

Support For Individuals Affected by Cleft Lip and Palate

Cleft lip and cleft palate affect more than 6,800 individuals and their families each year, leaving many people searching for support from others who understand their situation. The Cleft Palate Foundation (CPF) has compiled a list of support resources to help individuals and families affected by cleft lip and palate connect with each other. Each of the support groups and individuals listed below is responsible for its own content. The Cleft Palate Foundation is only responsible for its own information and not that of other sources listed below.

National Support Resources

Cleft Palate Foundation:

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

1504 East Franklin Street, Suite 102
Chapel Hill, NC 27514
800.24.CLEFT (242.5338), www.cleftline.org,
info@cleftline.org

Cleft Advocate:

A resource providing 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.

Post Office Box 75112
Las Vegas, NV 89136
800.486.1209, www.cleftadvocate.org
Debbie@cleftadvocate.org

FACES - The National Craniofacial Association:

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

Box 11082
Chattanooga, TN 37401
800.332.2373, www.faces-cranio.org, faces@faces-cranio.org

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.

333 East 30th St, Lobby Unit
New York, NY 10016
212.263.6656, www.nffr.org,

Specialized Training of Military Parents (STOMP):

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

6316 S. 12th
Tacoma, WA 98465
800.5.PARENT, www.stompproject.org

Other Support Resources

About Face:

www.aboutfaceusa.org

Provides information and emotional 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 monthly face-to-face meetings among people in their own local areas.

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.

Craniosynostosis and Positional Plagiocephaly Support (CAPPS)

www.cappskids.org

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

Pierre Robin Network:

www.pierrerobin.org

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

"Teeter's Page" (apert.org)

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

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.

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.

International families may be interested in the following groups:

Cleft Lip and Palate Association, London, UK

www.clapa.com

Cleft PALS, Australia

www.cleftpals.org.au

Afilapa, Asociacion de Afectados de Fisura Labiopalatina, Spain (website in Spanish only)

www.afilapa.com

Cleft Lip and Palate Association, Ireland

www.cleft.ie

Please visit the links section on our website at www.cleftline.org/links for more resources!