

a guide to understanding
**hemifacial
microsomia**

a publication of children's craniofacial association

a guide to understanding hemifacial microsomia

this parent's guide to hemifacial microsomia is designed to answer questions that are frequently asked by parents of a child with hemifacial microsomia. It is intended to provide a clearer understanding of the condition for patients, parents and others.

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This booklet is intended for information purposes only. It is not a recommendation for treatment. Decisions for treatment should be based on mutual agreement with the craniofacial team. Possible complications should be discussed with the physician prior to and throughout treatment.

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what is hemifacial microsomia?

hemifacial microsomia is a condition that simply comes “out of the blue.” It does not run in families and is not the result of a disease process. Simply stated, it is a birth defect. Some cases of hemifacial microsomia can be very mild, but others can be more severe. A doctor or medical team makes the clinical diagnosis because there are no gene tests for this condition.

how do I recognize this condition in my child?

hemifacial microsomia involves the entire face, with one side being smaller and the other side slightly larger. Typically, only the lower part of the face is involved, but sometimes the eye and forehead can also be smaller. The cheek is flat because the bone beneath has not grown properly and the lower face is vertically shorter. The mandible, or lower jaw, is also smaller and in some cases the jaw joint can be completely missing. The ear may be normal, partially formed, or completely absent; resulting in partial hearing loss on this side. There may be skin tags in front of the ear or in a line between the ear and the corner of the mouth.

are there different degrees of this condition?

Some doctors like to use the term craniofacial microsomia to describe this condition, while other doctors save this term for when the forehead and eye are involved. Another condition, Goldenhar syndrome, is very similar; however, children with this syndrome also have benign growths on the eye called epibulbar dermoids. Patients with Goldenhar syndrome may also have neck problems, with bony bridges occurring between the bones of the neck.

what treatment is available for hemifacial microsomia?

the treatment of hemifacial microsomia depends upon how much the face has been affected. Doctors first need to make sure that the smaller half of the face is not causing the child any problems with breathing at night. When the jaw joint is absent on one side, the child's tongue can fall back during sleep, partially obstructing the airway causing what is called obstructive sleep apnea (OSA). Sometimes a sleep study will be ordered to test for this problem.

Correcting the facial asymmetry to help normalize appearance can be done in different ways and at different times. Some doctors prefer to operate at an early age using a technique called distraction; this entails cutting the lower jaw bone and inserting a metal plate on the bone with a screw poking out through the skin, which is turned everyday to make the jaw bone longer. When surgery is done before a child has completed growth, it is likely that additional operations may be necessary once growth has stopped in teenage years. Other doctors prefer to wait until children are older and will perform upper and lower jaw surgery through the inside of the mouth, without any outside scars, completing the reconstruction in just one operation. For children born without a jaw joint, this joint can be constructed using the child's own ribs. For those children who require jaw surgery, orthodontic treatment will likely be needed.

what other problems and treatments might we expect?

Some children with this condition may have some facial weakness on the affected side. There is usually no treatment required for this condition. For those children born with an incompletely formed ear, a new ear can be rebuilt using a child's own rib cartilage. Other options for rebuilding ears include placing an artificial ear framework under the skin, or just attaching a completely prosthetic silicone ear on top of the skin. The prosthetic ears can look very realistic, but do not change color and may not match as well if a child gets tan in the summer. Those doctors who prefer to place artificial material under the child's skin to rebuild an ear, do this because it is a smaller and easier operation. Those that recommend using the child's own rib believe that these all-natural ears are more likely to last a lifetime. Most children with absent outer ears have a partial hearing loss on this side. Inner ear surgery might be recommended, or some type of external hearing aid might be suggested. If hearing is normal in the opposite ear, sometimes nothing else needs to be done.

where is the best place to have my child treated?

hemifacial microsomia is a complex condition. It requires the expert skill of several different specialists working together. Centers with craniofacial teams working together may have the advantage of greater experience, which usually leads to better results and fewer complications. It is also worthwhile to take the time to get more than one opinion, even if this means traveling to a different city. Take the time to learn about the different types of treatment, and what the positive and negatives are for each, before letting someone begin treatment on your child

how can children's craniofacial association (cca) benefit my family?

CCA understands that when one family member has a craniofacial condition, each person in the family is affected. We provide programs and services designed to address these needs. A detailed list of CCA's programs and services may be found on our website at www.ccakids.org or call us at 800.535.3643.



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