate in Uganda. In many cases, there is no known cause for the condition, although it can be rectified with surgery.

A cleft is a gap or split in the upper lip and/or palate (roof of the mouth). The cleft may occur as an isolated cleft lip, isolated palate or in combination- lip and palate. The cleft lip and palate combination constitutes the majority of the orofacial clefts. Clefts may be a part of a syndrome, occurring together with other congenital malformations for example of the heart and/or limbs.

**How common is cleft lip and palate?**  
Cleft lip and palate is a common congenital condition found worldwide. The distribution and prevalence rates vary widely; it is most common in Asia and least in Europe and the Americas. In Uganda, the prevalence rates are reported between 0.8- 1.3 per 100,000 live births which is approximately 1,100 babies born with clefts annually. More boys than girls are affected with cleft lip and palate. The combination of cleft lip and palate is more commonly seen compared to isolated cleft palates or cleft lip.

Children born with cleft lip and palate do not necessarily have learning disabilities however they may have challenges related to speech because of a cleft palate.



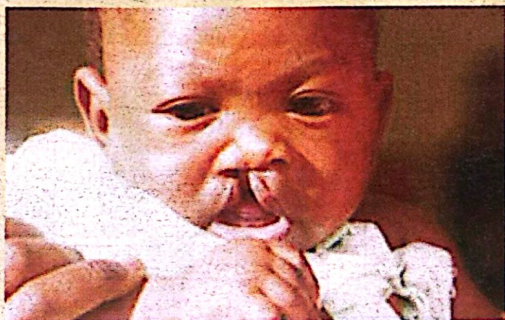
Excessive consumption of alcohol is an indirect risk factor in cleft lip births. PHOTOS BY RACHEL MABALA.

## WHAT CAUSES CLEFTS?

Clefting results when the tissue forming the lip or palate does not fuse completely during fetal development in early pregnancy.

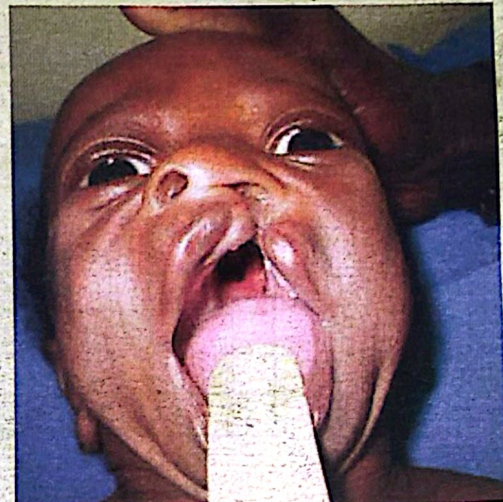
Most clefts occur sporadically, with no known direct linkable cause.

There are some indirect risk factors as is the case with other congenital malformations eg advanced maternal age, smoking, excessive alcohol and some antiepileptic drugs. There are some cases of clefts that are gene-linked and may be seen to run in families.



**Diagnosis**  
Generally, diagnosis of a cleft is made at birth. It is possible

to make the diagnosis by Ultrasound scan after the second trimester of pregnancy.



### PROBLEMS ASSOCIATED WITH CLEFT LIP AND PALATE

**Cosmetic**  
The appearance of a cleft lip is quite abnormal. This leads to a lot of psychosocial problems eg poor bonding between mother and child, child abuse and later in life, teasing. A good repair is almost imperceptible to the unkeen eye.

**Feeding**  
Infants with cleft palate, unlike those with isolated cleft lip, usually have problems feeding largely because they are unable to "suckle" during breastfeed. They take longer to feed, swallow more air and easily aspirate or choke during their feeds. They frequently suffer chest infections as a result of the aspirations. Malnutrition is commonly seen in cleft lip and palate infants. The infant with cleft palate can be assisted to feed better by holding the child more upright at about 45 degrees during feeding, use of a spoon and or cup, a bottle with a modified "nipple" to facilitate sucking. Other methods include use of an orthodontic feeding plate. Notably, feeding takes long and is tiresome to both the infant and mother. Nutritional rehabilitation is required for the infants that are malnourished, to prepare them for safe surgery and is usually continued for a while after the surgery.

**Speech**  
This is the biggest impairment for cleft lip and palate patients. The soft palate is important in speech clarity and articulation. In cleft palate, the muscles that move the soft palate to allow variability of air flow which is essential in speech; are malpositioned. In a cleft palate repair, these muscles are realigned to allow normal palatal movement, hence improve speech. Surgery alone doesn't produce normal speech, there is a great need for speech therapy as an adjunct in order to improve speech.

**Hearing problems**  
Children with cleft palate are susceptible to glue ear, a middle ear problem caused by poor drainage by the Eustachian canal leading to recurrent middle ear infection. Early repair of cleft palate is

associated with lower rates of middle ear infections hence less hearing loss.

**Dental problems**  
Because of the cleft, the alignment of the teeth is often not good. Early repair of the cleft lip in some ways improves gum alignment although best results are achieved through orthodontics. Alveolar bone grafting to bridge the bony cleft is required between ages 7-10 years to allow the permanent teeth to grow through bone. It is important to maintain good dental and oral hygiene as one would ordinarily.

**Psychosocial problems**  
It is very distressing for parent to find out that their child has a birth defect. It is not uncommon that family problems ensue following the birth of a child with a cleft. Parent-baby bonding is usually affected leading. A paucity of information and traditional beliefs regarding clefts further complicate the situation.

**Repair of the cleft**  
Repair of the cleft lip and palate is performed by surgeons specially trained in cleft repair. Presently, there are several hospitals in Uganda where cleft repairs are performed. It is important for a baby with a cleft to be seen by a surgeon and pediatrician after birth before they leave hospital. Referral should be made to the nearest plastic surgeon for planning and scheduling of the repair. Repairs can be safely performed after 3 months of age. There is no age limit for adults requiring cleft repair. Presently in Uganda, repairs for cleft lip and palate are provided free of charge to the families, thanks to funding from Smiletrain.

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