

Moebius Syndrome Awareness 2015

www.manyfacesofmoebius.com

The purpose of this booklet is to help educate and spread awareness about Moebius Syndrome. Please share this with anyone who wants to learn more about Moebius Syndrome.

What is Moebius Syndrome?

Moebius Syndrome is a rare disorder characterized by lifetime facial paralysis. People with Moebius Syndrome can't smile or frown, and they often can't blink or move their eyes from side to side. In some instances, the syndrome is also associated with physical problems in other parts of the body.

What are the Symptoms?

The most apparent symptoms are related to facial expressions and function. In newborn infants, the first sign is an impaired ability to suck. Excessive drooling and crossed eyes may be present. In addition, there can be deformities of the tongue and jaw, end even of some limbs, including club foot and missing or webbed fingers. Most children have low muscle tone, particularly of the upper body.

Symptoms may Include!

- **Lack of facial expression; inability to smile.**
- **Feeding, swallowing and choking problems.**
- **Keeping head back to swallow.**
- **Eye sensitivity due to inability to squint.**
- **Motor delays due to upper body weakness.**
- **Absence to lateral eye movement.**
- **Absence of blinking**
- **Strabismus.**
- **Drooling.**
- **High Palate**
- **Short of deformed tongue.**
- **Limited movement of tongue.**

- **Sub-mucous cleft palate.**
- **Teeth problems.**
- **Hearing problems.**
- **Speech difficulties.**
- **Minor Mid-line anomalies.**

How does it Occur?

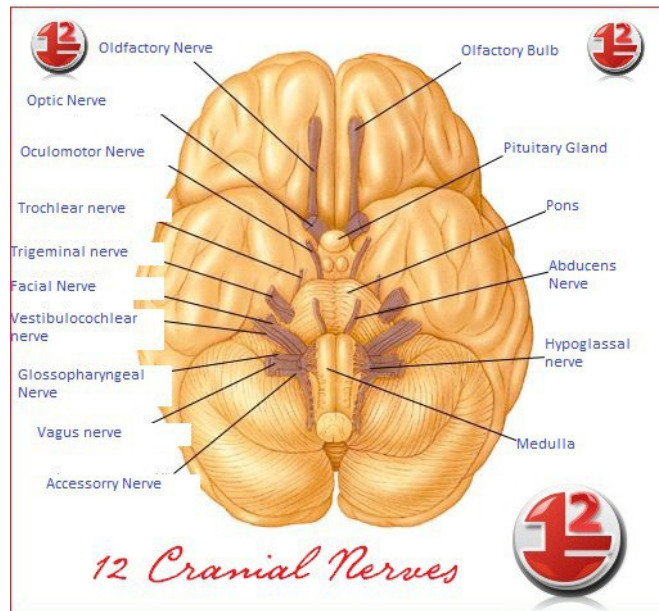
1. Children are born with Moebius Syndrome. Although it appears to be genetic, it's precise cause remains unknown and the medical literature presents conflicting theories. It affects boys and girls equally, and there appears to be, in some cases, an increased risk of transmitting the disorder from an affected parent to a child. Although no parental test for Moebius Syndrome is available, individuals may benefit from genetic counseling.

How is it Treated?

Infants sometimes require special bottles 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, plastic reconstructive surgery of the face can offer benefits in individual cases. In some cases, nerve and muscle transfers to the corners of themouth have been performed to provide an ability to smile.

How Can I Help?

One of the most frustrating aspects of coping with Moebius Syndrome is the surprising lack of awareness among physicians and nurses. It occurs so infrequently that many children go undiagnosed for months and sometimes years after birth. Parents and those affected spend a lot of time and emotional energy explaining and re-explaining this rare condition. The rarity of Moebius Syndrome becomes, in effect, an additional complication of the disorder. Because so few members of the professional and lay public have even heard of moebius syndrome, medical and social support, as well as reimbursement from Insurance companies, are severely limited. This lack of support services puts additional burdens on individuals and their families in their attempts to cope with Moebius Syndrome. Lack of awareness also plays a role in limiting research into potential treatments and cures for Moebius Syndrome.



12 Cranial Nerves

- **1st Olfactory nerve** - This is a type of sensory nerve that contributes in the sense of smell in human being. These basically provide the specific cells that are termed as olfactory epithelium. It carries the information from nasal epithelium to the olfactory center in brain.
- **2nd Optic nerve** - This again is a type of sensory nerve that transforms information about vision to the brain. To be specific this supplies information to the retina in the form of ganglion cells.
- **3rd Oculomotor nerve** - This is a form of motor nerve that supplies to different centers along midbrain. Its functions include superiorly uplifting eyelid, superiorly rotating eyeball, construction of pupil on the exposure to light and operating several eye muscles.
- **4th Trochlear nerve** - This motor nerve also supplies to the midbrain and performs the function of handling the eye muscles and turning the eye.
- **5th Trigeminal nerve** - This is a type of largest cranial nerve in all and performs many sensory functions related to nose, eyes, tongue and teeth. It basically is further divided in three branches that are ophthalmic, maxillary and mandibular nerve. This is a type of mixed nerve that performs sensory and motor functions in brain.
- **6th Abducent nerve** - This is again a type of motor nerve that supplies to the pons and perform function of turning eye laterally.
- **7th Facial nerve** - This motor nerve is responsible for different types of facial expressions. This also performs some functions of sensory nerve by supplying information about touch on face and senses of tongue in mouth. It is basically present over brain stem.

- **8th Vestibulocochlear nerve** - This motor nerve is basically functional in providing information related to balance of head and sense of sound or hearing. It carries vestibular as well as cochlear information to the brain and is placed near inner ear.
- **9th Glossopharyngeal nerve** - This is a sensory nerve which carries sensory information from pharynx (initial portion of throat) and some portion of tongue and palate. The information sent is about temperature, pressure and other related facts.
- **10th Vagus nerve** - This is also a type of mixed nerve that carries both motor and sensory functions. This basically deals with the area of pharynx, larynx, esophagus, trachea, bronchi, some portion of heart and palate. It works by constricting muscles of the above areas. In sensory part, it contributes in the tasting ability of the human being.
- **11th Spinal Accessory nerve** - As the name intimates this motor nerve supplies information about spinal cord, trapezius and other surrounding muscles. It also provides muscle movement of the shoulders and surrounding neck.
- **12th Hypoglossal nerve** - This is a typical motor nerve that deals with the muscles of tongue.

How Did Moebius Syndrome Awareness Day Get Started?

Moebius Syndrome Awareness Day is held every 24th of January, as it is the birth date of Professor Paul Julius Moebius who first diagnosed the disorder in 1888. The concept of a worldwide Moebius Syndrome awareness day in which people are encouraged to wear purple and spread awareness about the syndrome originated from The Many Faces Of Moebius Syndrome, an organization run by Tim Smith from Virginia, USA and Gavin Fouche from Cape Town, South Africa - both who have Moebius Syndrome. Most of their organization and preparation for the event is done through social media platforms such as Skype, Twitter and Facebook. Smith and Fouche have never physically met, but both share the same passion for spreading education and awareness about Moebius syndrome which will enable those affected by it to lead better lives, they believe.

The initial idea was pitched to Smith by Donnie Downs, a father of a son who is affected by Moebius syndrome. "People were a bit skeptical about the idea at first," says Smith, "Nobody could really see how raising awareness could benefit those like us who are affected by Moebius Syndrome."

In its first year an Australian television network ran a story on a boy who had Moebius which was then picked up by news media in the United States causing an unbelievably large number of hits to The Many Faces Of Moebius Syndrome website in its first 24 hours. "It was quite surreal

to see words that I had written appear in an American newspaper on the other side of the world." Says Fouche. Many who are affected by Moebius

Syndrome - both young children and adults - now use the day as a means to educate their teachers, classmates, friends and colleagues about Moebius Syndrome. Where once there were only feelings of alienation and nonacceptance there is now a sense of self-pride for both children and parents of children who are affected by the syndrome.

"We want to take Moebius Syndrome out of the Dark Ages," Says Fouche "We want to show the world that, despite our differences, those of us who have Moebius Syndrome are just as normal as the next guy."

Both the Moebius Syndrome Foundation and the Moebius Research Trust, fellow organizations specializing in the scientific research into the condition and the assistance to those who have it, are in full support of Moebius Syndrome Awareness Day. "Moebius Syndrome Awareness Day has become more successful than I ever dreamed possible. It took off like wildfire and spread right around the globe. Each year it gets bigger and bigger and more people get involved," Says Smith.

What Does The Many Faces Of Moebius Syndrome Do?

The mission of the Many Faces of Moebius Syndrome is, "To create a better tomorrow for ourselves and our children through education and public awareness." In addition to promoting the Moebius Syndrome Awareness Day each year, the The Many Faces Of Moebius Syndrome organization also runs their annual Moebius Syndrome Holiday Heroes campaign from November through January, highlighting those who are affected by Moebius syndrome.

How Can I Get Involved In Celebrating and Promoting MSAD 15?

"It's all about spreading awareness; anyone can participate" says Tim Smith. "People can do something simple, like pass out flyers or wear purple to show their support." But it doesn't stop there! Many families, relatives and supporters have gotten involved in years past, rallying around those in their community with Moebius Syndrome. Many times, individuals will work with local media outlets to run stories about Moebius, while others hold awareness events at schools or places of business. Most of all, people help spread the word on social media sites, commonly changing their profile pictures for the day, and posting status updates about the condition. The goal is to expose as many people as possible to the condition so there will be more education less misunderstanding in the general public. Click on the following link to go to our 2015 Awareness Page.

http://www.manyfacesofmoebius syndrome.com/official_2015_moebius_syndrome_awareness_day_page

Many Faces of Moebius Syndrome On Facebook

Please consider joining us on Facebook

<https://www.facebook.com/pages/Many-Faces-of-Moebius-Syndrome/189215821115287>.

Each time we get a new "LIKE" we are spreading awareness about moebius syndrome one step further. When we spread awareness we become better known. As we become better known people start to see us for our commonalities not our differences. More doors are opened for us and we are able to do more towards our mission goal of "Creating a better tomorrow for ourselves and our children through education and public awareness!" We have to keep going and growing. To do this we set our goals a little higher each year. This year our goal is 10,000 + likes to our Facebook page by MSAD on January 24 2015. If you haven't already done so please go to our Facebook page and click on the big "LIKE" button.