

Resource Handout

American Cleft Palate-Craniofacial Association

www.acpa-cpf.org.

As of 2017, ACPA and the Foundation are now one organization
Resources for Providers <http://acpa-cpf.org/healthcare-providers/>

Resources for families

<http://cleftline.org/family-resources>

Download: Brochures, Factsheets, Videos

- Cleft and craniofacial conditions
- Find a Team
- Feeding your baby

American Speech Language Hearing Association (ASHA)

For the public - <http://www.asha.org/public/>

ASHA Practice Portal for Cleft Lip/Palate for professionals

<http://www.asha.org/Practice-Portal/Clinical-Topics/Cleft-Lip-and-Palate/>

Genetics Home Reference and U.S. National Library of Medicine

www.ghr.nlm.nih.gov

Fauquier ENT Consultants

www.FauquierENT.net

Chris Chang, M.D. ENT collaborated on this video describing Velopharyngeal (VP) function. See animation to describe the action of the VP port and MRI study of the VP port movement during speech (first 50 seconds). Includes additional info on diagnosis of velopharyngeal dysfunction.

<https://www.youtube.com/watch?v=WM5fVCdBPHs>

INOVA Children's Hospital Craniofacial Program

<https://www.inovachildrens.org/craniofacial-services>

Video overview of this center's interdisciplinary team care for cleft palate.

Children with Cleft Lip & Palate: A Parent's Guide to Early Speech Language Development and Treatment

Hardin-Jones, M.A., Chapman, K.L., & Scherer, N.J. (2015).

Bethesda, MD: Woodbine House, Inc.

(excellent print resource for families and all Early Intervention providers)

LEADERS Project

<http://leadersproject.org>

Catherine Crowley, J.D., Ph.D. at Teachers College Columbia University

Excellent resource for families and practitioners providing educational videos, tutorials and downloadable resources for working with cleft palate speech and feeding issues.

Free continuing education units based on video tutorials and readings.

Tips for Feeding Baby with Cleft Lip/Palate

Seattle Children's Hospital Craniofacial Team

www.seattlechildrens.org

Patient and Family Resources

A good review of why feeding problems occur with CL/P and how to feed a baby with CL/P. The four most commonly used specialty bottles/nipples are pictured and described.

American Cleft Palate-Craniofacial Association Family Services

www.acpa-cpf.org

"Feeding your Baby". A feeding video.

Commonly used Specialty Feeders

1. Mead Johnson Enfamil Cleft Nurser
2. Medela Special Needs Feeder (formerly Haberman Feeder)
3. Respironics Pigeon Cleft Palate Nurser
4. Dr. Brown's Specialty Feeding System