

## For Parents of Newborn Babies with Cleft Lip/Cleft Palate

### **What is cleft lip? What is cleft palate?**

A cleft lip is an opening in the lip. A cleft palate is an opening in the roof of the mouth. Clefts happen because of incomplete development of the lip or palate while the baby is forming before birth.

Babies' lips and palates develop during the first three months of pregnancy. Normally, the left and right parts of the lip come together, or "fuse," creating a normal lip.

The two vertical lines on the normal upper lip are created when the left and right parts fuse. In a similar way, the left and right parts of the palate come together to create a normal palate. A front-to-back line along the roof of the mouth can usually be seen where the "fusion" occurred.

### **Why didn't our baby's mouth fully develop?**

We don't know the answer to this question, but you can be assured it was usually not because you did something wrong. It was not your fault.

Scientists have learned that there are many possible causes for clefts. Research is under way to discover more about these causes. Sometimes clefts occur in combination with other problems which are associated with a syndrome. Meeting with a special doctor known as a geneticist can help you understand about the possible causes of clefts.

### **How many babies are born with clefts?**

Clefts are among the most common problems found in newborn babies. Annually in the U.S., over 6,800 newborns (or about one in 600 babies) are born with a cleft.

### **What can be done to help our baby?**

A cleft lip usually can be repaired during the first few months of life. A cleft palate usually can be repaired some months later. The exact time of these repairs depends on the baby's health as determined by the doctor who does the surgery.

### **Can our baby be fed properly?**

Babies with cleft lips alone usually have few problems feeding, while those with cleft palates often have more difficulty. Use of special bottles and nipples, along with careful positioning of the baby, are usually helpful. Your pediatrician should refer you to a cleft palate treatment team, as soon as your baby is born, for proper guidance in feeding.

### **Will our baby's teeth grow properly?**

If the cleft affects only the lip, the teeth will probably not be affected. If the cleft affects the gums where teeth grow, however, the care of dental specialists will probably be needed.

### **Will our baby have trouble learning to talk?**

If the cleft affects only the lip, speech problems are unlikely. However, many children with cleft palate need the help of a speech pathologist, and some many need an additional operation to improve speech. The most common problem these children experience is an overly nasal tone to their speech.

### **Will our baby be intellectually disabled?**

There is no relationship between intellectual disability and cleft lip and palate. However, if the cleft is a part of a cluster or other problems, learning ability is sometimes affected.

**How can we pay for the treatment our baby will need?**

Health insurance will pay for all or part of the necessary care. Additional financial assistance should be available from an agency in your state that is supported by your tax dollars. Your family physician can direct you to the proper agency.

**How do other parents feel when their child is born with a cleft?**

It is natural for parents to be upset at this time. Feelings of concern, anxiety and grief are not unusual. Your family physician and the hospital staff members will guide you to a team of specialists who will provide you and your baby with the help you will need. Remember that your baby is probably normal in every other way and can be treated like any other child in most aspects of his/her care.

**How can we tell our relatives and friends about the baby's cleft?**

Most parents feel that telling others is a little difficult. If the people closest to you can visit while the mother and baby are still in the hospital, it may be easier. You should try to tell them about the baby as honestly and directly as you can. You may want to share this factsheet with your family members and close friends. It is important, even though you may feel uncomfortable, to tell relatives and friends very early.

**I have read the term "hare lip." What does it mean?**

The word "hare" refers to the rabbit, which has a natural indentation in the center of its lip. This term is rarely used by professionals because it is an insensitive and inaccurate term. "Cleft lip" is the correct description of the condition.

**For further information on cleft lip and palate, or for a referral to a cleft palate/craniofacial team, please contact:**

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