

# Craniofacial Microsomia

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Children with craniofacial microsomia (CFM) have a small or underdeveloped part of the face, usually the ear and jaw. The eye, cheek and neck may also be affected, as well as heart, spine and kidneys.

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## What is craniofacial microsomia?

Craniofacial (crane-ee-oh-fay-shul) refers to the skull (cranium) and face. Microsomia (mike-roe-so-mia) means extra small body structures. Children with craniofacial microsomia (CFM) have a small or underdeveloped part of their face. Most often this is the ear and jaw. The eye, cheek and neck may also be affected. CFM can happen on one side or both sides of the face.

CFM is the second most common facial condition after cleft lip and palate. Other names for CFM include:

- Hemifacial microsomia
  - First and second branchial arch syndrome
  - Otomandibular dysostosis
  - Oculo-auriculo-vertebral sequence
  - Facio-auriculo-vertebral syndrome
  - Goldenhar syndrome
  - Lateral facial dysplasia
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## What are the features of craniofacial microsomia?

Some children have only a slightly smaller jaw with a raised piece of skin (skin tag) in front of their ear. Others have one side of their face looking much smaller than the other. And some children can have a very small, abnormally shaped ear. Some of the features that are often seen in CFM include:

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### Ears

- Underdeveloped ear (called microtia)
  - No ear canal (called aural atresia)
  - Hearing loss
  - Tags of skin in front of the ear or on the face (called preauricular or facial tags)
  - Other ear differences
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### Face

- Difficulty moving face muscles (called facial palsy)
  - Small cheekbones
  - A pinkish-white growth on the eye (called epibulbar dermoid)
  - A cleft or opening along the corner of the mouth (called macrostomia or a lateral oral cleft)
  - Cleft lip and/or palate
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### To Learn More

- Craniofacial Clinic  
206-987-2528
- Ask your child's healthcare provider
- [seattlechildrens.org](http://seattlechildrens.org)

### Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

### Jaw

- Limited opening of the mouth
- Shorter or crooked lower jaw
- Teeth do not fit together well (called malocclusion)
- Difficulty making certain sounds with speech

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### Are there other parts of the body that can be affected?

Sometimes children with CFM have other parts of their body affected.

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### Kidneys

Some children with CFM will also have kidney problems. We suggest that your child have an ultrasound to check the shape of their kidneys. This test is easy and takes about 20 minutes.

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### Spine

A small number of children with CFM will have differences in the way the bones of the upper spine (called “cervical spine”) and lower (“thoracic spine”) fit together. We will get X-rays of your child’s cervical spine when these bones are well formed. This is at about 3 years of age. If there are abnormalities on the X-ray, we will refer your child to a bone (orthopedic) doctor. We will also watch your child’s spine to make sure that it is straight.

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### Heart

It is rare for children with CFM to have problems with their hearts. If there are concerns about your child’s heart, the doctor may suggest that your child have an ultrasound of the heart (echocardiogram) to check for problems.

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### What causes CFM?

We don’t know why children are born with CFM. We know that something affects the development of the face during early pregnancy (around the fifth to sixth week). We do not think that CFM is caused by anything that the mother did or did not do during the pregnancy.

For most children, CFM is not inherited and will not be passed on from a parent to a child. Once two parents have had a child with CFM, the chance that they will have another child with CFM is slightly higher (about 2 to 3 percent).

In rare cases, there are families that have an even higher chance of having another child with CFM. For children who have relatives with similar facial differences, we suggest you talk to a genetics doctor and genetic counselor. They will talk about the chances of having another child with similar problems.

### How is CFM treated?

Our craniofacial team has experience treating children with CFM and will help you and your child through the stages of treatment. As your child grows, different types of specialists will be involved in their care. Our team will work together to create a plan that will include medical tests and possibly surgery.

A craniofacial pediatrician and nurse will work closely with you to help coordinate your child's care and answer all your questions. Your child's treatment plan will be based on their needs. The following team members may also be involved in your child's care:

- Hearing specialist (audiologist)
- Dietitian
- Genetic counselor
- Geneticist (specializes in possible genetic or inherited causes of conditions)
- Eye doctor (ophthalmologist)
- Surgeon specializing in the mouth and jaw (oral and maxillofacial surgeon or plastic and reconstructive surgeon)
- Orthodontist (dental professional who prevents or corrects misaligned teeth and jaws)
- Ear, nose and throat doctor or ENT (otolaryngologist/head and neck surgeon)
- Pediatric dentist
- Plastic and reconstructive surgeon
- Psychologist, social worker
- Speech pathologist

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### What are treatment goals?

The goals of treatment for CFM are to maximize hearing, speech, eating, nutrition and breathing. We also want to help the jaws and teeth fit together. There are treatments that can improve how well the face is balanced (called facial symmetry). Treatment depends on your child's age and how much your child is impacted.

As your child grows, their face grows, too. Timing the treatment carefully is important to getting the best results.

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### What other medical issues might my child have?

The following is a list of medical issues that your child may have. Not every child with CFM will have problems in each of these areas.

### Feeding and breathing

Babies with CFM may have a small jaw or a cleft palate. Some babies may have trouble with breast-feeding and bottle-feeding, so we check to be sure your baby is feeding well and gaining weight. If breathing is a problem, your doctors will discuss how to improve it. Some babies will need positioning devices to help with breathing during sleep, tubes or jaw advancement surgery to help them breathe well. In some cases, a breathing tube placed in the windpipe is needed. This is called a tracheostomy. We will continue to assess breathing as children get older and make sure that your child is breathing well during sleep.

### Jaw and teeth

Taking care of your child's teeth is extra important for children with CFM. A dentist or orthodontist will check your child to assess their dental health, to see if there is crowding of the teeth, and to check how well their upper and lower jaws fit together. Some children with CFM have teeth missing, and we will discuss treatment for this with you. Some children may need a dental appliance or braces to provide the best dental appearance and function.

If your child has a small jawbone, your doctor may recommend using an extra piece of bone (bone graft) to lengthen the jaw or make a new jaw joint. We typically first consider this option when your child is between the ages of 4 to 7 years. In some cases, your surgeon may recommend using a technique called distraction osteogenesis to lengthen the jawbone. This technique uses a small metal device to slowly lengthen the bone.

When facial and jaw growth is nearly complete (age 13 to 16 years), most children with CFM will need orthodontics. Many will also benefit from surgery to reposition the jaw (orthognathic surgery).

### Hearing

All newborns should have their hearing checked at the birth hospital or within a few days of birth. If we find problems, we will do more testing. A hearing specialist (audiologist) will do different hearing tests as your child grows.

Hearing loss can be related to an absent ear canal (aural atresia) and we may suggest hearing aids. Sometimes, the bones of the middle ear are poorly formed or not present at all. Sometimes, these bones are nearly normal.

At about 5 years of age, when growth of the ear is nearly complete, your child may need a CT scan (computerized tomography) to look at the middle and inner ear structures. CT scans are used to find out whether surgery to restore hearing will be helpful.

Our ear, nose and throat doctor (otolaryngologist) and hearing specialist will talk with you and your child about hearing issues. This includes items such as the best place for your child to sit in the school classroom, whether hearing aids are needed and how to prevent further hearing loss.

### Eyes

We will refer your baby to the eye doctor (ophthalmologist) if they have a pinkish-white growth on the eye (epibulbar dermoid). The eye doctor will check that the growth is not interfering with your child's vision. They may surgically remove the growth if they are large or getting in the way of vision. For children who have differences in the eyelids, difficulty closing the lids, or difficulty with vision, we recommend a visit with the eye doctor.

### Face

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#### Skin tags

Skin tags are small pieces of extra tissue on the face. They are painless. If your child has skin tags, talk to your child's doctor to see if they recommend removal.

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#### Clefts of the lip, palate or mouth

For babies who have a cleft lip, we often repair it using surgery around 6 months of age. If your child also has a cleft palate, we often repair it at about 1 year of age. We usually do surgery for clefts of the side of the mouth (lateral oral clefts) when babies are 6 to 12 months.

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#### Soft Tissue

Some patients may have less soft tissue on one or both sides of their face. This can be treated with fat injections. The fat is taken from the abdomen or thighs and is injected into the areas of the face that need more fullness.

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### Facial Reanimation

[seattlechildrens.org/clinics/craniofacial/services/facial-reanimation](https://seattlechildrens.org/clinics/craniofacial/services/facial-reanimation)

Facial reanimation procedures help children move their face or make more even movements on both sides of their face. The nerve that controls the face muscles is called the "facial nerve." If the facial nerve does not work properly, it will affect your child's ability to move the muscles in their face. This is sometimes called "facial palsy." Surgery can involve helping the patient achieve eyelid closure or "smile surgery" to improve their ability to smile symmetrically.

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### Ears

There are many options for treating abnormally shaped ears. We will discuss these with you and your child. Some families choose to do nothing; others choose to have surgery. For more information read our handouts "Microtia" [seattlechildrens.org/pdf/PE752.pdf](https://seattlechildrens.org/pdf/PE752.pdf) and "Treatment Options for Microtia" [seattlechildrens.org/pdf/PE2362.pdf](https://seattlechildrens.org/pdf/PE2362.pdf).

For children who would like surgical reconstruction, this includes (1) creating an ear using your child's rib cartilage or (2) surgery using a pre-made synthetic ear framework. Your doctor can show you pictures of other children who have had ear reconstruction. The ear looks different after the surgeries, but it will not look completely normal (e.g. like the other ear).

Another way of treating an abnormally shaped ear is to make an artificial or prosthetic ear. It is an option for making an ear that matches the other ear. This is done with several surgeries. Although prosthetic ears look normal, they need to be removed and cleaned once a day.

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### Speech

Some children with CFM have differences in the muscles in the back of their mouth. This can affect the way they speak (called velopharyngeal insufficiency or VPI). If you or your doctors have concerns about your child's speech, the speech pathologist will check your child.

### **Family and social support**

Our team is sensitive to the emotional and social issues of you and your child. Our social workers and psychologists will help you access community resources and provide you support and guidance. They can help when making decisions about surgery and support you as you adjust to having a child with a facial difference. A social worker may also talk with your child about how their craniofacial condition impacts their life.

Our child life specialists work with children as they prepare for surgery and being in the hospital. They use special techniques with children of all ages to reduce stress and help them learn about their condition and treatment.

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