

Cleft Lip / Cleft Palate

Version: April 2009



Image credit: Centers for Disease Control and Prevention (CDC)

Condition & Description

A “cleft” means a split or separation; the palate is the “roof” of the mouth. Therefore, a cleft palate or lip is a split in the oral (mouth) structure¹. A child can be born with a cleft lip and a cleft palate or a cleft in just one of the areas. Clefts in the lip can range from a tiny notch in the upper lip to a split that extends into the nose. A cleft palate can vary in severity as well. In addition, clefts can occur on one side of the mouth (unilateral) or on both sides (bilateral). Oral clefting occurs between the 6th and 11th week of pregnancy¹. In the United States, clefts occur in 1 in 700 to 1,000 births, making it one of the most common major birth defects^{2,4}. Oral clefting may be detected during a prenatal ultrasound.

Associated Conditions

Cleft lip/palate is associated with more than 400 conditions, including some genetic syndromes. Approximately 30 percent of cleft deformities are associated with a syndrome, so a thorough medical evaluation and genetic counseling is recommended for cleft patients¹ and their families.

Causes & Risk Factors

No one knows exactly what causes clefts, but it is thought they are caused by one or more factors: an inherited characteristic (gene) from one or both parents, environmental (poor early pregnancy health or exposure to toxins such as alcohol, certain anti-seizure drugs, and maternal smoking³ or deficiency of the B vitamin folic acid), or genetic¹ and environmental conditions combined.

Prevention

There are a number of steps a woman can take to reduce her risk of having a baby with a birth defect. Please see CBDMP's fact sheet on [Reducing the Risk of Birth Defects](#).

Preconception & Prenatal Care

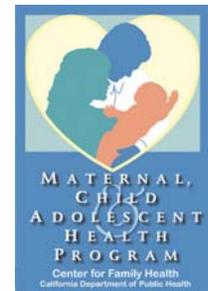
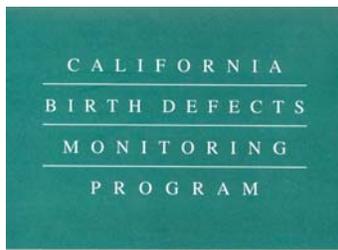
Folic acid is a B vitamin that plays an important role in the development of the fetal brain and spinal cord during very early pregnancy, often before many women know they are pregnant. For this reason, and because many pregnancies are unplanned, it is recommended that all women of childbearing age take 400 micrograms of folic acid per day through dietary supplements or foods that are fortified with folate³. With advances in ultrasound technology, the prenatal diagnosis of cleft lip is more frequent. However, the diagnosis of cleft palate still usually occurs after the baby is born. Ultrasounds between 18-24 weeks gestation have been the most accurate. If a cleft lip/palate is seen, it is common for the family to be referred for genetic counseling, and other testing may be recommended. It is also common for the family to be referred to a cleft lip/palate team to learn about care and management of clefts, even though a complete and accurate diagnosis will not be made until after the baby is born⁵.

Medical Care

There have been many medical advancements in the treatment of oral clefting. Reconstructive and plastic surgery can repair oral clefting². A child will need to see a multi-disciplinary team that will work together to determine the best course of treatment for his/her individual needs. Surgery to repair cleft lip is usually done between 10 and 12 weeks of age and surgery to repair a cleft palate is generally done between 9 and 18 months of age¹. A concern of many parents is how a cleft lip/cleft palate will affect a baby's ability to eat. Babies born with an isolated cleft lip do not generally have much trouble feeding³. Babies born with a cleft lip/cleft palate or isolated cleft palate generally have difficulty with breast and bottle feeding. There are many specialized bottles available to assist with feeding a baby born with a cleft lip/cleft palate. See below for resources.

Long Term Outcomes

Both cleft lip and cleft palate are treatable birth defects. Most kids who are born with these conditions can have reconstructive surgery within the first 12 to 18 months of life to correct the defect and significantly improve facial appearance². Many children will need additional surgical procedures as they grow³. Some long-term complications of cleft lip and palate include frequent colds, ear infections and hearing loss, speech and language delays, dental problems, and difficulties in psychological wellbeing and social relationships⁶. A baby born with a cleft lip and/or palate that is treated by a multi-faceted health care team should live a normal and healthy life⁷.



Cleft Lip / Cleft Palate

Version: April 2009

Resources For Families

California Children's Services (CCS)

California Children's Services (CCS) is a state program for children with certain diseases or health problems. Through this program, children up to 21 years old can get the health care and services they need. CCS will connect you with doctors and trained health care people who know how to care for your child with special health care needs.

(Service eligibility is income-based, but you may be eligible for services if the health care costs exceed 20% of your income.)

Find your local CCS Office –

1. In the phone book under *California Children's Services* or *County Health Department*
2. Or online at: www.dhs.ca.gov/ccs

Family Resources Centers Networks of California

Their mission is to support families of children with disabilities, special healthcare needs, and those at risk by ensuring the continuance, expansion, promotion and quality of family-centered, parent-directed, family resource centers.

Find your local Family Resource Center –

- In the phone book business pages under *Social and Human Services for Families and Individuals* or *Family Resource Centers*
- Or online at: <http://www.frcnca.org/>

California Healthy Families Program

Healthy Families is low cost insurance for children and teens. It provides health, dental and vision coverage to children who do not have insurance and do not qualify for free Medi-Cal.

- Phone: 1-800-880-5305 if you do not already have a child enrolled in Healthy Families.
- E-mail: HealthyFamilies@MAXIMUS.com
Be sure to include your name and phone number.
- In person: Many community organizations have people who are trained to help you apply. Call to find a *Certified Application Assistants*, or CAAs in your area: 1-888-747-1222. The call is free.
- Website: www.healthyfamilies.ca.gov

Birth Defects Research for Children, Inc.

Birth Defect Research for Children is a resource for free birth defect information, parent networking and birth defect research through the National Birth Defect Registry.

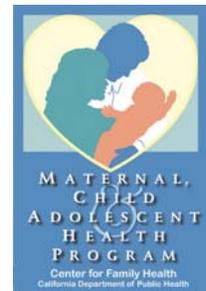
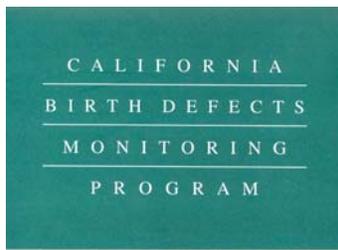
- Birth Defect Research for Children, Inc.
800 Celebration Avenue, Suite 225
Celebration, FL 34747
- Phone: 407-566-8304
- Fax: 407-566-8341
- Website: <http://www.birthdefects.org/>

Other Information & Support Groups

- California Parents Helping Parents: provides lifetime guidance, supports and services to families of children with any special need and the professionals who serve them. Phone number (408) 727-5777. www.php.com
- Foundation for Faces of Children: <http://www.facesofchildren.org>
- About Face: <http://www.aboutfaceinternational.org>
- Cleft Palate Foundation: <http://www.cleftline.org/>
- Smiles: www.cleft.org/
- Self Expressions: <http://www.selfexpressions.com>
- International Craniofacial Institute: <http://www.craniofacial.net>

References

1. American Academy of Otolaryngology - Head and Neck Surgery (2008). Fact sheet: Cleft lip and cleft palate. Retrieved September 24, 2008, from <http://www.entnet.org/HealthInformation/cleftLipPalate.cfm>.
2. KidsHealth (2005). Cleft lip and palate. Retrieved July 24, 2008, from http://kidshealth.org/parent/medical/ears/cleft_lip_palate.html.
3. March of Dimes (2007). Cleft lip and cleft palate. Retrieved September 24, 2008, from http://www.marchofdimes.com/printableArticles/4439_1210.asp.
4. MayoClinic (April 19, 2008). Cleft lip and cleft palate. Retrieved July 24, 2008, from <http://www.mayoclinic.com/print/cleft-palate/DS00738/METHOD=print&DSECTION=all>.
5. The Center for Children with Special Health Needs - Children's Hospital and Regional Medical Center. (2006). *Cleft Lip and Palate Critical Elements of Care* (4th ed.) [Brochure]. Seattle, WA.
6. Habel, A., Sell, D., & Mars, M. (1996). Management of cleft lip and palate. *Archives of Disease in Childhood*. 74, 360-366.
7. University of Virginia Health Systems (2008). Cleft lip and palate tutorial. Retrieved October 2, 2008, from http://www.healthsystem.virginia.edu/UVAHealth/peds_craniofacial/cleft.cfm.



Cleft Lip / Cleft Palate

Version: April 2009