

TRIUMPH Over ADVERSITY

**"Moebius Syndrome:
Live Life – No
Restrictions. The
Moebius Syndrome
Conference intro-
duced us to friends
from all walks of life,
and we look forward
to attending the next conference."**

-Selena and her daughter, Emori, Irving, TX



"Having courage is difficult for anyone, but I think it's especially difficult for those of us who may look or feel different and carry the baggage from life with a medical condition. But at the same time, I think having to be strong and deal with a lot of experiences other people do not makes it easier in some ways to have courage in difficult situations and move forward. I think it's a truly mixed bag, but I cannot imagine having learned what I learned about life without being born with Moebius syndrome."

-Natalie, Philadelphia, PA

Questions & Answers About MOEBIUS SYNDROME

What is Moebius syndrome?

People with Moebius syndrome have no facial expression — they can't smile, frown, grimace, blink or move their eyes laterally. Moebius syndrome is a rare congenital neurological condition defined by partial or complete paralysis of the 6th and 7th cranial nerves; any of the other 12 cranial nerves may also be affected. While the inability to show facial expression is physical, there may be social and/or psychological implications, including autism spectrum disorders. Additional conditions may include respiratory problems, speech and swallowing difficulties, dental problems, club feet, visual or hearing impairments, strabismus, sensory integration issues, sleep disorders, and weak upper body strength.

What are the symptoms?

The most apparent symptoms are related to facial expression. In newborn infants, the first sign is often an impaired ability to suck. The inability to blink may cause dryness and irritation of the eyes. Excessive drooling and crossed eyes (strabismus) may be present, as well as deformities of the tongue, jaw, limbs, club feet, missing or webbed fingers or toes and missing hands or feet.

What causes Moebius syndrome?

Moebius syndrome is congenital (present at birth). Its precise cause remains unknown. It affects males and females equally. No prenatal test for Moebius syndrome is currently available. Research is currently being conducted to better understand the causes of Moebius syndrome.

How is it treated?

Infants often require special bottles or feeding tubes due to the inability to suck. Strabismus (crossed eyes) at times can be corrected with surgery. Physical and occupational therapies help improve gross and fine motor skills, coordination and sensory integration issues. Speech and oral motor therapies help with speaking and eating. Limb and jaw deformities and facial expression may be addressed through surgery.

Are health care providers aware of Moebius syndrome?

Because Moebius syndrome is such a rare condition, physicians and health care providers may not be able to provide an immediate diagnosis. It is not uncommon for people with Moebius syndrome to go undiagnosed for some time. The Moebius Syndrome Foundation works to educate professionals and families of those with Moebius syndrome so that treatment can begin as soon as possible.

**More information about
Moebius Syndrome is available at:**



Facebook.com/moebiusyndrome



Twitter.com/moebiusyndrome



Youtube.com/moebiusyndrome



ABOUT THE MOEBIUS SYNDROME FOUNDATION

The Moebius Syndrome Foundation offers information, networking and support to individuals with Moebius syndrome and fosters scientific research into the condition. Conferences are held every two years for adults and children with Moebius syndrome, their families, and professionals. Moebius Syndrome Conferences feature presentations by world renowned physicians and researchers, workshops, and opportunities to interact with the speakers. The conferences also offer an opportunity for people with Moebius syndrome and their families to network and share experiences as well as learn about and participate in new research and therapies. The Moebius Syndrome Foundation Medical Advisory Board consists of leading medical professionals and researchers who focus their work on Moebius syndrome. Our medical advisors come from a broad set of disciplines, all of which are crucial to understanding and treating this complex, rare condition.

OUR MISSION

The Moebius Syndrome Foundation is a nonprofit organization founded by parents of children with Moebius syndrome. The mission of the Moebius Syndrome Foundation is to provide information and support to individuals with Moebius syndrome and their families, promote greater awareness and understanding of Moebius syndrome, and to advocate for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions.



Your tax deductible contributions help fund the Moebius Syndrome Foundation conferences and newsletters, and help support research into the causes and treatments for Moebius syndrome. The Moebius Syndrome Foundation is a 501 (c) 3 charitable organization with no paid staff. All work is done by volunteers.

For more information on Moebius syndrome, to be added to our mailing list, or to make a tax deductible donation contact:

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MOEBIUS SYNDROME FOUNDATION



Dedicated to helping children,

adults, families and

medical professionals

understand and cope

with this rare

neurological condition

and realize their

full potential.



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