

## FOR THE PARENT OF NEWBORNS WITH CLEFT LIP AND/OR CLEFT PALATE

### What is a cleft lip? What is a cleft palate?

A *cleft lip* is an opening in the upper lip. A cleft lip can range in size from a small notch in the red portion of the lip, called the *vermillion*, to a complete separation that extends to the bottom of the nose. A cleft can occur on one side of the lip, called *unilateral*, or on both sides, called *bilateral*. A cleft can also occur in the gums where the teeth will grow.

A *cleft palate* is an opening in the roof of the mouth. A cleft palate can occur in the bony, front part of the palate, called the *hard palate*, in the fleshy, flexible, back part of the palate, called the *soft palate*, or in both parts.

A person can be born with cleft lip, a cleft palate, or both.

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

A cleft occurs when the lip and/or palate don't come together during the first three months of pregnancy. Scientists don't fully know why cleft lip and/or palate occur, but they have learned of many possible causes. Usually, the cause is not related to the actions of the parents. Sometimes clefts occur in combination with other physical differences; these conditions are called *syndromes*. A *geneticist*, a doctor who studies genes and heredity, can help you understand more about the possible causes of cleft in your case.

### How many babies are born with clefts?

Clefts are one of the most common birth conditions in the US. Each year, about one in 700 babies are born with a cleft lip, with or without cleft palate.

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

A baby with cleft lip and/or palate should be treated by a *cleft palate or craniofacial team*. A team is a group of specialists who work together to treat a person's cleft. Sometimes, a cleft can be seen on an ultrasound before a baby is born. Many families find it helpful to meet with members of the team before birth. To find a cleft team in your area, visit the ACPA Family Services website at [www.cleftline.org](http://www.cleftline.org).

A surgeon on the team will usually recommend closing a cleft lip through surgery during the first few months of life. Palate surgery generally takes place a few months later. A baby born with a cleft palate will often undergo additional planned surgeries throughout childhood and sometimes into early adulthood. The team will determine the exact timing of these procedures.



### What is the role of the cleft team?

The specialists on the cleft team work together to plan all aspects of treatment and are active partners on the team. One of the goals of this approach is to reduce stress on families, allowing them to focus on other life tasks.

When meeting with the cleft team, be sure to ask all your questions or to ask for further explanations if something is unclear.

It is not unusual to feel overwhelmed by the thought of long-term treatment. While a child may undergo several surgical procedures over the course of his or her childhood, it is important to note that there may be many years where a child needs little to no attention related to his or her cleft care.

### How can we feed our baby?

A baby with a cleft lip alone (*isolated cleft lip*) can usually feed normally. A baby with a cleft palate will need to drink from special bottles and nipples, and will need to be positioned carefully during feeding. If your birth hospital is not familiar with

feeding a baby with a cleft, be sure to contact members of the cleft team so they can help you learn to feed your baby. In a majority of cases, a baby born with a cleft palate cannot nurse.

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

If a person is born with a cleft lip only, his or her teeth will probably not be affected by the cleft. If the cleft goes into the gum line, however, a child may need several stages of treatment, including orthodontics and possible surgery later in childhood.

### Will our baby have trouble learning to speak?

Many children born with a cleft palate need the help of a speech-language pathologist to learn to make speech sounds correctly. Some children undergo an additional surgery during childhood to improve speech. Surgery is usually recommended, for example, if a child has an overly nasal tone of voice. Speech problems are unlikely for a baby born with a cleft lip only.

### How will our child do in school?

There is no relationship between cleft lip and/or palate and overall intelligence. Some children born with a cleft lip and/or palate have deficits with language or other areas, however, that can affect them academically. Children with learning differences can receive additional assistance at school. These children can still be successful in the general classroom.

Academic performance can be affected by other factors, too. As a child grows, it is important to seek help for a child when needed, especially in areas of social adjustment or mental health. As parents, you can request meetings with school staff to address ongoing needs. You can also ask members of the cleft team to help if issues arise. While a mental health professional may not be a part of the core team, ACPA Approved Teams are required to offer access to mental health professionals, either for a parent or for a child.

### How can we pay for treatment for our baby?

Health insurance usually pays for all or part of cleft treatment. Additional financial assistance may be available from an agency in your state or from other resources. Ask your cleft team for information about funding sources in your area.

### How do parents feel when their child is born with a cleft lip and/or palate?

It is normal to have a range of feelings when you learn the news of your child's cleft lip and/or palate, whether you find out during an ultrasound or when the baby is born. It is not unusual to feel anxiety, anger, guilt, and grief along with joy, love, and excitement.

Occasionally, parents have problems coping. A member of the treatment team can refer you to a mental health professional who is familiar with this issue and can help. Some treatment teams also offer parent support groups. These groups have many benefits. Talking with others can help you cope. It can also help you realize that you are not alone.

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

In order to share the news with others, parents first need to care for themselves. It is important to allow space to process your own emotions. If you have questions about your child's care, be sure to ask the treatment team. While not all questions can be answered right away, it may be helpful to gather information and to take time to work through it. This way, you will be able to have informed conversations with friends and family when you are ready.

It is important to be honest and direct with loved ones about your child's cleft. Their support can be extremely valuable for you and for your child. Having support can even have a positive effect on treatment, starting in infancy and extending into childhood and beyond.

## Congratulations on the birth of your baby!

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**Special thanks to: Members of the ACPA Learning Resources Committee**

**Subject Matter Experts:** Deanna Johnston, M.A., LPC  
and Claudia C. Malic, MRCS, MD, FRCS(Plast)

**Editors-in-chief:** Ron Aronovich, DMD and Angela J. Dixon, MA, CCC-SLP

**Managing Editor:** Alexis L. Johns, PhD, ABPP

**Associate Editors:** Lora A. Hindenburg, RN, MSN,  
Michael S. Jaskolka, DDS, MD, FACS, and Martha S. Matthews, MD

**Writing Consultant:** Amy F. Mendillo, MPP

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