

What is Goldenhar Syndrome?

Goldenhar Syndrome, also known as Oculoauricular Dysplasia or OAV, is a congenital birth defect which involves deformities of the face. It usually affects one side of the face only. Characteristics include:

- a partially formed or totally absent ear (microtia)
- the chin may be closer to the affected ear
- one corner of the mouth may be higher than the other
- benign growths of the eye
- a missing eye

Why did this happen?

Doctors are uncertain why Goldenhar occurs. However, they do not believe it is the result of anything the mother did while she was pregnant. Environmental factors may play a part and there does seem to be an increased incidence of Goldenhar among the children of Gulf War Veterans.

Will this happen to children I have in the future?

The chances of having another child with Goldenhar is less than 1% or less. Your child has about a 3% chance of passing it on to his or her children.

What kinds of problems could my child have?

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

- hearing problems

- weakness in moving the side of the face that is smaller
- dental problems
- the soft palate may move to the unaffected side of the face
- the tongue may be smaller on the affected side of the face
- fusion of the bones of the neck

Will my child need surgery?

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

- lowering of the jaw on the affected side
- lengthening of the lower jaw
- 3 to 4 operations to rebuild the outer ear
- addition of bone to build up the cheeks
- soft tissue may need to be added to the face

New advances in procedures to correct the symptoms of Goldenhar 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
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.

Goldenhar Syndrome Support Network

websites:

<http://health.groups.yahoo.com/group/goldenharsyndrome/>

and

<http://health.groups.yahoo.com/group/goldenharadults/>

Barb Miles, a parent of a child with Goldenhar Syndrome, created this support and information network. Be sure to sign up for these two on line support groups. They are both active and will provide great support and information.

Let's Face It

University of Michigan
School of Dentistry / Dentistry Library
1011 N. University
Ann Arbor, MI 48109-1078
email: faceit@umich.edu
website: www.dent.umich.edu/faceit/

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.

Federation for Children with Special Needs

529 Main Street - Suite 1102
Boston, MA 02129
(617) 482-2915
e-mail: FCSNinfo@fcsn.org
website: www.fcsn.org

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. Published by Amazon, 1996.

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

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.