

a guide to understanding
**moebius
syndrome**

a publication of children's craniofacial association

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This parent's guide to Moebius syndrome is designed to answer questions that are frequently asked by parents of a child with Moebius syndrome. 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 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.

The information provided here was written by Richard J. Redett, MD, FACS, FAAP

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 moebius syndrome?

moebius syndrome is a rare congenital (present at birth) developmental disorder, characterized by absence or underdevelopment of the nerves that control facial (cranial nerve 7) and eye movements (cranial nerve 6). Most people with Moebius syndrome have weakness or complete paralysis of the facial muscles. Children and adults with facial paralysis may be unable to smile, frown, raise their eyebrows, close their eyelids or pucker their lips. This not only results in lack of facial expression but may also result in drooling and difficulty with speech. Infants can have difficulty with sucking and swallowing. Other features of Moebius syndrome can include:

- Motor delays due to upper body weakness
- Strabismus (crossed eyes)
- Dry eyes and irritability
- Dental problems
- High palate
- Cleft palate
- Hand and feet problems including club foot and missing or fused fingers (syndactyly)
- Hearing problems
- Poland's syndrome (chest wall and upper limb anomalies)

Although they crawl and walk later, most children with Moebius syndrome eventually catch up. Speech problems often respond to therapy, but may persist due to impaired mobility of the tongue and lips. As children get older, the lack of facial expression and an inability to smile become the dominant visible symptoms. As a result, people who are unfamiliar with your child may misinterpret what your child is thinking or feeling.

what causes moebius syndrome?

although it appears to be genetic, its precise cause remains unknown and the medical literature presents conflicting theories. It affects boys and girls equally, and there appears to be, in some cases, an increased risk of transmitting the disorder from an affected parent to a child. Although no prenatal test for Moebius syndrome is currently available, individuals may benefit from genetic counseling.

are there other names for this condition?

moebius syndrome is a type of congenital facial paralysis or palsy. Not all children born with facial paralysis have Moebius syndrome. There are other causes of congenital facial paralysis including birth trauma. Moebius syndrome is always present at birth and is usually bilateral (involves both sides of the face). Other types of congenital facial paralysis usually involve only one side of the face.

what other problems might occur?

Speech and Feeding Problems

Cranial nerves 5, 9, 10 and 12 can also be affected in Moebius syndrome. These are the nerves that control the muscles of the jaw, tongue, throat and larynx and help produce speech. Abnormalities of these nerves and muscles may lead to articulation, voice and resonance problems. An experienced speech pathologist and otolaryngologist (ear nose and throat specialist) can help with your child's voice problems.

Many of the nerves and muscles that produce speech are also responsible for chewing and swallowing. Children with Moebius syndrome may have difficulty sucking soon after birth. Infants with swallowing problems may aspirate (inhale) small amounts of food or liquid. Frequent aspiration can lead to pneumonia. Most of the feeding problems seen in Moebius syndrome improve as the child develops improved motor control of the muscles responsible for swallowing. Some children may require a feeding tube placed through the nose or stomach to improve nutrition if the feeding problems are severe.

Dental Problems

Because of the tongue movement abnormalities seen in Moebius syndrome, food may accumulate behind the teeth and cause decay. Careful dental hygiene with frequent tooth brushing and flossing will help prevent the build up of food and protect the teeth and gums. If your child has a cleft palate in addition to Moebius syndrome, they may require orthodontics to align the teeth and jaws when he/she is an adolescent.

Hearing Loss

As hearing problems can be present in children with Moebius syndrome, it is important to have your child's hearing tested early in life. If your child has a cleft palate in addition to Moebius syndrome he/she may experience frequent ear infections (otitis media), which, if untreated, can contribute to hearing loss. Pressure equalizing tubes may be placed in the ear drums to reduce the risk of hearing loss.

Intellectual Development

Most persons with Moebius syndrome have normal intelligence. A small percentage of people with Moebius syndrome have mental retardation.

Cleft Palate

Some children with Moebius syndrome are born with a cleft palate. A cleft palate is an opening in the hard or soft portion of the roof of the mouth. The opening should be surgically closed at around 10 to 12 months of age. A cleft palate decreases an infant's ability to suck which can contribute to early feeding problems. In addition, the opening in the roof of the mouth allows for the passage of food and liquid out of the nose. Fortunately, cleft-related feeding problems usually improve soon after birth with proper positioning during feeding and the use of special nipples. A feeding specialist can help teach you how to feed your child.

how is moebius syndrome treated?

a multidisciplinary team approach through a Craniofacial Center is often the most effective way to treat Moebius syndrome. Specialists, including neurologists, ophthalmologists, plastic surgeons, otolaryngologists (ear, nose and throat specialists) and speech pathologists familiar with Moebius syndrome may be required for your child's medical care.

Infants sometimes require special bottles (i.e., Haberman Feeder) or feeding tubes to maintain sufficient nutrition. Strabismus (crossed eyes) is usually correctable with surgery. Children with Moebius syndrome can also benefit from physical and speech therapy to improve their gross motor skills and coordination, and to gain better control over speaking and eating.

Limb and jaw deformities may often be improved through surgery. In addition, reconstructive surgery of the face can offer benefits in individual cases. In some cases, nerve and muscle transfers to the corners of the mouth have been performed to provide the ability to smile.



children's craniofacial association

13140 Coit Road, Suite 517 • Dallas, TX 75240

VOICE 214-570-9099
FAX 214-570-8811
TOLL-FREE 800-535-3643

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