

## **Cleft Lip/Palate**

### **What is Cleft lip/palate?**

Cleft lip/palate is a congenital birth defect. Congenital means present at birth. They occur early in pregnancy sometimes before a woman even knows she is pregnant. For every 1000 babies born, approximately 1 or 2 will have a cleft lip and or palate.

The word “cleft” means a split or gap between two things. In babies with cleft lip, the upper lip does not form completely and there is a split in the lip. A cleft palate is a split in the roof of the mouth.

Cleft lip can vary in severity from a tiny indentation in the upper lip to a split that continues into the nose. In the same way, a cleft palate can range from a small separation in the roof of the mouth to a very large separation that interferes with feeding.

Clefts are referred to as unilateral which means the split is on one side, or bilateral means the split is on both sides. Cleft lip and cleft palate can occur separately or together. About half of the time, clefts include both the lip and palate.

Isolated cleft lip means a cleft involves only the lip and not the roof of the mouth. Isolated cleft palate means a cleft involves only the roof of the mouth and not the lip. About half of the time, the cleft involves either an isolated cleft lip or an isolated cleft palate.

A cleft lip/palate can sometimes be identified during a prenatal ultrasound. But some are not diagnosed until after birth. Cleft palate is especially difficult to see on ultrasound and many are not diagnosed until after birth.

### **What causes Cleft lip/palate?**

Cleft lip/palate may have a genetic link causing them to occur more often in certain families. Some times cleft lip/palate is part of a genetic condition or syndrome, meaning there are problems in other body parts too. Some medications and some maternal conditions are associated with cleft lip/palate. But most often a cleft lip/palate occurs by chance and can happen to anyone.

### **What does this mean?**

Some babies with cleft lip/palate will have another condition or syndrome. It is important to check the baby for these other problems because it will help us tell you what it means for the development of your baby.

It is important to know that most babies born with a cleft are otherwise healthy with no other birth abnormalities. For babies with cleft lip/palate that have no other health problems the long term outlook is excellent.

## **What other tests should we consider?**

Because there is a chance that the baby has other health problems, it is important to check the baby closely. Further tests include a detailed ultrasound that is used to assess the baby's other organs. A fetal echocardiogram, which is a detailed ultrasound of your baby's heart, will also be done.

An amniocentesis to look for genetic or chromosome problems will be offered. During an amniocentesis, a small amount of amniotic fluid is taken from the area around the baby and tested for genetic problems.

## **What will happen around the time of the baby's birth?**

Because babies with cleft lip/palate can have problems with feeding, it is important for them to be born where there is trained staff to support and manage any feeding issues. This level of care may not be available in your hospital and you may need to deliver at another centre. Your doctor will be able to tell you where your baby needs to be delivered.

A referral to a Cleft Lip and Palate Program in your area will be made either during your pregnancy or after the baby is born. The cleft lip and palate team is made up of many specialists including a plastic surgeon, a pediatric dentist, an ear, nose and throat doctor, an orthodontist, a pediatrician, an audiologist (hearing specialist), a speech-language specialist, an occupational therapist, and a nurse coordinator.

In hospital, you may meet the occupational therapist, who is a feeding specialist. They can assist with any feeding problems. There are special nipples and bottles that are designed to help babies with cleft lip/palate. Breastfeeding may be possible for a baby that has only a cleft lip without the cleft palate. When there is a cleft palate, the baby may be unable to create enough suction to breastfeed successfully. However, breastmilk can be pumped and given to the baby using the special nipple and bottle. The occupational therapist will be able to help you identify what type of help your baby needs.

## **What does this mean for the future?**

All babies with cleft lip and or palate will need surgery. Most of the time the cleft lip is repaired at approximately 3 months of age. Cleft palate is usually repaired between 6 and 18 months. Some babies need other surgeries as they grow.

Babies are usually seen by the plastic surgeon within the first week or two of life. The plastic surgeon will assess the cleft lip/palate and discuss a treatment plan. The plastic surgeon will be able to discuss with you the type of surgery your baby will need.

As discussed, babies with cleft lip/palate frequently have feeding difficulties. Especially babies with cleft palate as they can have trouble with sucking and swallowing. Babies

with cleft lip/palate are followed closely to make certain they gain enough weight and continue to grow well.

Babies with cleft lip/palate may have frequent ear infections. This is because they are more likely to have fluid build up in the ear and this fluid can become infected. Frequent ear infections can lead to hearing loss. Your baby will have regular check ups by a hearing specialist and an ear, nose and throat doctor.

Babies with cleft palate may have speech difficulties because a cleft palate may make it difficult for the child to say words clearly. Your baby will receive regular evaluations by a speech-language specialist. This specialist will be able to help treat any problems in speech development.

Children with cleft palate or a cleft in the gum need ongoing care from a pediatric dentist and orthodontist, as most of these children will have problems with their teeth and/or jaw. These dentists will become involved in your child's care early in life however treatment may not start until your child is older.

## **What do we do now?**

Your doctor may make a referral to Medical Genetics where you will receive counseling regarding cleft lip/palate. They will be able to discuss with you in detail your options for further testing, discuss with you test results and provide you with options. They will be able to answer any questions you may have.

Should further testing show your baby has other health problems; you will meet with an obstetrician that specializes in high-risk obstetrics. The doctor will discuss these other problems with you in further detail, be able to answer any questions and provide you with treatment options.

## **Where can I get more information?**

The Ontario Cleft Lip and Palate/Craniofacial Dental Program  
<http://www.health.gov.on.ca/english/public/pub/child/cleft.html>

Sick Kids Toronto  
Cleft Lip and Palate Program  
<http://www.sickkids.ca/cleftlip/>

Children's Hospital of Philadelphia  
Cleft Lip/Cleft Palate  
<http://www.chop.edu/healthinfo/cleft-lip-cleft-palate.html>