

What Is Moebius Syndrome?

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Many Faces of Moebius Syndrome (MFOMS) has announced the 15th anniversary of Moebius Syndrome Awareness Day (MSAD), set for January 24, 2026. Since its inception in 2011, MSAD has united individuals, families, and communities across the world to raise awareness, reduce stigma, and celebrate the voices of people with Moebius syndrome.

I have enjoyed practicing general dentistry in San Antonio for over 44 years. SADDS has always been there to help in each phase as I attempted to offer care for my patients. Out of gratitude and the desire to hopefully expand someone's knowledge, I would like to present information I think you may find interesting about this rare disorder called Moebius Syndrome.

There are some unique dental, orthodontic and sleep issues related to the syndrome. Learning about this disorder may help you with caring for the general population. I would dare say my learning about

Moebius Syndrome helped shape my career towards Dental Sleep Medicine many years ago.

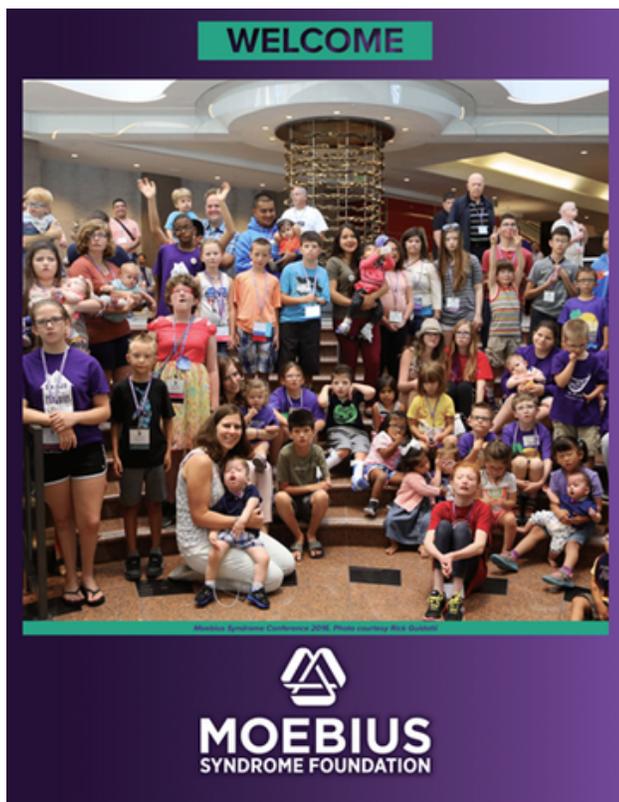
In 1993, my youngest of three daughters was born with Moebius Syndrome. The next year Moebius Syndrome Foundation was founded, and the first conference was held in Los Angeles. My family and I have attended several of these conferences since the first one. As the only dentist/father of a Moebius child at the conferences, I was often asked dental questions by those attending.

I eventually was asked to do presentations specific to dental concerns unique to Moebius. I summarized all this for the Foundation website a long time ago, with updates every few years.

You can read my summary by going to the link at the end of this article "A Message from a Dentist and a Moebius Dad". Please feel free to help me update/ improve the summary so other families can

benefit in the future. This past summer I was asked to present some of the dental and sleep concerns in Salt Lake City at the 30th Anniversary Moebius Conference. I was able to screen several participants for obstructive sleep apnea.

Part of my motivation in presenting this to my dental colleagues is to familiarize you with this rare congenital disorder, known primarily for the inability of a person to smile!



What Is Moebius Syndrome?

As a very simple explanation, Moebius syndrome is a form of facial paralysis combined with outward, to the side, eye paralysis.

Individuals with Moebius syndrome typically cannot make facial expressions, such as smiling, frowning, squinting, or blinking. Speech, eating, and lip movement may also be affected.

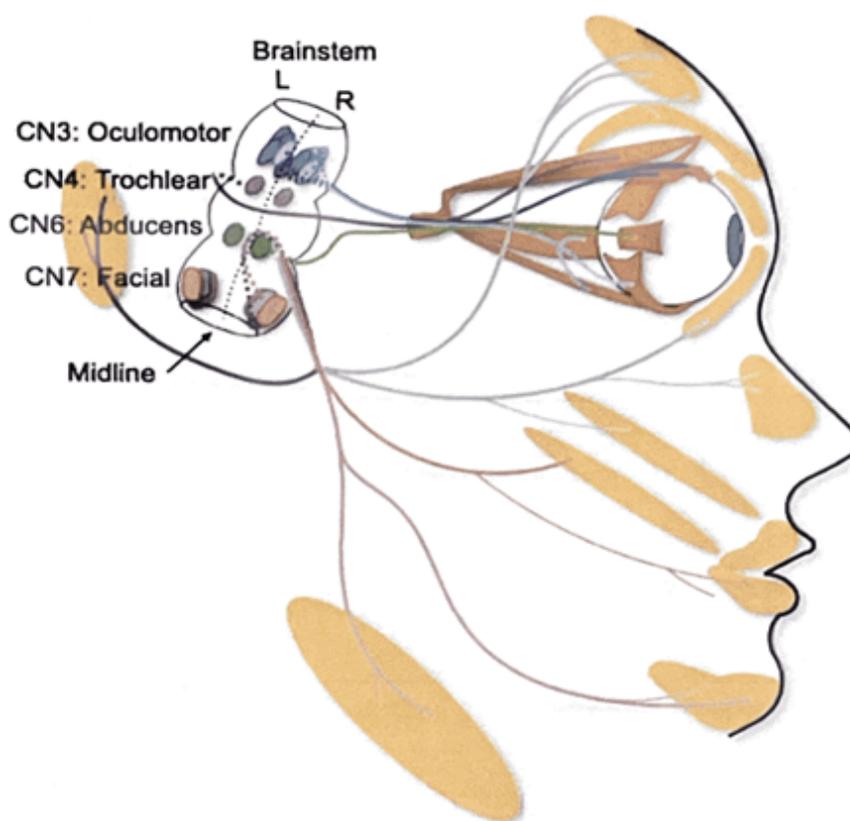
People with Moebius syndrome also cannot move their eyes out to the side, as you would if you were looking over your shoulder without turning your head. The syndrome has a wide range of presentations and may occur on one or both sides of the face.

Moebius syndrome is a congenital, non-progressive facial weakness with limited outward horizontal movement of one or both eyes.

Congenital facial weakness and the inability to abduct (move the eye away from the nose) in one or both eyes, must be present for a diagnosis of Moebius syndrome. These two symptoms may be due to the underdevelopment or absence of the facial nerve (cranial nerve 7) and the abducens nerve (cranial nerve 6), respectively.

Facial weakness caused by Moebius syndrome may present on one (unilateral) or both (bilateral) sides of the face.

Moebius syndrome may affect other cranial nerves (typically the lower ones, such as nerves 9, 11, and 12) in addition to nerves 6 and 7.



Lateral view of human brainstem and face highlighting a subset of cranial motor nuclei and nerves. Eye and face movements are accomplished through four of our twelve cranial nerves (CN). Oculomotor (CN3), trochlear (CN4) and abducens (CN6) innervate the extraocular muscles while facial (CN7) innervates the facial muscles.

Additional Clinical Presentations

Moebius syndrome may occur with other clinical symptoms, including:

- Strabismus (cross-eyes or misalignment of the eyes), which may develop over time and not be present at birth
- Hearing loss
- Club foot
- Limb differences (hand, foot, or other limb anomalies)
- Muscular hypotonia (low muscle tone)
- Congenital heart disease
- Developmental delays (delayed timing to reach milestones such as independent sitting, walking, and/or speech)
- Autism
- Dental concerns
- Sleep disorders
- Poland syndrome (an underdeveloped chest wall muscle, webbed fingers, and a small hand)

In most cases of Moebius syndrome, cognitive development is typical.

When intellectual disability is present, affected persons tend to have additional clinical features such as congenital heart disease, cleft palate, and other systemic

(body-wide) involvement and symptoms.



My pretty daughter Caitlin, ready for Fiesta, is in the middle picture.

What is the cause of Moebius syndrome?

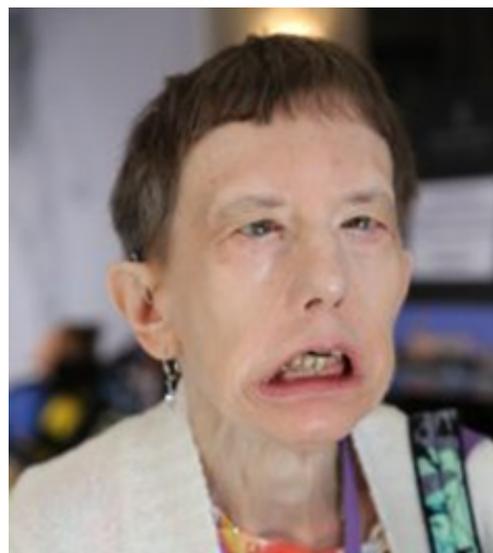
The cause of Moebius syndrome is not well understood. Genetic research into the condition has not shown a clear genetic pattern.

There is no family history of Moebius syndrome, and it occurs sporadically. There are some conditions with overlapping features to Moebius syndrome that may run in families, but in studies supported by the Moebius Syndrome Foundation, no individuals with classic Moebius syndrome have more than one affected family member in their families.



How often does Moebius syndrome occur?

The estimated incidence of Moebius syndrome is roughly 2 to 20 cases per 1 million births. Moebius syndrome occurs equally in all populations. The condition occurs in all ethnicities. There is no gender bias; males and females are affected equally.





Common dental issues include:

1. Malocclusion: Class II malocclusion (overbite) due to a small or recessed lower jaw (micrognathia or retrognathia). Open bite or crossbite caused by abnormal growth of the jaws or improper alignment. Misalignment can lead to difficulties with chewing, speaking, and maintaining oral hygiene.

2. High-Arched or Cleft Palate: A high-arched palate or Cleft palate (common in Moebius syndrome) can affect the positioning of teeth and make oral hygiene challenging. Palatal abnormalities may also complicate orthodontic or prosthodontic treatments.

3. Delayed Eruption of Teeth: Teeth may erupt later than normal, which can delay the development of proper dental alignment.

4. Poor Oral Hygiene: Facial paralysis and limited tongue mobility can impair the ability to clear food debris naturally, increasing the risk of caries and gingivitis/ periodontitis. Reduced muscle control may make brushing and flossing more difficult.

5. Enamel Hypoplasia: Some individuals may experience defects in enamel development, leading to weaker teeth that are more prone to decay.

6. Bruxism: Jaw misalignment, stress, and sleep breathing disorders may contribute to bruxism, which can wear down teeth and cause jaw discomfort.

7. Xerostomia: Impaired salivary gland function or medications may lead to dry mouth, increasing the risk of cavities and gum disease.

8. Dental Trauma: Limited facial muscle function may reduce protective reflexes, making the teeth more vulnerable to injury.

9. Orthodontic Challenges: Facial paralysis, jaw abnormalities, and tongue dysfunction can complicate traditional orthodontic treatments, requiring customized approaches

Management and Preventive Care

1. **Regular Dental Visits**: Frequent check-ups to monitor dental health and address issues early.

2. **Improved Oral Hygiene Techniques**: Adaptive tools, such as electric toothbrushes and water flossers, can help overcome difficulties with manual dexterity or muscle control.

3. **Fluoride Treatments**: Use of fluoride toothpaste or professional fluoride treatments to strengthen enamel and prevent decay.

4. **Orthodontic Care**: Early orthodontic evaluation (often by age 7) to plan for corrective measures like braces or palate expanders. Customized treatment to accommodate facial and jaw abnormalities.

5. **Prosthodontics**: Replacement of missing teeth or correction of functional issues using dental prostheses, when needed.

6. **Speech and Feeding Therapy**: Collaboration with therapists to address functional issues related to oral health.

7. **Preventive Measures**: Diet modifications to reduce sugar intake and protect against cavities. Use of mouthguards to prevent trauma or manage bruxism.

8. **Multidisciplinary Care**: Collaboration between dentists, orthodontists, maxillofacial surgeons, and speech therapists ensures comprehensive management of dental and oral health challenges.



This picture of Caitlin's mouth shows how form follows dysfunction.

She cannot close her mouth, swallow, or form a suction. Her tongue presses the lower arch teeth facially creating spacing. The upper arch does not have the pressure from the tongue to shape it, so the arch collapses and the teeth crowd up.

Caitlin has the more severe form of Moebius Syndrome. She cannot walk, talk, or blink her eyes. She has a tracheostomy tube for breathing and a gastrostomy tube for feeding. Yet she is a happy girl. She can get around home in her power chair with a joystick.

She loves to go outside. She has never had a cavity! Individuals with Moebius Syndrome keep adapting.

At age 30 she started communicating with us with an eye gaze communication device for the first time.

General Sleep Information:

Sleep Development: Sleep evolves in duration, continuity, and day/night cycles. Newborns sleep 16-20 hours/day, while 6-12-year-olds sleep 10-11 hours/night.

Sleep Disorders: Includes insomnia, sleep apnea, narcolepsy, parasomnias, and REM behavior disorders.

Insomnia is common in children with Autism Spectrum Disorder (ASD), while obstructive sleep apnea (OSA) and narcolepsy are linked to structural brainstem changes in Moebius syndrome.

Sleep Disorders Insomnia: Persistent sleep issues despite adequate opportunity, often seen in children with ASD. Parasomnias: Includes sleepwalking, sleep terrors, and nightmares, triggered by sleep deprivation, illness, or medications.

Narcolepsy: Characterized by excessive daytime sleepiness, fragmented nighttime sleep, and REM intrusion into wakefulness. Cataplexy is a distinctive feature.

Sleep in Moebius Syndrome: Associated with multiple sleep disorders, including parasomnias, sleep apnea, and narcolepsy. Structural brainstem abnormalities may contribute to these issues.

Diagnosis: Includes sleep-focused history, physical exams, questionnaires, and polysomnography.

Treatment: Behavioral modifications, melatonin, addressing medical issues including sleep apnea.

Promoting Good Sleep: Regular bedtime routines, consistent schedules, limiting caffeine, keeping electronics out of the bedroom, and creating an optimal sleep environment (quiet, dark, cool, comfortable).

Research Needs: More studies on sleep problems in Moebius syndrome, potentially through surveys in support groups.

Increased risk for Obstructive Sleep Apnea (OSA)

1. Craniofacial Abnormalities: Many individuals with Moebius syndrome have structural abnormalities in the face, jaw, and palate, such as a small or recessed jaw (micrognathia or retrognathia), which can narrow the airway. High arched or cleft palates, often seen in this population, may further contribute to airway obstruction during sleep.

2. Weak or Impaired Facial and Pharyngeal Muscles: Moebius syndrome is characterized by paralysis or weakness of the cranial nerves, which can affect the muscles responsible for maintaining airway patency. Weaknesses in the tongue or pharyngeal muscles may increase the likelihood of airway collapse during sleep.

Treatment Options for OSA in People with Moebius Syndrome

1. Continuous Positive Airway Pressure (CPAP):

CPAP is a first-line treatment for severe OSA and helps keep the airway open during sleep. It can be effective, but adherence may be challenging due to discomfort or facial structural differences. Mask customization may be required for individuals with unique facial anatomy.

2. Surgical Interventions:

Adenotonsillectomy: If enlarged tonsils or adenoids are contributing to airway obstruction, their removal may help.

Maxillomandibular Advancement: This can increase airway space by repositioning the jaw.

Tracheostomy: In severe cases where other treatments fail, a tracheostomy may provide a reliable airway.

An implantable device: Stimulates the hypoglossal nerve, which controls the muscles that keep the airway open during sleep.

3. Oral Appliances: Mandibular advancement devices (MADs) can reposition the lower jaw and tongue to reduce airway obstruction for some cases.

4. Weight Management: If obesity contributes to OSA, weight management strategies, including dietary changes and exercise, can be beneficial.

5. Positional Therapy: Encouraging sleeping positions that reduce airway obstruction (e.g., side-sleeping instead of back-sleeping) can help in mild cases.

6. Speech and Swallowing Therapy: While not direct treatment for OSA, addressing related issues like swallowing difficulties can improve overall airway function.

7. Multidisciplinary Approach: A team including sleep specialists, ENT surgeons, orthodontists, and neurologists is often necessary to provide comprehensive care.

Systematic Characterization of Moebius Syndrome:

This study investigates the phenotypic and genetic characteristics of Moebius Syndrome.

- Conducted clinical phenotyping of 149 individuals with Moebius Syndrome.
- All cases were sporadic with no familial recurrence.
- Common co-occurring phenotypes included:
 - Tongue hypoplasia (81.9%)
 - Micrognathia (66.4%)
 - Congenital talipes equinovarus (42.3%)
 - Intellectual disability (30.9%)
 - Sleep difficulties (22.8%)
- Performed exome and/or genome sequencing on 67 individuals and 117 unaffected family members.
- Identified 173 single-nucleotide variants/indels in 113 genes, but no recurrently mutated genes were found.

Clinical Features and Phenotypic Spectrum

The study outlines the diverse clinical features associated with Moebius Syndrome

- All individuals exhibited congenital, nonprogressive facial weakness and limited ocular abduction.
- Bilateral facial weakness was present in 92.0% of cases.

- Co-occurring neurological issues included:
 - Intellectual disability (30.9%)
 - Autism spectrum disorders (10.1%)
 - Seizures (10.7%)
- Common craniofacial features included:
 - Tongue hypoplasia (81.9%)
 - Abnormal palate (58.4%)
 - Cleft palate/bifid uvula (16.8%)
- Limb anomalies were prevalent, with 42.3% having clubfoot and 31.5% having major limb anomalies.

Genetic Findings and Future Directions

This study concludes with insights into the genetic basis of MBS and future research directions.

- No compelling recurrent variants identified; suggests non-Mendelian origin.
- Future research should focus on somatic genetic changes and environmental factors.
- Emphasizes the need for strict diagnostic criteria in genetic counseling and testing.

A GUIDE FOR HEALTHCARE PROVIDERS:

- <https://moebiussyndrome.org/wp-content/uploads/2023/07/MSF-PhysiciansGuide-Final-1.pdf>

A Message from a Dentist and a Moebius Dad:

<https://moebiussyndrome.org/dental-concerns/>

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The Moebius Syndrome Foundation gratefully acknowledges the contributions of the following members of our Scientific Advisory Board.

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Bryn D. Webb, Julie A. Jurgens, Narisu Narisu⁷, Zhongyang Zhang, et al, Systematic phenotype and genotype characterization of Moebius syndrome, *Genetics in Medicine Open* (2025) 3, 103437

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