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 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
e-mail: 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 online 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
e-mail: 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
e-mail: cranio700@gmail.com
website: www.thecraniofacialcenter.org
Visit Dr. Jeffrey Fearon’s informative website that is very lay friendly and easy to understand.

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