

FACES:

The National Craniofacial Association 1-800-332-2373

What is Cleft Lip and Palate?

Cleft lip (split of the upper lip) and **cleft palate** (split of the roof of the mouth) are the most common types of congenital facial difference.

A unilateral cleft lip occurs on one side of the upper lip. A bilateral cleft lip occurs on both sides of the upper lip. In its most severe form, the cleft may extend through the base of the nose.

Cleft palate is an opening in the roof of the mouth. There are several types, which vary in severity. Incomplete cleft palate involves only the v-shaped portion of the back of the throat (uvula) and the muscular soft palate (velum). Complete cleft palate extends the entire length of the palate. Cleft palates can be unilateral or bilateral.

It is possible for a child to have a cleft lip, cleft palate, or both cleft lip and palate.

Why did this happen?

The exact cause is unknown. The majority appear to be caused by a combination of genetic and environmental factors during the early part of the pregnancy. Clefts may also appear with other syndromes.

Will this happen to children I have in the future?

FACES suggests that you be tested by a geneticist. Cleft lip, with or without cleft palate, can run in families. In families where the cause is genetic, there is often a 50% chance of another child being born with it. However, in families where there is no history of clefts, the chances are very small of another child being born with a cleft.

What kinds of problems could my child have?

In addition to the physical characteristics common to clefts, your child may have the following problems:

- dental development - teeth in the area of the cleft may be missing or improperly positioned. This may affect your child's appearance and chewing ability

- speech difficulties - cleft lip does not usually result in speech problems; however, often children with cleft palates benefit greatly from early speech therapy
- frequent colds, sore throats, fluid in the ears and tonsil and adenoid problems

Will my child need surgery?

Depending on the severity of the cleft lip or palate, your child may have some or all of the following surgeries:

- lip closure - to bring the separated lip muscle parts into place
- lip adhesion and definitive lip repair to improve lip and nose contour
- cleft palate surgery to close the hard palate, to maximize jaw growth and development, and to produce normal speech
- palatal surgery to increase the soft palate's length and to close the palatal cleft space
- soft palate surgery to close and/or to improve muscle control
- surgery on adenoids and tonsils
- ear tubes-often done in combination with another surgery to decrease fluids in the ears and subsequent ear infections

New advances in procedures to correct cleft lip and palate occur all the time. Be an advocate for your child!

How do I get help for my child?

Your child should be treated by a qualified craniofacial medical team at a craniofacial center. Currently, FACES has information on many of these teams. This is by no means a comprehensive list of all the craniofacial teams. Please contact FACES for details.

Am I alone?

No! There are many families and organizations that will be glad to talk with you and help you with information and support. Don't forget books, videos, and web sites.

The listing below will get you started.

FACES: The National Craniofacial Association
P.O. Box 11082
Chattanooga, TN 37401
(800) 332-2373
e-mail: faces@faces-cranio.org
website: www.faces-cranio.org

We provide financial support for nonmedical expenses to patients traveling to a craniofacial center for treatment. Eligibility is based on financial and medical need. Resources include newsletters, information about craniofacial conditions, and networking opportunities.

The Cleft Palate Foundation (CPF)
1504 East Franklin Street - Suite 102
Chapel Hill, NC 27514
(800) 24-CLEFT or 800-242-5338
e-mail: info@cleftline.org
website: www.cleftline.org

Information on clefts, as well as outstanding resource of educational information and free publications. Information in Spanish also.

Cleft Advocate
P.O. Box 751112
Las Vegas, NV 89136
(888) 486-1209 or (702) 769-9264
email: Debbie@cleftadvocate.org
website: www.cleftadvocate.org

This organization is an excellent resource for getting in touch with other parents, providing answers to treatment & surgery, advocacy, and insurance issues.

Smile Train
41 Madison Ave., 28th Floor
New York, NY 10010
(800) 932-9541
e-mail: info@smiletrain.org
website: www.smiletrain.org

This excellent new resource has instant access to full transcripts of numerous articles and studies related to every major cleft issue. Great resource for both patients and professionals.

Foundation for Faces of Children
258 Harvard St. Suite 367
Brookline, MA 02446-2904 - (617) 355-8299
e-mail: info@facesofchildren.org
website: www.facesofchildren.org

New England parent support network for awareness and education. This site is for parents who are just learning that their child has a craniofacial condition.

Award-winning **FREE** video for new parents of a child with a cleft (*Understanding Cleft Lip & Palate, A Guide for New Parents*). English and Spanish versions available

Craniology.org

Offering parents and individuals inspiration, emotional support, educational literature and information on community resources. Helping parents or individuals with Cleft, Craniosynostosis, Hemifacial Microsomia, Plagiocephaly, and others syndromes to meet other parents or family members that deal with the same problems.

Website: www.craniology.org

National Health Law Program
1444 I Street, NW - Suite 1105
Washington, DC 20005 - (202) 289-7661
website: www.healthlaw.org

Provides extensive information on health care laws affecting families of children with special needs.

Children with Facial Difference: A Parent's Guide.

Written by Hope Charkins, MSW.

Excellent resource for parents to help them cope with medical, emotional, social, educational, legal, and financial challenges present by facial differences of their children. Look for this book in larger bookstore chains.

Available at: www.Amazon.com

The Cleft Palate Story. Written by Samuel Berkowitz, DDS, MS, FICD.

Surgical procedures performed from birth to adolescence are treated in depth; helps parents to understand options and what to expect; appendices on financial assistance, agencies, support groups, and a glossary of terms.

Available at www.amazon.com.

Don't Despair Cleft Repair is a book authored by Karen Lipman from her perspective of being the mom of a child born with a cleft.

Available at www.amazon.com.

Florida Cleft Palate-Craniofacial Association

Office of the Secretary
Post Office Box 6006
Brandon, FL 33508
(800) 726-2029

E-mail: info@floridacleft.org
website: www.floridacleft.org

This state wide program can assist FL hospitals and families in obtaining specially designed bottles and nipples for feeding, provide them with informational materials, and incorporate them as part of the family network. It can also provide a list of treatment centers closest to their community.

Parents and Clefts Blog Home

This site addresses practical and emotional issues for parents of kids born with cleft lip and palate. It will eventually become a book authored by Amy Mendillo, parent of a child born with cleft lip and palate.

www.parentsandclefts.com