

a guide to understanding

craniofacial microsomia

goldenhar syndrome

a publication of children's craniofacial association

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This guide to craniofacial microsomia (CFM) is designed to address questions that are frequently asked by parents or caregivers of a child with CFM. It is intended to provide a clearer understanding of the condition for patients, parents, and others.

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

CCA understands that craniofacial conditions can affect all members of a family and their community in different ways. CCA provides 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.com or call us at 800.535.3643.

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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 craniofacial microsomia?

Craniofacial microsomia (CFM) is a condition in which different parts of a person's face are small or do not develop as expected. Often a person with CFM will have differences in the size and shape of their facial features between the left and right sides of their face, but both sides can be affected. The diagnosis of CFM is made by a healthcare professional. CFM is the second most common craniofacial anomaly after cleft lip and palate.

how do I recognize this condition in my child?

Craniofacial microsomia (CFM) can affect a person's entire face or one side more than the other. The affected features and severity vary between people. The most common features to be affected are the jaw and ears. The jaw can be small or underdeveloped in individuals with CFM. This can cause dental problems, difficulties with feeding and speech, and differences in the external features of the face. In more severe cases, the underdevelopment of the jaw can lead to breathing issues.

Ear differences can occur in the inner and/or outer ear and cause hearing loss in some people. Individuals can also have skin tags, a cleft lip and/or palate, differences in their eyes, and facial palsy, which is a condition that makes it difficult or not possible to move certain muscles in the face.

In more rare cases, a person can have changes in their spine (vertebrae), kidneys, and heart, but these are not common.

are there other names for this condition?

Craniofacial microsomia has many other names including:

- hemifacial microsomia (HFM)
- oculo-auriculo-vertebral syndrome (OAVS)
- facio-auriculo-vertebral syndrome
- otomandibular dysostosis
- first and second branchial arch syndrome
- goldenhar syndrome

what causes craniofacial microsomia?

the cause for craniofacial microsomia is not well understood. Usually it is something that just happens and it is not passed from one family member to another (inherited). Researchers agree genetic changes are likely contributing to the reason someone has CFM, but in most cases, a single gene or genetic test cannot determine the cause for CFM. The risk for someone with CFM to have a child of their own with CFM is estimated to be 2-3%.

what treatment is available for craniofacial microsomia?

the treatment of CFM depends on the features affected and your child's age. It is recommended to work with a multidisciplinary craniofacial team when possible. In infancy, if the jaw is small, surgery may be necessary to improve the position of the airway with a procedure called distraction. Distraction surgery slowly repositions the jaw and pulls it forward. Additional jaw surgeries may be required when children are older, often in teenage years after their bones are done growing.

Some infants may also require specialized bottles or feeding techniques. This is common in infants who have a cleft lip and/or palate. *For more information about management and care for cleft lip and palate, see our Cleft Lip and Palate (CLP) booklet.*

All babies have a hearing test at birth. If your child does not pass this test, they will see an audiologist and/or an otolaryngologist who may recommend treatments such as hearing aids, hearing devices like a BAHA, or a cochlear implant. A person with CFM may have differences in how their ear appears externally but have normal hearing. Other people can have no external differences of their ear, but still have hearing loss.

CCA encourages families to research teams on the list of approved teams maintained by American Cleft-Palate Craniofacial Association (ACPA), found at: <https://acpacares.org/find-a-care-team> .

what other concerns might we expect and how will they be treated?

Other types of surgeries and procedures may be recommended throughout childhood and teenage years. These include removal of skin tags, surgery to reposition facial bones, and procedures to improve the movement of the facial muscles. Some patients will need orthodontics to improve teeth alignment and will benefit from speech and language therapy. Children can also have obstructive sleep apnea (OSA) which is diagnosed with a sleep test. Surgeries like removal of tonsils and adenoids, specialized orthodontic devices, or sleeping devices are often necessary to treat OSA. For individuals with external ear differences or an absent ear (microtia), reconstructive surgery may be discussed or a prosthetic ear can be used.

If your child has an epibulbar dermoid cyst (a noncancerous growth on the surface of the eye), they can see an ophthalmologist to monitor it. These typically do not affect vision and often do not need to be removed. Your child will also follow with an eye doctor if their eye is smaller than expected or it is not positioned as expected on the face.

Your child may also have x-rays of their spine, ultrasound of their kidneys, and an echocardiogram (ultrasound of the heart).

how do I talk to my child about surgery?

As your child matures, you will want to bring them into the conversation. Your care team will likely have recommendations on how to do this, but if they do not, we advise you to be proactive. Many kids are developmentally ready to start participating (in a limited capacity) in care decisions as early as 7 years old. Again, this is a staged process, but important to start early and prepare long in advance for the transition to adult care. *(Please refer to our “Educational Overviews” for more information about helping you and your child prepare for surgery.)*

mental health

Children and adults may face mental health struggles when living with a facial difference. CCA advocates that parents try a multifaceted approach to creating mental resiliency, including counseling/therapy, social support groups/networking, and encouraging self-care for the entire family.



children's craniofacial association

to support and inspire individuals and families affected by facial differences

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