

FACES: The National Craniofacial Association 800-332-2373

What is Saethre-Chotzen Syndrome?

Saethre-Chotzen Syndrome is a very rare disorder characterized by the following traits:

- fusion of the cranial structures which sometimes produces an asymmetric head and face
- low-set hairline
- droopy eyelids (ptosis) and/or widely spaced eyes
- “beaked” nose and possible deviated septum
- Abnormalities of the fingers and/or toes -- they are often short (brachydactyly) and some mild webbing (syndactyly) may be present
- intelligence is usually not impaired

Why did this happen?

Saethre-Chotzen is usually found in several generations of a family, as it is an inherited disorder; however, because the features are often so minor, many times it is never diagnosed. It is an “autosomal dominant” disorder caused by a change or “mutation” in only one copy of a gene from one biologic parent. The altered gene is located on chromosome 7.

Will this happen to children I have in the future?

Because it is an “autosomal dominant” disorder, there is a 50% chance of passing on Saethre-Chotzen to the child.

What kinds of problems could my child have?

In addition to the physical characteristics, growth delays may occur, leading to less than average adult height.

Will my child need surgery?

Very often, the physical characteristics are so mild that no surgical treatment is necessary. Facial appearance tends to improve as the child grows; however, the following may be necessary:

- surgery to correct the fusion of the cranial structures
- surgery to correct the webbing of the fingers
- reconstructive surgery to eyelids and nose

New advances and research into the problems connected to Saethre-Chotzen Syndrome are constantly occurring. 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 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 who will be glad to talk with you and help you with information and support. Don't forget books, videos, and websites. The listing on the back of this page will get you started.

FACES: The National Craniofacial Association

Post Office 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.

Headlines, Craniofacial Support Group

128 Beesmoor Road

Frampton Cotterell

Bristol

BS36 23P

United Kingdom

email: info@headlines.org.uk

website: www.headlines.org.uk

This excellent international organization has a booklet on Saethre-Chotzen Syndrome, as well as a support network of families dealing with this syndrome. They also have a number of journal articles relating to Saethre-Chotzen.

Alliance of Genetic Support Groups

4301 Connecticut Avenue, NW - Suite 404

Washington, DC 20008

(202) 966-5557

email: info@geneticalliance.org

website: <http://www.geneticalliance.org>

Request information about Saethre-Chotzen Syndrome.

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..

Website: www.Amazon.com

Let's Face It

University of Michigan

School of Dentistry

1011 N. University

Ann Arbor, MI 48109-1078

No phone, Internet only

email: faceit@umich.edu

website: www.media.dent.umich.edu

This booklet of information and support networks, educational resources and more will ONLY be available at this website.

There will be no more printed Resource Booklets.