

## 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](http://www.cleftline.org),  
[info@cleftline.org](mailto: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](http://www.cleftadvocate.org)  
[Debbie@cleftadvocate.org](mailto: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](http://www.faces-cranio.org), [faces@faces-cranio.org](mailto: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 30<sup>th</sup> St, Lobby Unit  
New York, NY 10016  
212.263.6656, [www.nffr.org](http://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. 12<sup>th</sup>  
Tacoma, WA 98465  
800.5.PARENT, [www.stompproject.org](http://www.stompproject.org)

### Other Support Resources

#### **About Face:**

[www.aboutfaceusa.org](http://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](http://www.ccakids.org)

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

**Cleft Meetup:**

[www.cleft.meetup.com](http://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](http://www.crouzon.org)

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

**Friendly Faces:**

[www.friendlyfaces.org](http://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](http://www.cappskids.org)

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

**Pierre Robin Network:**

[www.pierrerobin.org](http://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](http://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](http://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](http://www.clapa.com)

**Cleft PALS**, Australia

[www.cleftpals.org.au](http://www.cleftpals.org.au)

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

[www.afilapa.com](http://www.afilapa.com)

**Cleft Lip and Palate Association**, Ireland

[www.cleft.ie](http://www.cleft.ie)

**Please visit the links section on our website at [www.cleftline.org/links](http://www.cleftline.org/links) for more resources!**