



MOEBIUS
SYNDROME FOUNDATION

A GUIDE FOR EDUCATORS

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This booklet is designed to help educators and school staff better understand what Moebius syndrome is, and how to best help a student with Moebius syndrome have a successful academic year.



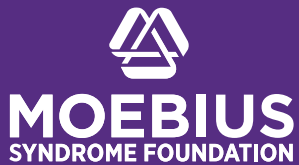
DEAR EDUCATOR,

_____ (name of child) has **Moebius syndrome** (pronounced “mo-bee-us”). It’s a very rare, non-progressive condition that is present at birth in an estimated 1 in 100,000 children. It affects facial movement and some gross-motor functions. The main feature of Moebius syndrome is almost-complete facial paralysis. People with Moebius syndrome cannot blink or squint, or move their eyes left to right. This is challenging in terms of peripheral vision. They cannot frown, and many cannot close their mouth fully, or smile, like you and I. This is very challenging at mealtimes since they cannot close their mouth even to eat. It is also challenging when pictures are taken and the photographer asks them to “smile.”

Moebius syndrome is not progressive, but new challenges arise with age and new social situations. In our experience, some children (and even adults) stare at _____ (name of child), and some avoid him/her. This can be upsetting. We recommend telling kids that it is not okay to stare, rather encourage them to say “hi!”

Common presumptions for people with Moebius syndrome include intellectual disability, not happy, staring etc. Things we read in others’ faces and take for granted. If you have further questions, the parent of _____ (name of child) can answer them or reach out to the Moebius Syndrome Foundation via the contact information found on the back of this brochure.

Other than the symptoms of Moebius syndrome, _____ (name of child) is a “typical” ____ year old. He/She wants to have friends, join in with peers and learn new things each day.



moebius syndrome.org



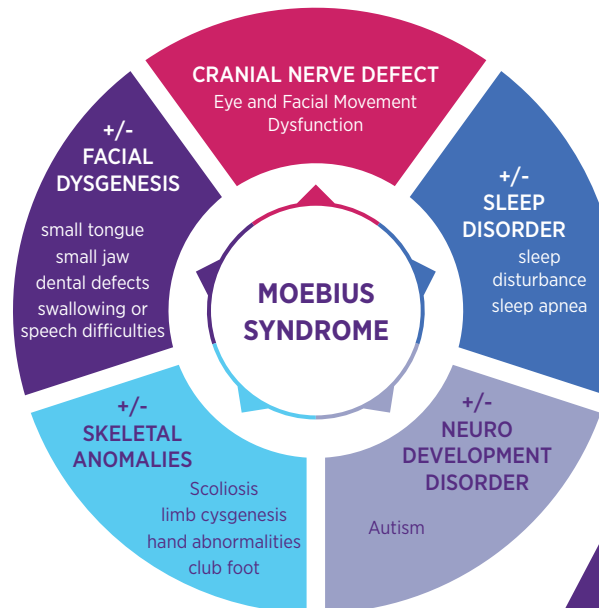
WHAT IS MOEBIUS SYNDROME?

Moebius syndrome is a **rare congenital (present at birth) condition** that results from underdevelopment of the facial nerves that control some of the eye movements and facial expressions. The condition usually affects both sides of the face.

While researchers have not identified the cause(s) of Moebius syndrome, studies suggest a combination of genetic and environmental risk factors.

Treating Moebius syndrome may require a team of doctors to address symptoms, including:

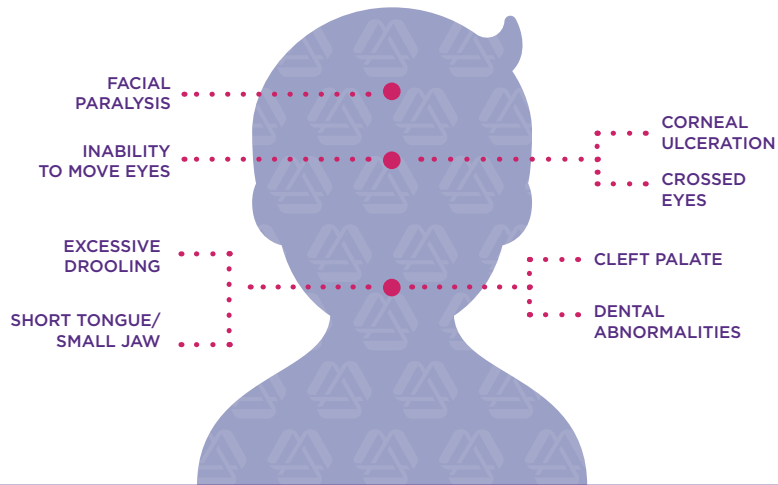
- Other cranial nerve involvement
- Strabismus (misalignment of the eyes)
- Hearing loss
- Club foot
- Limb reduction deficits
- Other limb anomalies
- Poland anomaly
- Muscular hypotonia
- Congenital heart disease
- Developmental delay/intellectual disability
- Autism
- Cleft palate



Does not include all symptoms that occur with Moebius syndrome.



COMMON FACIAL SYMPTOMS



- 1 Facial paralysis or weakness affecting at least one but usually both sides of the face
- 2 Paralysis of sideways (lateral) movement of the eyes
- 3 Infants with Moebius syndrome may drool excessively
- 4 Exhibit crossed eyes (strabismus). Because the eyes do not move from side-to-side (laterally), the child is forced to turn the head to follow objects.
- 5 Corneal ulceration may occur because the eyelids remain open during sleep.
- 6 Short, malformed tongue and/or an abnormally small jaw (micrognathia).

- 7 Cleft palate may also be present. These abnormalities contribute to feeding and breathing difficulties. Children with cleft palate are prone to ear infections (otitis media). There may be external ear anomalies including underdevelopment of the outer portion of the ear (microtia) or total absence of the outer portion of the ear (anotia). If the 8th cranial nerve is affected, there is likely hearing loss.
- 8 Dental abnormalities are not uncommon. There is an increased risk for childhood cavities. Some affected children have difficulties with speech and delays in speech development.

My child experiences the following symptoms in the cranial area:

Number(s) _____

Notes: _____

COMMON FULL BODY SYMPTOMS

My child experiences the following full body symptoms:

Number(s) _____

Notes: _____

- 1 Skeletal malformations of the limbs occur in over half of children with Moebius syndrome.
- 2 Lower limb malformations include clubbed feet and underdevelopment of the lower legs; upper extremities may have webbing of the fingers (syndactyly), underdevelopment or absence of the fingers, and/or underdevelopment of the hand.
- 3 In a few children there may be abnormal side-to-side curvature of the spine (scoliosis)
- 4 In approximately 15% of patients underdevelopment of the chest (pectoral) muscles and the breast on one side of the body also occur (see Poland-Moebius syndrome in the Related Disorder section below).
- 5 Moebius syndrome rarely is associated with minor intellectual disability. Some children have been classified as being on the “autistic spectrum”.
- 6 Moebius syndrome is often associated with a variety of social and psychological consequences. The lack of facial expressions and the inability to smile can cause observers to misinterpret what an affected individual is thinking or feeling or intends. Although clinical anxiety and depression are not more common in children and adolescents with Moebius syndrome, affected individuals may avoid social situations due to apprehension and frustration.



SUCCESS PLAN

The following will best help my child in school this year:

- | | |
|---|---|
| <input type="checkbox"/> Create an IEP/504 Plan | <input type="checkbox"/> Additional teacher's aide or support from a Special Education department |
| <input type="checkbox"/> Preferential seating | <input type="checkbox"/> Buddy system: my child would benefit from being partnered with a like-minded student |
| <input type="checkbox"/> Sit close to teacher, or | |
| <input type="checkbox"/> Sit at front of classroom | |
| <input type="checkbox"/> Hearing accommodation | <input type="checkbox"/> Calm down strategies, frustration tolerances |
| <input type="checkbox"/> Help with attention span | |
| <input type="checkbox"/> My child benefits from a fidget tool, and/or | |
| <input type="checkbox"/> Stretching and standing breaks | |

Additionally, _____
(name of child)

BULLYING AND MENTAL HEALTH: RESOURCES TO HELP ADDRESS AND PREVENT BULLYING IN SCHOOLS

The Wonder Project:

myFace, a non-profit dedicated to transforming the lives of children and adults with facial differences, is engaging schools across the country through the myFace Wonder Project. This impactful program helps students choose kindness through action and intention, and combat the all-too-common issue of bullying.



The Goal: More than ever before, choosing kindness is critical to the wellbeing of our children and the health of our communities. As parents, caregivers, and educators, it is up to us to promote empathy and kindness and to teach acceptance for those with differences. Our goal is to ensure that students are inspired to always choose kindness.

How it works:

- myFace speakers present a virtual or in-person assembly that encourages acceptance and kindness through their real-life stories from people with facial differences.
- Each student takes the Upstander pledge, choosing to speak up for others.
- Teachers are provided with lesson plans, morning announcements, and activity sheets that help students to identify acts of kindness to launch on their own.

To learn more about the work at myFace check out myFace.org/wonder or contact Dina Zuckerberg at dina@myface.org.

Other resources that support educators for bullying and mentorship:

Kid Power
www.kidpower.org



Children's Craniofacial Association
www.ccakids.org





info@moebiussyndrome.org
moebiussyndrome.org

