

SUPPORT FOR INDIVIDUALS AFFECTED BY CLEFT LIP AND PALATE

Cleft lip and cleft palate affect more than 7,000 individuals in the U.S. each year, leaving many people searching for support from others who understand their situation. American Cleft Palate-Craniofacial Association (ACPA) has compiled a list of support resources to help individuals and families affected by cleft lip and palate connect with each other. Each organization, group, or individual listed below is responsible for their own content.



National Support Resources

American Cleft Palate-Craniofacial Association:

Operates a 24-hour hotline assisting parents and adult patients with questions about cleft lip and palate and other craniofacial anomalies. Also provides referrals to cleft palate/craniofacial teams, distributes free educational publications, and annually awards college scholarships and scientific research grants.

www.cleftline.org, info@cleftline.org

1504 East Franklin Street, Suite 102
Chapel Hill, NC 27514
800.24.CLEFT (242.5338)

Ameriface/Cleft Advocate:

Provides general information and networking, as well as advice for people who are fighting insurance denials for their medical care. Has the Pathfinders program, an outreach network that helps families find answers based on local services and experiences, and a state resource guide.

www.cleftadvocate.org, Debbie@cleftadvocate.org

Post Office Box 75112
Las Vegas, NV 89136
888.486.1209, 702.769.9264

FACES—The National Craniofacial Association:

Provides support to people with craniofacial differences through newsletters, information packets, and financial assistance for non-medical costs.

www.faces-cranio.org, faces@faces-cranio.org

Box 11082
Chattanooga, TN 37401
800.332.2373

National Foundation of Facial Reconstruction:

Provides comprehensive medical treatment, psychological counseling, research and education through the Institute of Reconstructive Plastic Surgery at NYU Langone Medical Center.

www.nffr.org

333 East 30th St, Lobby Unit
New York, NY 10016
212.263.6656

Specialized Training of Military Parents (STOMP):

Provides international medical information and training to military families who have children with special needs.

www.stompproject.org

6316 S. 12th
Tacoma, WA 98465
800.5.PARENT

Other Support Resources

About Face:

www.aboutfaceusa.org

Provides information and support for individuals with facial differences and their families by linking people with similar experiences through a Peer Network. Offers a newsletter and publications.

Children's Craniofacial Association:

www.ccakids.org

CCA addresses the medical, financial, psychosocial, emotional, and educational concerns relating to craniofacial conditions.

Cleft Meetup:

www.cleft.meetup.com

An online message board helping to facilitate face-to-face meetings among people in their own local areas.

Craniosynostosis and Positional Plagiocephaly Support (CAPPS)

www.cappskids.org

Online support group and information for parents of children with craniosynostosis and positional plagiocephaly.

Crouzon Support Network:

www.crouzon.org

Online group for individuals and families affected by Crouzon Syndrome and other craniofacial anomalies.

Friendly Faces:

www.friendlyfaces.org

A resource for, and a network of, individuals with facial differences, parents, families, friends, and health care professionals.

Moebius Syndrome Community (through RareConnect)

www.rareconnect.org/en/community/moebius-syndrome

Hosted by patient advocates, this is a place where individuals affected by Moebius syndrome can connect with others.

Moebius Syndrome Foundation

www.moebiusyndrome.com

Provides information and support to individuals with Moebius syndrome and their families.

Pierre Robin Network:

www.pierrerobin.org

A network of families whose children have been diagnosed with Pierre Robin Syndrome.

“Teeter’s Page”

www.apert.org

An online support and information source for individuals and families affected by Apert Syndrome.

Treacher Collins Foundation:

www.treachercollinsfnd.org

An organization of families, individuals and medical professionals who are interested in developing and sharing knowledge and experiences about Treacher Collins Syndrome and related conditions.

Velo-Cardio-Facial (VCFS) Educational Foundation

www.vcfsef.org

The VCFS Educational Foundation is a non-profit organization that provides support and information to individuals and families who are affected by Velo-Cardio-Facial syndrome.

International Support Resources

Australia:

Cleft Pals, www.cleftpalsnsw.org.au

Canada:

About Face International, www.aboutface.ca

Ireland:

Cleft Lip and Palate Association, www.cleft.ie

United Kingdom:

Cleft Lip and Palate Association, www.clapa.com

For more information, or for a referral to a cleft or craniofacial team, please contact:

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1504 East Franklin Street, Suite 102

Chapel Hill, NC 27514

919.933.9044

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info@acpa-cpf.org