

Craniofacial Online Resources

Note: This resource list is not exhaustive or specifically endorsed by APA/Division 54.

American Cleft Palate Craniofacial Association (ACPA)

Provides information and research that enhances the quality of life for individuals affected by cleft lip and palate and other craniofacial diagnoses

<http://cleftline.org/>

Available topics through ACPA Family Services include:

Life Stages

- [Prenatal Diagnosis](#)
- [For Parents of Newborn Babies with Cleft Lip/Cleft Palate](#)
- [Your Baby's First Year](#)
- [Toddlers and Preschoolers](#)
- [The School-Aged Child](#)
- [As you Get Older \(Teen\)](#)
- [Information for Adults](#) (booklet)
- [Information about Treatment for Adults with Cleft Lip and Palate](#) (fact sheet)

En Español:

- [A Los Padres de Los Bebés Recién Nacidos con Labio Hendido/Paladar Hendido](#)
- [El Primer Año de Su Bebé](#)
- [Niños Pequeños y de Edad Preescolar](#)
- [Los Niños de Edad Escolar](#)
- [Tratamientos para Adultos con Labio Hendido y Paladar Hendido](#)

Treatment and Care

- [Information about Choosing a Cleft Palate or Craniofacial Team](#)
- [Feeding Your Baby](#) (booklet)
- [Feeding Your Baby](#) (video)
- [What about Breastfeeding?](#)
- [Contact Information for Manufacturers of Cleft Nursers](#)
- [Neonatal Cleft Lip and Palate: Instructions for Newborn Nurseries](#)
- [Cleft Surgery](#)
- [Information about Surgical Scars](#)
- [Information about Submucous Cleft Palate](#)
- [Treatment Options for Better Speech](#)
- [Help with Hearing](#)
- [Bone Grafting the Cleft Maxilla](#)
- [Dental Care for a Child with Cleft Lip and Palate](#)
- [Replacing a Missing Tooth](#)
- [Speech Development](#)
- [Support for Individuals Affected by Cleft Lip and Palate](#)
- [Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate and Other Craniofacial Anomalies](#)

En Español:

- [Alimentando a Su Bebé](#)
- [Y...¿Qué acerca de la Lactancia Materna?](#)
- [Información de Contacto para las Vendedores de Biberones](#)
- [Cirugía de la Hendidura](#)
- [Respuestas a las Preguntas Más Comunes Sobres las Cicatrices](#)
- [Información sobre la Hendidura Submucosa del Paladar](#)
- [Opciones de Tratamiento para Mejorar el Habla](#)
- [Ayuda con el Oído](#)
- [Cuidado Dental para un Niño con Labio Hendido y/o Paladar Hendido](#)
- [Desarrollo del Habla](#)

Craniofacial Syndromes

- [Information about Crouzon Syndrome \(Craniofacial Dysostosis\)](#)
- [Information about Pierre Robin Sequence/Complex](#)
- [Information about Treacher Collins Syndrome \(Mandibulofacial Dysostosis\)](#)
- [Positional Plagiocephaly \(Head Shape Deformity\)](#)

En Español:

- [Información acerca del Síndrome Crouzon](#)
- [Información acerca de la Secuencia/Compleja Pierre Robin](#)
- [Información acerca del Síndrome Treacher Collins \(Disotosis Mandíbulo-Facial\)](#)

Other Topics

- [Genetics and You](#)
- [Letter to the Teacher of a Child with Cleft](#)
- [Letter to the Parent of a Child with a Cleft](#)
- [Preparing Your Child for Social Situations](#)
- [Information about Financial Assistance](#)
- [Dealing with your Insurance Company/HMO](#)
- [Special Considerations for Speech and Language Development for the Child Who is Adopted Internationally](#)

En Español:

- [Carta a un/a Maestro/a](#)
- [Carta a Los Padres de Niños con Hendiduras](#)
- [Prepare a Su Hijo/a para las Situaciones Sociales con Las Que Se Pueda Encontrar](#)
- [Información sobre Ayuda Financiera](#)
- [Escoger un Equipo de Expertos en Paladar Hendidos o Problemas Craneofaciales](#)

Children's Craniofacial Association (CCA)

CCA is a national nonprofit organization dedicated to improving the quality of life for people with facial differences and their families. CCA addresses the medical, financial, psychosocial, emotional, and educational concerns relating to craniofacial conditions.

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

Booklets in English and Spanish for Guides to Understanding Diagnoses:

<https://ccakids.org/syndromes.html>

Apert Syndrome https://ccakids.org/assets/syndromebk_apert.pdf

Cleft Lip and/or Palate https://ccakids.org/assets/syndromebk_clp.pdf

Craniosynostosis https://ccakids.org/assets/syndromebk_craniosynostosis_2015.pdf

Crouzon Syndrome https://ccakids.org/assets/syndromebk_crouzon.pdf

Facial Palsy https://ccakids.org/assets/syndromebk_facial_palsy.pdf

Fibrous Dysplasia [\[content/uploads/2018/05/SyndromeBk_fibrous_dysplasia.pdf\]\(https://ccakids.org/wp-content/uploads/2018/05/SyndromeBk_fibrous_dysplasia.pdf\)](https://ccakids.org/wp-</p></div><div data-bbox=)

Frontonasal Dysplasia https://ccakids.org/assets/syndromebk_frontonasal_dysplasia.pdf

Hemangiomas [\[content/uploads/2018/03/SyndromeBk_hemangiomas.pdf\]\(https://ccakids.org/wp-content/uploads/2018/03/SyndromeBk_hemangiomas.pdf\)](https://ccakids.org/wp-</p></div><div data-bbox=)

Hemifacial/Craniofacial Microsomia

https://ccakids.org/assets/syndromebk_hemifacial.pdf

Microtia/Atresia https://ccakids.org/assets/syndromebk_microtia.pdf

Moebius Syndrome https://ccakids.org/assets/syndromebk_moebius-guide_2015.pdf

Pfeiffer Syndrome https://ccakids.org/assets/syndromebk_pfeiffer.pdf

Pierre Robin Sequence https://ccakids.org/assets/syndromebk_pierrerobin.pdf

Treacher Collins Syndrome https://ccakids.org/assets/syndromebk_treacher-collins.pdf

Brief Educational Overview Topics:

<https://ccakids.org/one-sheet-overviews.html>

1. A Parent's Journey to Acceptance [PDF](#)
español: La travesía de los padres hacia la aceptación [PDF](#)
2. Anthropology and Craniofacial Anomalies [PDF](#)
3. Apert Feet [PDF](#)
4. As Your Teen Gets Older: Preparing for the Next Steps [PDF](#)
5. Cleidocranial Dysplasia [PDF](#)
6. Cyberbullying: An Overview [PDF](#)
7. Dramatically Increasing the Quality of Life with Prosthetic Devices [PDF](#)
8. Empowering Children to Cope with Teasing [PDF](#)
español: Capacitando los niños para lidiar con las burlas [PDF](#)
9. Family Dynamics [PDF](#)
10. Fostering Tolerance: Stand Up to Bullying [PDF](#)
11. Helping Your Child Prepare For Surgery [PDF](#)
12. Hydrocephalus [PDF](#)
13. Pain Management in Children [PDF](#)
14. Parents: You are the Care Manager! [PDF](#)
español: Padres: ¡Ustedes son los supervisores oficiales de cuidados! [PDF](#)
15. Prosthetic Devices
16. Responding to People in Your Community [PDF](#)
17. The 7 Things to Know Before Surgery [PDF](#)
18. Sleep Apnea [PDF](#)

19. Talking to Your Child about Surgery [PDF](#)
20. Tips for External Distraction Devices [PDF](#)
21. Transition Planning: As Your Teen Gets Older, Next Steps
22. Welcoming a Child Back to School After Surgery [PDF](#)
23. What to Expect When Your Child Goes to Surgery [PDF](#)
español: Qué puede esperar cuando su niño tenga cirugía [PDF](#)
24. What to Pack for the Hospital [PDF](#)

Changing Faces

Changing Faces is a UK charity that supports and represents people who have differences in their face, hand or body from any cause.

<http://www.changingfaces.org.uk/Home>

Self-Help Guides for Children and Young People Topics:

<https://www.changingfaces.org.uk/adviceandsupport/self-help-guides/children-young-people>

- Building Your Confidence
- Finding Out
- Looking Different
- Feeling Different
- When Teasing Becomes Bullying

Self-Help Guides for Parents of Children and Young People Topics:

<https://www.changingfaces.org.uk/adviceandsupport/self-help-guides/parents-children-young-people>

- You and Your Baby
- You and Your Child
- Talking with Your Child
- Preparing for School
- Preparing for Hospital
- When Teasing Becomes Bullying
- Communicating with Confidence

Self-Help Guides for Adults Topics:

<https://www.changingfaces.org.uk/adviceandsupport/self-help-guides/self-help-guides-adults>

- Living with Confidence
- Communicating with Confidence
- Intimacy, love, and Relationships

Anti-Bullying Resources for parents, teachers, and peers

<https://www.changingfaces.org.uk/resources/education/anti-bullying-week-2016>

Additional Family Resource Webpages

ACPA Family Services

In addition to providing information, ACPA Family services covers referrals, telephone support services, holds a Connections conference for families, has Cleftline Teddy bears, advocates for families, and awards scholarships.

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

AboutFace

Advocacy on behalf of those touched by facial difference with peer connections, information, emotional support, and opportunities to enhance their life circumstances.

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

Cleft Advocate (Ameriface Program)

Online resource for patients and families dealing with a cleft to help address questions about feeding, surgery, speech therapy, social issues, and dealing with insurance companies.

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

Foundation for Faces of Children

Online resource and advocacy for patients with craniofacial differences, including cleft lip, cleft palate, and other head and facial conditions.

www.facesofchildren.org

Smiles

SMILES is a group of families who have developed a first-hand understanding of the needs of children with cleft lip, cleft palate and craniofacial diagnoses.

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

Individualized Education Programs (IEPs)

<https://kidshealth.org/en/parents/iep.html>

https://www.superduperinc.com/handouts/pdf/77_ABC_IEP.pdf

<http://www.parentcenterhub.org/pa12/>