

Neonatal Cleft Lip and Palate: Instructions for Newborn Nurseries

Reassure parents that the baby's cleft is **not their fault** and was not likely caused by anything they did.

Reassure parents that cleft lip and palate is correctable with surgery, and introduce the concept of a <u>cleft palate/craniofacial team</u>. A team is a group of specialized health care professionals (surgeons, dentists, speech pathologists, nurses, mental health specialists, and others) who work together to treat a child with a facial birth difference. please visit <u>ACPAcares.org</u> to find your local team, or call the American Cleft Palate Craniofacial Association (ACPA) at 919-933-9044.

Review feeding instructions and refer to the <u>Feeding</u> <u>Your Baby video series</u>, available online in English, Spanish, and Mandarin, at <u>ACPAcares.org</u>, or call ACPA's national office.

Newborns with cleft lip only may be able to feed using standard techniques. Newborns with cleft palate may benefit from the information below. Assess feeding regularly to ensure that the child is receiving adequate nutrition. Please consider the following guidelines for successful feeding:

- Make sure the child is feeding in an upright position. Gravity will help prevent milk from coming through the baby's nose if he/she has cleft palate.
- Mothers interested in breastfeeding may choose to initiate pumping breast milk. Direct breastfeeding is extremely challenging for a child with cleft palate since good suction is prevented by the cleft.
- Use a cleft palate nurser or other squeezable bottle with a larger x-cut hole in the nipple. The hole in an orthodontic nipple can be turned into a "x" shaped opening using a razor blade if a specialized bottle is not immediately available. Please see ACPA's Feeding Your Baby videos or booklet for specific instructions.
- Mom should take her time, and burp the baby frequently. Infants with cleft palate tend to swallow a lot of air during feedings.
- Eventually, feeding time should be no more than 30 minutes for 2-3 ounces.
- If the child is still having difficulty feeding, consult a feeding specialist with a cleft palate/ craniofacial team. The team's nurse, speech-language pathologist, or social worker may provide this support.



Consult with a hospital social worker to provide the family with emotional support and community referrals. The American Cleft Palate-Craniofacial Association also offers email and phone support for urgent family needs: info@ACPAcares.org or 919-933-9044. Contact the pediatrician or family doctor. Ask a physician where to refer for cleft palate/craniofacial team care and make this referral before the child is discharged from the nursery. Consult with a **public health nurse** if the child shows signs of feeding difficulty. Make sure that either the public health nurse or the treatment team's nurse will follow up with the family promptly. Follow up with the family after discharge with a phone call to confirm that any new challenges are being addressed by the cleft palate/craniofacial team or other healthcare specialists.

Please visit <u>www.ACPAcares.org</u> for information on **ordering specialty bottles** for infants with cleft lip/ palate and for **free publications** related to infant cleft care.