

FACES:

The National Craniofacial Association 1-800-332-2373

What is Pfeiffer's Syndrome?

Pfeiffer's Syndrome (first reported in 1964) 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*)
- underdevelopment of the midface
- broad, short thumbs and big toes
- possible webbing of the hands and feet

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 Pfeiffer's Syndrome. Doctors believe it is caused by changes in the gene (FGFR 1 & FGFR 2) mapped to chromosome's 8 & 10. The cause of the change is not currently known.

Will this happen to children I have in the future?

If you have Pfeiffer's 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 Pfeiffer's Syndrome, your child may have the following problems:

- dental problems due to crowded teeth & often a high palate
- poor vision
- hearing loss in about 50% of children

Will my child need surgery?

Depending on the severity of Pfeiffer's 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

With the proper treatment, most children with Pfeiffer's Syndrome grow up to have completely normal intelligence and normal lives!

New advances in procedures to correct Pfeiffer's 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 who 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 next 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.

Apert International, Inc.

Cathie Sears

1900 Shadowood Drive

Columbia, SC 29212

(803) 732-2372

website: <http://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 and Pfeiffer Syndrome concerns. Read stories and meet other families; a great support network.

Headlines, Craniofacial Support Group

128 Beesmoor Road

Frampton Cotterell

Bristol

BS36 23P

United Kingdom

email: info@headlines.org.uk

website: <http://www.headlines.org.uk>

This excellent international organization has literature on Pfeiffer's and a support network of many families dealing with it, as well.

Pfeiffer Syndrome Support Group

A place for parents of children with Pfeiffer Syndrome to join with other parents and learn about what they can expect for the future of their children. This group includes parents of children with Pfeiffer Syndrome, as well as young adults with Pfeiffer Syndrome who can give a unique perspective of having gone through the necessary surgeries. To join send an e-mail request to mrksanb@gmail.com

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.

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

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

Other helpful websites:

The Craniofacial Center

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

7777 Forest Lane, Suite C-700

Dallas, TX 75230

(800) 443-3996 or (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.