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

**What is Craniosynostosis?**
Craniosynostosis is caused by the premature closing of one or more of the sutures of the bones which make up the skull. Usually, CT scans are taken to determine if the abnormal skull shape is Craniosynostosis, rather that just a result of fetal head position or birth trauma. There are four types of Craniosynostosis:

Scaphocephaly is caused by the fusion of the sagittal suture which runs from front to back down the middle of the top of the skull. This is the most common type of Craniosynostosis. Characteristics include:

- a long narrow shaped head from front to back
- narrow from ear to ear
- the head appears boat-shaped

Trigonocephaly is the fusion of the metopic suture, which runs from the top of the head, down the middle of the forehead, towards the nose. Characteristics include:

- triangular shaped forehead
- eyes are closer together than usual

Plagiocephaly is the premature fusion of one of the coronal sutures, which extend from ear to ear over the top of the head. Characteristics include:

- fusion of either the right or left side
- the forehead and brow look like they are pushed backwards
- the eye on the affected side has a different shape than the one on the unaffected side

Brachycephaly results when both sides of the coronal sutures fuse prematurely. Characteristics include:

- wide-shaped head, with short skull
- fusion prevents the entire forehead from growing in a forward direction, causing a tall, flattened forehead

**Why did this happen?**
At this time, doctors are unsure why Craniosynostosis happens. In some families, it does appear to be an inherited trait. It is most likely that some mutation occurred in the early development to one of the baby's genes, however, research cannot yet give us definitive answers on this. There is no indication that there is anything the mother did or did not do to cause this.

**Will this happen to children I have in the future?**
The chances that other children will have this problem are very slim...0-4%. These are also the chances of your child's children being born with Craniosynostosis. The only exception is when the Craniosynostosis is a part of Crouzon or Apert Syndromes, in which there is a 50% chance of being passed on from parent to child.

**What kinds of problems could my child have?**
Depending on the severity of the Craniosynostosis, your child may have some or all of these problems:

- abnormal skull shape
- abnormal forehead
- asymmetrical eyes and or ears
- intracranial pressure (pressure inside the skull) which can cause delays in development or permanent brain damage if not corrected

**Will my child need surgery?**
Babies born with Craniosynostosis usually will need surgery, unless it is a very mild case. It is important that the proper X-rays and CT scans are made in order for your physician to make a correct diagnosis, as well as show you the fused sutures and how they will be reconstructed. Usually, only one surgery is required to separate the sutures, reshape the bones, and place them in the proper position. Only 10% of children will need a second surgery.

Surgery to correct Craniosynostosis is usually performed between four and eight months of age.

***New advances in procedures to correct Craniosynostosis are being developed all the time. 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. 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 information on craniofacial conditions, related organizations, and quarterly newsletters.*

CAPPS
(Craniosynostosis and Positional Plagiocephgaly Support)
Jennifer Pitchke, Executive Director
6905 Xandu Court
Fredericksburg, VA 22407
email: CAPPSORG@aol.com
website: www.CAPPSkids.org
website: www.plagiocephaly.org
*Support organization for parents of children with craniosynostosis. Provides an online support group, newsletters, resources, and hospital care packages.*

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
*Dr. Fearon's website is very lay friendly.*

Avery's Angel Network - Little Avery was born with Craniosynostosis, and her mom started this network. She uses her talents to make beautiful headbands for the girls and do-rags for the boys who have had surgery to correct their craniosynostosis. This is her mission, and judging from the smiles on the faces of the little ones wearing the headbands and do-rags, the kids love them also. Website: www.cranioangelnetwork.com

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

For families living in the New York City area, Monroe Orthotics & Prosthetics has 4 office locations, Brooklyn, NY, Suffern, NY, Monroe, NY and Poughkeepsie, NY, which serves the Brooklyn, Queens, Long Island, Northern New Jersey, North Western Connecticut and the Hudson Valley areas, which includes the Westchester, Rockland, Orange, Sullivan, Ulster, Dutchess, Putnam and Greene counties. Monroe makes cranial remolding orthosis that is used to treat deformational Craniosynostosis and other head shape deformities in infants 3-18 months of age.
(888) 435-6382 local (845) 782-9191
email: Erica@monroeOandP.com
website: MonroeOandP.com

Craniology.org
Offering parents and individuals inspiration, emotional support, educational literature and information on community resources. Helping parents or individuals with Cleft, Craniosynostosis, Hemifacial Microsomia, Plagiocephaly, and others syndromes to meet other parents or family members that deal with the same problems.
Website: www.craniology.org

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

## WORLD WIDE WEB!

The following are some useful internet sites concerned with craniosynostosis, including some with information on cranial molding helmets:

http://www.columbianeurosurgery.org
This site includes descriptions of the various types of craniosynostosis, as well as diagrams of each.

https://digital.library.adelaide.edu.au
*This site gives excellent information and diagrams on craniosynostosis, as well as on Crouzon, Apert, and Pfeiffer Syndromes.*

The following websites have information on positional craniosynostosis:
www.kidsplastsurg.com/cranmold.html

www.cranialtech.com