

Cleft Palate/Craniofacial Differences
Resources in the Kreamer Family Resource Center



Books for parents:

Berkowitz—The Cleft Palate Story

CHARGE Syndrome: A Management Manual for Parents (also in *Spanish*)

Charkins—Children with Facial Difference: A Parent's Guide

Feeding an Infant with a Cleft

Frances--Educating Children with Facial Disfigurement

Gruman-Trinkner--Your Cleft-Affected Child

Health-Related Disorders in Children and Adolescents, see chapters on Cleft lip and palate, Craniofacial osseointegration and maxillofacial surgery, and on various craniofacial syndromes.

McDermott--Babyface: A Story of Heart and Bones (Apert Syndrome)

Moebius Syndrome

[reference] Complete Directory for Pediatric Disorders, entries for Cleft lip and palate, Craniosynostosis, and various craniofacial syndromes. Other reference books in the collection also list various craniofacial syndromes.



Books for children:

Brink--David's Story: A Book about Surgery (craniofacial reconstruction)

Graham - A special smile



Videos:

The Special Touch Babies Need: Caring for the Infant with Cleft Lip/Palate (16:30 minutes, Children's Mercy Hospital, 1996)

Facing Cleft: Encouraging Healthy Development (36 min., 2002)

Electronic Resource:

National Organization of Rare Disorders database: the Kreamer FRC subscribes and can provide full reports on a wide variety of craniofacial syndromes.

Local Resources:

AboutFace lists Volunteer Pathfinders (people who have been there and can offer support and advice) for Missouri (<http://www.cleftadvocate.org/MO.html>) and Kansas (<http://www.cleftadvocate.org/KS.html>).

World Wide Web:

MedlinePlus Health Topic: Cleft Lip and Palate (English and some **Spanish**)

<http://www.nlm.nih.gov/medlineplus/cleftlipandpalate.html>

MedlinePlus Health Topic: Facial Injuries and Disorders (English and some **Spanish**; includes many specific craniofacial syndromes)

<http://www.nlm.nih.gov/medlineplus/facialinjuriesanddisorders.html>

MedlinePlus Health Topic: Head and Brain Malformations

<http://www.nlm.nih.gov/medlineplus/headandbrainmalformations.html>

See also MedlinePlus Health Encyclopedia entries (in English and **Spanish**) at

<http://medlineplus.gov>

Cleft Palate Foundation (in English and **Spanish**)

<http://www.cleftline.org/>

WIDE SMILES: Cleft Lip and Palate Resource (parent networking and support, before-and-after photo gallery, includes KIDZ Club area)

<http://www.widesmiles.org/index.html>

The Story of Thumper, the Cleft-Affected Bunny by Joanne Green (online children's book)

http://www.widesmiles.org/Kids_Lit/thumper/

SMILES (parent support for clefts and craniofacial conditions)

<http://www.cleft.org/>

AboutFace USA (patient and parent support for facial disfigurement)

<http://www.aboutfaceusa.org/>

Children's Craniofacial Association (information and support for facial disfigurement, including online booklets on several specific conditions/syndromes)

<http://www.ccakids.com/>

FACES: The National Craniofacial Association (support, information on many disorders)

<http://www.faces-cranio.org/>

The Smile Train Cleft Information Public Library

<http://medpro.smiletrain.org/library/PublicLibrary.html>

Craniofacial Anomalies (Columbia-Presbyterian Medical Center, NYC--includes a pictorial guide—see below)

<http://cpmcnet.columbia.edu/dept/nsg/PNS/Craniofacial.html>

Pictorial Guide to Craniosyctosis anatomy and etiology

<http://cpmcnet.columbia.edu/dept/nsg/PNS/cf/cf.html>

Johns Hopkins Center for Craniofacial Development & Disorders

<http://www.hopkinsmedicine.org/craniofacial>

Apert Syndrome (parent-driven page)

<http://www.apert.org/>

Sagittal Synostosis Homepage (parent-driven page)

<http://www.geocities.com/HotSprings/6751/>

Craniosyctosis (NIH)

http://www.ninds.nih.gov/health_and_medical/disorders/craniosyctosis_doc.htm

See NINDS Disorders page for more cranial disorders and syndromes

http://www.ninds.nih.gov/disorders/disorder_index.htm

Asher's Craniosynostosis Page (parent-driven page)

<http://www.geocities.com/HotSprings/Villa/3462/index.html>

Craniofacial Syndromes (Family Village)

http://www.familyvillage.wisc.edu/lib_cran.htm

Velo-Cardio-Facial Syndrome (Family Village)

http://www.familyvillage.wisc.edu/lib_vcfs.htm

VCFS Educational Foundation (**English**, also **Arabic**, **French**, **Hebrew**, **Spanish**)

<http://www.vcfsef.org/>

Let's Face It USA (Facial Difference Support)

<http://www.dent.umich.edu/faceit/>

CHARGE Syndrome Foundation (links to **German**, **French**, **Spanish** web sites in Resources)

<http://www.chargesyndrome.org/>

CHARGE Syndrome (parent-driven, includes message boards, links to **Spanish** and **Japanese** pages)

<http://www.geocities.com/Heartland/1220/>

Joubert Syndrome (NINDS)

<http://www.ninds.nih.gov/disorders/joubert/joubert.htm>

Joubert Syndrome Foundation & Related Cerebellar Disorders

<http://www.joubertsyndrome.org/index.htm>

Lissencephaly (NINDS)

<http://www.ninds.nih.gov/disorders/lissencephaly/lissencephaly.htm>

Lissencephaly Network

<http://www.lissencephaly.org/>

Coffin Lowry Syndrome (NINDS)

http://www.ninds.nih.gov/disorders/coffin_lowry/coffin_lowry.htm

Coffin-Lowry Syndrome Foundation

<http://clsf.info/>

Facial Fractures in Children

<http://www.childrenshospital.org/az/Site865/mainpageS865PO.html>

Pierre Robin Network

<http://www.pierrerobin.org/>

Pfeiffer Syndrome

<http://ghr.nlm.nih.gov/condition=pfeiffersyndrome>

Treacher Collins Syndrome

<http://ghr.nlm.nih.gov/condition=treachercollinsyndrome>

Search additional specific craniofacial syndromes or conditions at

Family Village

<http://www.familyvillage.wisc.edu/>

Alliance of Genetic Support Groups

<http://www.geneticalliance.org/>

Genetics Home Reference

<http://ghr.nlm.nih.gov/>

National Institute of Dental & Craniofacial Research

<http://www.nidr.nih.gov/>

These resources and others are available in the Kreamer Family Resource Center, ground floor of the Sutherland Tower in Children's Mercy Hospital, or call 816-234-3900 to arrange pick up from the Children's Mercy South Information desk. If you are not a patient of Children's Mercy Hospital & Clinics, books may be borrowed through Interlibrary Loan; contact your local librarian to arrange this.

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Kreamer Family Resource Center

Children's Mercy Hospitals & Clinics

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Kansas City MO 64108

816-234-3900



Children's Mercy

HOSPITALS & CLINICS

www.childrens-mercy.org