

What is Treacher Collins Syndrome?

Treacher Collins Syndrome, also called Mandibulofacial Dysostosis, affects the head and face. Characteristics include:

- down-slanting eyes
- notched lower eyelids
- underdevelopment or absence of cheekbones and the side wall and floor of the eye socket
- lower jaw is often small and slanting
- forward hair in the sideburn area
- underdeveloped, malformed and/or prominent ears

Most children with Treacher Collins have normal development and intelligence; however, it is important that there be early hearing tests. Most children with Treacher Collins Syndrome benefit from early intervention speech and language programs.

Why did this happen?

Treacher Collins is believed to be caused by a change in the gene on chromosome 5, which affects facial development. About 40 percent of the time, one parent has the Treacher Collins Syndrome gene. Geneticists can now determine whether the Treacher Collins gene is a new mutation or one that has been passed on. There are new studies being done to see about the possibilities of there being other genes that could be involved with this syndrome.

Will this happen to children I have in the future?

Treacher Collins Syndrome may be inherited from a parent affected with Treacher Collins. There is a 50% chance of passing it on if you have it. It may also occur in children of unaffected parents. The chances of Treacher Collins occurring again in children of unaffected parents is minute, however, new genetic studies could change this opinion.

What kind of problems could my child have?

In addition to the physical characteristics common to Treacher Collins Syndrome, your child may have some or all of the following problems:

- breathing problems and/or eating difficulties
- most children have a 40% hearing loss in each ear due to abnormalities of the outer and middle ear, which conduct sound to the nerve endings
- the eyes have a tendency to dry out, which can lead to infection
- cleft palate often occurs with Treacher Collins

Will my child need surgery?

Depending on the severity of the Treacher Collins, your child may need some or all of the following procedures:

- a conductive hearing aid
- correction of the cleft palate
- repair of the sidewall and floor of the eye socket
- repair of the cheekbones
- repair of the eyelid notches
- correction of the undeveloped jaw and chin
- surgery to correct the beak-like nose
- reconstruction of the ears

New advances in the procedures to treat Treacher Collins 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. The listing below 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..

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. Look for this book at your larger bookstore chains.

Available at : www.Amazon.com

Also on the internet is a page put together by and updated by Amie, a doctor who was born with Treacher Collins and practices in Houston, Texas. The website address is: www.treachercollins.org