# CLEFTPALATE

March of Dimes

University of South Florida

Florida Department of Health

## Welcoming your new baby into your family.

Your baby was born with a special condition. This condition is known as cleft palate. We know this is not easy for you and you may not know how to feel. That's okay. Parents of children with cleft palate feel shock, denial, grief, and even anger. It is all right to feel like this and no one will blame you. It will get better. You are not alone. Soon you will find lots of people and programs to help you. You may want to join a support group. Get to know your baby. Enjoy your baby.

# What is a cleft palate?

- A cleft palate (say: pa-lit) is a split in the roof of the mouth. This
  leaves a hole between the nose and the mouth.
- It happens between the first 6 and 12 weeks of pregnancy.

# How does a baby get a cleft palate?

- We do not know the answer to this question.
- Sometimes cleft palates run in families. This means that a baby with a cleft palate may have a relative with a cleft palate.
- Sometimes, a cleft palate occurs by itself and other times with birth defects in other body parts.
- Sometimes a baby with a cleft palate also has a cleft lip.

# How will this affect my baby?

- Your baby may have problems with feeding and speech and may need surgery to help him or her talk and swallow the right way.
- Babies with a cleft palate can get fluid in the middle ear. They may need special tubes in their ears. They will need to have their ears checked once a year.
- Children with a cleft palate may have funny-shaped or missing teeth. They need to see the dentist often and keep their teeth clean. Most need to wear braces.

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# How can I feed my baby?

- It is not easy for a baby with a cleft palate to suck hard enough to get milk through a nipple. Some babies also have problems with gagging, choking, or milk coming out through the nose while feeding.
- Your doctor will also tell you about special bottles and nipples you can use to help your baby.
- Here are some ways you can help your baby:
  - Make sure he or she is in an upright position when feeding. This helps prevent milk from coming through his or her nose.
  - Take your time and burp the baby often. Babies with cleft palate tend to swallow a lot of air during feedings.
  - Do not feed your baby for more than 30 minutes. Sometimes it is helpful to feed smaller amounts more often.

# How and when will they fix the hole?

- Most often a cleft palate is fixed at about age 9 12 months. As your baby grows, he or she may have more surgeries to fix the cleft palate.
- Ask your doctor to refer you to a team of health experts, called a Cleft Palate Team, or a Craniofacial (say: kray-nee-o-fay-shel) Team. A surgeon who will repair the palate is on the Craniofacial Team.
- This team will work on a plan to meet all of your baby's needs. Then you will know what to expect with your baby.

## Will my baby be retarded?

- Your baby will most likely grow up to be normal and healthy.
- If the cleft is part of other problems (syndrome), he/she should be seen by a geneticist to identify the problem. A geneticist is a doctor who is an expert in diseases that run in families (hereditary).

# Where can I go for help?

- Faces: The National Craniofacial Association: 1-800-332-2373 for more information, resources and financial assistance for traveling expenses to a treatment center.
- Florida Family Support Network to find Craniofacial teams, resources, genetic counselors and for help feeding your newborn baby: 1-800-726-2029 or visit: www.floridacleft.org
- For health services: Children's Medical Services (CMS): call your local county health department for a CMS clinic in your area or visit: www.cms-kids.com
- For more information: Cleft Palate Foundation: 1-800-24-CLEFT (a 24 hour help line) or www.cleftline.org
- La Leche League for breastfeeding help: 1-800-LALECHE
- March of Dimes: visit marchofdimes.com
- MUMS National Parent to Parent Organization: 1-877-336-5333 (toll free) to get in touch with parents in your area whose children also have a cleft palate.

Funded by a community grant from the March of Dimes.





