

CLEFT LIP AND PALATE

What is a cleft lip and palate?

A cleft lip and palate is an opening or gap in the lip, gum, and palate (roof of the mouth). A cleft lip can extend into the nose or stop at any point below and be on one side or both sides. Having a cleft lip also changes the shape of the nose.

Cleft lip and palate occur during the first trimester of pregnancy, often before a woman knows she is pregnant. It is one of the most common birth differences in the USA.



What causes cleft lip and palate?

In about two thirds of children, there is no known cause for their cleft. Sometimes, clefts may run in families, or may be associated with other problems and may be part of a **syndrome**. A syndrome is a disorder that has a recognized group of symptoms or features. We have learned there are many things that can increase the chances of a baby having a cleft, but more still needs to be learned through scientific research.

A medical specialist in the field of genetics helps families understand the possible causes of clefts, and if the cleft is associated with a syndrome. We will help set up this appointment for you.

Is feeding difficult for babies with cleft lip and palate?



Babies with cleft lip and palate may have a hard time feeding. Because of the cleft palate, or opening between the mouth and nose, the baby can not generate the suction needed to pull milk from the bottle or breast. It is like trying to drink through a straw with a hole in it. This makes it difficult to breastfeed or use a regular bottle. Babies may look like they are nursing and sucking but they are really using up a lot of energy and getting very little milk.

Our feeding specialist will evaluate your baby and determine which feeding system is best suited for your child. We will also provide you with a starter supply and a list of resources where you can obtain more bottles and nipples. Mothers are encouraged to express their breast milk to use in bottle feeding.

Your baby may have milk come out of the nose. This is called “nasal regurgitation” and is not dangerous. It does not mean your baby is choking. Holding your baby in a more upright position during feeding can help decrease the amount of milk out the nose. There is no need to use a bulb syringe to suck milk out of the nose—the nose clears and cleans itself.

A baby with a cleft lip and palate may also swallow more air while feeding. Burping your baby more frequently ensures the baby is comfortable.

Do you recommend the use of orthopedic devices for babies with cleft lip and palate?

At our Center, every child has an individualized treatment plan developed with the family. We do not routinely recommend the use of orthopedic devices, such as Latham appliances or naso-alveolar molding (NAM). These devices are expensive, labor intensive for families, and have not been proven to have a long term benefit to children. Sometimes we recommend gentle taping of the lip at our first evaluation after the baby is born. If it will benefit your baby, we will give you the tape and teach you how to apply it.

What other areas are affected?

The muscles in the palate normally help the middle ear to drain and stay healthy. Because of the cleft, these muscles may not work properly and fluid can build up in the middle ear. For this reason, babies with cleft palates often do not pass their newborn hearing screen. This does not mean your child can not hear. Our hearing specialist will follow your baby and perform further evaluation if needed.

Speech may also be affected by the cleft. The palate separates the mouth and the nose area to allow normal speech. You will notice that your baby's babbling will sound more nasal. Some sounds are affected more than others – "mama" will sound clear, but "dada" may sound nasal (like "nana"). After the palate is repaired, this will improve.

When there is a cleft through the gum, certain teeth may be affected. Sometimes there is a missing tooth or an extra tooth near the cleft, and most children need braces.

How is Cleft Lip and Palate Treated?

Our team recommends that every baby with cleft lip and palate be evaluated while in the hospital, or as soon as possible after going home. We ask each family with a newborn with a cleft lip and palate to have their baby weighed once a week, on the same set of scales, and call us with the information. A two week follow up appointment will be scheduled by our clinic coordinator. We encourage families to call us with **any** questions or concerns.

A baby born with cleft lip and palate will need surgery to correct these conditions. Our center recommends surgery for the lip around 10 weeks of age. We repair the baby's nose at the same time. During the procedure, an ear specialist will examine your baby's ears and place tiny drainage tubes if necessary. We use a special closure technique so there are no stitches that will need to come out. Our babies feed the same way before and after the operation, so you will not have to make any changes in your baby's feeding. We do not use any arm restraints ("No-No's"), or protective facial appliances. Because the risks from anesthesia are much lower in 10 week old babies, babies are discharged the same day as the surgery and do not need to spend the night in the hospital.

Cleft palate repair is usually performed between 8 and 12 months of age. The surgery rearranges the muscles at the back of the palate ("soft palate") and the tissue of the hard palate to close the cleft. The surgeon does not take tissue from other parts of the body or use any artificial material to close the palate.

Taking care of a child with a cleft lip and palate is more than just performing surgical procedures. Having a cleft lip and palate can affect a child's appearance, self esteem, teeth, and speech. This is why all children with a cleft lip and palate are followed regularly by our multidisciplinary team. Experts dedicated to the care of children with craniofacial conditions from a wide range of pediatric specialties work together to make sure your child gets the best care possible.

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FOR MORE INFORMATION, CONTACT THE VCU CENTER FOR
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