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
Cutler-Landsman—Educating Children with Velo-Cardio-Facial Syndrome
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
Guerra—Gianna’s wild strawberry: a story about a little girl with a birthmark
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)
MedlinePlus Health Topic: Facial Injuries and Disorders (English and some Spanish; includes many specific craniofacial syndromes)
MedlinePlus Health Topic: Head and Brain Malformations
See also MedlinePlus Health Encyclopedia entries (in English and Spanish) at http://medlineplus.gov
Cleft Palate Foundation (in English and Spanish; includes “Feeding your baby” online videos)
http://www.cleftline.org/
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/
AboutFace International (includes French)
http://www.aboutfaceinternational.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-- pictorial guide)
Collaboration 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/
Craniosyntosis (NIH)
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)
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/
Crouzon Syndrome, Pierre Robin Sequence, Treacher-Collins Syndrome fact sheets
http://www.cleftline.org/what_we_do/cpf_fs
Joubert Syndrome (NINDS)
Joubert Syndrome Foundation & Related Cerebellar Disorders
http://www.joubertsyndrome.org/
Lissencephaly (NINDS)
http://www.ninds.nih.gov/disorders/lissencephaly/lissencephaly.htm
Coffin Lowry Syndrome (NINDS)
Coffin-Lowry Syndrome Foundation
http://clfis.info/
Facial Fractures in Children
http://www.childrenshospital.org/az/Site865/mainpageS865P0.html
Pierre Robin Network
http://www.pierrerobin.org/
Pfeiffer Syndrome
Treacher Collins Syndrome

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
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
2401 Gillham Road
Kansas City MO 64108
816-234-3900

Children’s Mercy
HOSPITALS & CLINICS
www.childrens-mercy.org