

FACES:

The National Craniofacial Association 1-800-332-2373

What is Apert Syndrome?

Apert Syndrome is a condition involving distortions of the head and face and webbing of the hands and feet. Characteristics include:

- skull - short from back to front, wide on the sides, and overly tall (craniosynostosis)
- eyes - slightly side-spaced, bulging, the eyelids tilt downward abnormally at the sides
- face - the mid-face has a sunken-in appearance, the upper jaw slopes backward, lower teeth project in front of the upper teeth
- hands and feet - webbing and/or fusion including finger bones, toe bones, and joints of fingers and toes

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 Apert Syndrome. Doctors believe Apert Syndrome occurs when a gene mutates early in the pregnancy.

Will this happen to children I have in the future?

The chances of having another child with Apert Syndrome is almost non-existent if both parents are unaffected. If one parent has Apert Syndrome, there is a 50% chance that his/her children will have Apert Syndrome.

What kinds of problems could my child have?

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

- cleft palate - about 30% of children with Apert Syndrome are affected
- slower learning rates and abilities - about 50% of children with Apert Syndrome are affected; however, as the children grow older, they often catch up with others

- vision problems caused by imbalance of the eye muscles
- recurrent ear infections which can cause hearing loss
- noisy breathing - the smaller nose and airway passages may make breathing difficult
- hyperactive sweat glands may cause your child to sweat a lot, especially while sleeping
- problems with acne are more likely, especially during puberty

Will my child need surgery?

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

- total skull reshaping to correct the tower skull problems at three to four months of age
- frontal-orbital advancement to increase space within the skull and the size of both orbits (the part of the skull which holds the eyeball) at three to four months of age
- mid-facial advancement - usually prior to starting school
- facial bi-partition to widen the upper jaw, derotate the orbits, and to narrow the upper face
- osteotomy (cutting through the bone of the upper and lower jaw to correct further problems usually during the teen years)
- rhinoplasty - plastic surgery of the nose
- genioplasty - plastic surgery of the chin or cheek
- eyelid surgery to correct the abnormal downward tilt
- separation of the fingers and/or toes

New advances and procedures concerning Apert 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 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 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.

Apert International, Inc.

Cathie Sears

P.O. Box 2571

Columbia, SC 29202

(803) 732-2372

Website: www.apert.org (Teeters Page)

This web site on Apert Syndrome will give you directions to the on-line discussion network that will also help you with Apert Syndrome concerns. The Annual Apert Conference is usually held each year in Myrtle Beach, South Carolina at the Crown Reef Resort. It is open to families who have been affected by Apert Syndrome or any other similar craniofacial difference. Registration is free, but families pay for travel costs, lodging, and food.

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. Jeffrey Fearon's informative website that is very lay friendly and easy to understand.

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. Available at most bookstores. 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 Jeanne McDermott, the mom of a son born with Apert Syndrome. This wonderful, passionate book highlights the first two years of Nate's life, and this gifted writer expresses the thoughts and feelings that are a part of the journey of having a child who is born with a rare disorder. This is a book you will want to share with your friends and family members..

Available at: www.Amazon.com

Maggie

Written by Steve Doherty

Written by the father of a child born with Apert Syndrome, Maggie takes the reader on the adventure of having a child born with Apert Syndrome, through all of its ups, downs, trials, and triumphs. A true love story.

Read the online book here: www.apert.org