

## **What is Hemifacial Microsomia?**

Hemifacial Microsomia is a condition in which the lower half of one side of the face is underdeveloped and does not grow normally. It is sometimes also referred to as first and second brachial arch syndrome, oral-mandibular-auricular syndrome, lateral facial dysplasia, or otomandibular dysostosis. The syndrome varies in severity, but always includes the maldevelopment of the ear and the mandible. This is the second most common facial birth defect after clefts.

## **Why did this happen?**

Researchers are still not sure why this happens, however, most agree that something occurred in the early stages of development such as a disturbance of the blood supply to the first and second branchial arches in the first 6 to 8 weeks of pregnancy. Studies do NOT link this condition with the mother's activities or actions during her pregnancy.

## **Will this happen to children I have in the future?**

For parents with one child with Hemifacial Microsomia, the chances are between 0 and 1%. Adults with this condition have a 3% chance of passing it to their children.

## **Will my child need surgery?**

The surgeries recommended for children with Hemifacial Microsomia have a goal to improve facial symmetry, by reconstructing the bony and soft tissue, and establishing normal occlusion and joint junction. The timing for such surgeries vary among the surgeons and the severity of the problems. Common surgeries include:

- lowering the upper jaw to match the opposite side and lengthening the lower jaw. Sometimes a bone graft is used to lengthen the jaw and sometimes a distraction device is used.

- Ear reconstruction at about 5-6 years of age, involves 3 to 4 surgeries.
- Occasionally, it may be necessary to add bone to build up the cheekbone.
- Some children benefit from the addition of soft tissues to further balance the face.

## **What kinds of Problems could my child have?**

- Your child may have skin tags in front of the ear or on different parts of the face.
- Hearing problems depend on the structures that are involved.
- Some children have some weakness in movement on the affected side of the face.

**New advances in procedures to correct the symptoms of Hemifacial Microsomia 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 on the back of this page will get you started.

FACES: The National Craniofacial Association  
Post Office Box 11082  
Chattanooga, TN 37401  
(800) 332-2373

website: [www.faces-cranio.org](http://www.faces-cranio.org)

email: [faces@faces-cranio.org](mailto:faces@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..*

### 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](http://www.Amazon.com)

### **Let's Face It**

University of Michigan

Email: <mailto:faceit@umich.edu>

Website:

<http://www.media.dent.umich.edu/faceit/info>

*A website of information and support networks, educational resources and more! A good site for anyone with a facial difference.*

### Federation for Children with Special Needs

529 Main Street, Suite 1102

Boston, MA 02129

(617) 236-7210

e-mail: [FCSNinfo@fcsn.org](mailto:FCSNinfo@fcsn.org)

website: [www.fcsn.org](http://www.fcsn.org)

### National Health Law Program

1444 I Street, NW - Suite # 1105

Washington, DC 20005

(202) 289-7661

website: [www.healthlaw.org](http://www.healthlaw.org)

*Provides extensive information on health care laws affecting families of children with special needs.*

### Goldenhar Syndrome Support Network:

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

*Barb Miles, a parent of a child with Goldenhar Syndrome, created this support and information network. Goldenhar Syndrome is very similar to Hemifacial Microsomia, but includes more extensive problems. Be sure to sign up for these two on line support groups. They are both active and will provide great support and information.*

### The Craniofacial Center

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Website: [www.thecraniofacialcenter.org](http://www.thecraniofacialcenter.org)

Visit Dr. Jeffrey Fearon's informative website that is very lay friendly and easy to understand.