



The National Craniofacial Association

P. O. Box 11082 * Chattanooga, TN 37401

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
- 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 the discoloration begin between the ages of 2 and 4.
- AN generally does not advance after the age of 12.

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 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. If you or a family member has Crouzon Syndrome, we encourage you to consider participating in a current study through The Johns Hopkins Medical Institutions. Details are given below.

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 diseases 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 treat 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 thirty-two craniofacial teams located in 20 states, the District of Columbia, and Canada. 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 who will be glad to talk with you and help you with information and support. Don't forget books, videos, and websites. This listing below 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.

Family Crouzon Information

This website is maintained by a mother born with Crouzon Syndrome, who has two children with Crouzon Syndrome. You will find comprehensive information on Crouzon, as well as informative and helpful guides to dealing with surgeries, schools, teasing, and raising happy and successful children.

Crouzon Support Network

This is an online network designed to offer support to individuals and families affected by Crouzon Syndrome. The group offers opportunities to have online discussions and periodic meetings and social events.

[Crouzon Support Yahoo Group Network](#)

This link will take you to the active online discussion group where you can meet other families whose members have Crouzon Syndrome.

National Health Law Program

1101 14th Street, NW, Suite 405

Washington, DC 20005

(202) 289-7661

Website: www.healthlaw.org

Provides extensive information on health care law affecting families with children who have special health care needs.

Children with Facial Difference: A Parent's Guide.

Written by Hope Charkins, MSW. Order from Amazon.com if you cannot find it in your local bookstore.

Excellent resource for parents to help them cope with medical, emotional, social, educational, legal, and financial challenges presented by facial differences of their children.

Babyface: A Story of Heart & Bones

Written by Jeanne McDermott. Published by [Woodbine House](#), 2000. 1-800-843-7323.

Jeanne McDermott, the mother of a child born with Apert Syndrome, tells the story of the challenges and triumphs that her family goes through during her son's first year of life. A must read for any family who has a child with Apert, Pfeiffer, or Crouzon Syndrome.

The Craniofacial Center

Dr. Jeffery A. Fearon, MD, FACS, FAAP, Director

7777 Forest Lane, Suite C-700

Dallas, TX 75230

(800) 443-3996

Email: cranio700@aol.com

Visit Dr. Jeffrey Fearon's informative website that is very lay-friendly and easy to understand. He has excellent information on Crouzon Syndrome and what surgeries are often necessary.

Plastic & Craniofacial Surgery for Infants & Children

6300 Harry Hines Boulevard, Suite 600

Dallas, TX 75235

(214) 456-8888

Children's Hospital & Regional Medical Center

P O Box 5371/4H-5

Seattle, WA 98105

(206) 987-2188

Cleft Palate Foundation Publications

(800) 242-5338

Invitation for Participation in a Research Study

The following is a letter from McKusick-Nathans Institute of Genetic Medicine

The Johns Hopkins Hospital
600 N. Wolfe Street
Baltimore, MD 21287-3914
Email: IGMStudy2@yahoo.com

We are interested in finding out how certain genetic changes, especially those causing the craniofacial disorders Crouzon and Pfeiffer syndromes occur. We are looking for other genetic changes near the ones causing Crouzon and Pfeiffer syndromes to see if there is an association with certain changes.

We would like to invite families to participate in our study. We are recruiting families in which the parents do not have Crouzon or Pfeiffer syndromes, but a child does. Each family member will need to sign a consent form and buccal cell and/or blood samples will be collected. Blood sample collection can be arranged at the Johns Hopkins Hospital or a local/family physician's office. If you choose to have the blood samples collected by a facility other than the Johns Hopkins Hospital, a collection kit and the appropriate packaging will be sent to you. Buccal cell samples can be collected at home and a kit will be provided through the mail. This is a painless and simple procedure where a special swab like a Q-tip is rubbed on the inside of the cheek to collect loose cells. Packaging and postage will be provided to return the samples and consent form to the laboratory. The DNA will then be isolated and analyzed in the laboratory.

The families will not benefit directly and will not be able to find out their results. We hope that this research will help us better understand how certain genetic changes occur. All samples will be coded by identification number and will remain anonymous.

All costs for participation are paid by our institution.

If you are interested in participating or if you have any questions regarding this study, please email IGMStudy2@yahoo.com or contact us by telephone at 410-955-0327 for additional information or to make arrangements. Thank you for taking time to consider participation in this study.