FACES: The National Craniofacial Association 1-800-332-2373

What is Crouzon Syndrome?

Crouzon Syndrome is a condition resulting from premature fusion of the sutures of the skull and deformity of the skull. Characteristics include:

- skull is prematurely fused and unable to grow normally (*craniosynostosis*)
- bulging wide-set eyes due to shallow eye sockets (*ocular proptosis*)
- a small underdeveloped upper jaw (*maxilla*)
- downward slanting eyelids
- curved, parrot-like nose
- high, narrow, arched palate

Crouzon Syndrome with Acanthosis Nigricans (AN) is found in an estimated 5-10% of all Crouzon cases. In addition to the facial characteristics, it includes some of the following:

- darkened, rough patches of skin found in the folds of the body (armpits, neck, groin, elbows, knees, chin/mouth area, eye area, or stomach).
- Signs of this begin between the ages of 2-4.
- AN generally does not advance after the age of 12. So, the texture and color stay the same from then on.

Why did this happen?

There is no link between anything the mother did or did not do while she was pregnant and the occurrence of Crouzon Syndrome. Doctors believe it is caused by changes in the gene (FGFR2) mapped to chromosome 10. Crouzon Syndrome with Acanthosis Nigricans is caused by changes in the gene (FGFR3) mapped to chromosome 4. The cause of the change is not currently known.

Will this happen to children I have in the future?

If you have Crouzon Syndrome, there is a 50% chance that other children you have will be born with it. If both parents are unaffected, the risk is very small that it will occur in other children.

What kinds of problems could my child have?

In addition to the physical characteristics common to Crouzon Syndrome, your child may have the following problems:

- dental problems due to crowded teeth and a narrow palate
- poor vision
- ear disease and hearing loss in about 50% of children
- difficulty breathing due to small airway
- possible fluid on the brain (*hydrocephalus*)

Will my child need surgery?

Depending on the severity of Crouzon Syndrome, your child may have some or all of the following surgeries:

- frontal orbital advancement to allow the skull to grow properly and to increase the size of the eye sockets
- jaw surgery
- orthodontics work
- surgical advancement of the mid-face

New advances in procedures to correct Crouzon Syndrome are constantly being developed. Be an advocate for your child!

How do I get help for my child?

Your child should be treated by a qualified craniofacial medical team at a craniofacial center. Currently, FACES has information on many of these teams. This is by no means a comprehensive list of all the craniofacial teams. Please contact FACES for details.

Am I alone?

No! There are many families and organizations that will be glad to talk with you and help you with information and support. Don't forget books, videos, and websites. This listing on the back of this page will get you started.

FACES: The National Craniofacial Association
P.O. Box 11082
Chattanooga, TN 37401
(800) 332-2373
Email: faces@faces-cranio.org
Website: www.faces-cranio.org
We provide financial support for non-medical expenses to patients traveling to a craniofacial center for treatment. Eligibility is based on financial and medical need. Resources include newsletters, information about craniofacial conditions, and networking opportunities.

National Health Law Program
1444 I Street, NW - Suite # 1105
Washington DC 20005
(202) 289-7661
Website: www.healthlaw.org
Provides extensive information on health care laws affecting families of children with special needs.

Children with Facial Difference: A Parent's Guide.
Written by Hope Charkins, MSW.
Excellent resource for parents to help them cope with medical, emotional, social, educational, legal, and financial challenges presented by facial differences of their children. Look for this book at your larger bookstore chains.
Available at: www.Amazon.com

Babyface: A Story of Heart & Bones
Written by Jeanne McDermott.
Written by the mother of a child born with Apert Syndrome, Babyface, tells the story of the challenges and triumphs that her family goes through during her son's first year of life. A must for any family who has a child with Apert, Pfeiffer, or Crouzon Syndrome.
Available at: www.Amazon.com

Other helpful websites:
If you don't have internet access, please call the number listed for information and/or booklet on crouzon.

The Craniofacial Center
Dr. Jeffery A. Fearon, MD, FACS, FAAP, Director
7777 Forest Lane, Suite C-700
Dallas, TX 75230
(972) 566-6464
Email: cranio700@gmail.com
Website: www.thecraniofacialcenter.org
Visit Dr. Fearon's informative website that is very lay-friendly and easy to understand or call the 800# for a copy of a booklet on crouzon.

Plastic & Craniofacial Surgery for Infants and Children
7777 Forest Lane, Suite B-300
Dallas, TX 75230
(469) 375-3838
Website: www.kidsplastsurg.com/crouzon.html

Children's Hospital & Regional Medical Center
4800 Sand Point Way NE
P.O. Box 5371/4H-5
Seattle, WA 98105
(206) 987-2188
www.seattlechildrens.org

Cleft Palate Foundation Publications
(800) 242-5338
www.cleftline.org

Crouzon Support Network
www.crouzon.org
Online network designed to offer support to individuals and families affected by Crouzon. This group offers online discussions and periodic meetings and social events.

Worldwide Crouzon Map
Here is a link to a map showing where people with Crouzon live. If you would like to add yourself, please do!
www.diseasemaps.org