

## Frequently Asked Questions

### Does my child have Moebius syndrome?

The Moebius Syndrome Foundation cannot diagnose individuals, but we can work with you to recognize symptoms. If you suspect that your child has Moebius syndrome, you should consult your physician.

[Click here](#) to read about Moebius syndrome. Does your child have any of these symptoms:

- Lack of facial expression; inability to smile or frown
- Feeding, swallowing or choking problems
- Keeping head back to swallow
- Eye sensitivity due to inability to squint
- Motor delays due to upper body weakness
- Absence of lateral eye movement
- Absence of blinking
- Strabismus (crossed eyes)
- Drooling
- High palate
- Short or deformed tongue
- Limited movement of tongue
- Submucous cleft palate
- Dental problems
- Hearing impairment
- Articulation / speech disorders
- Lack of pectoral muscles (Poland syndrome)
- Club feet
- Hand/feet deformities

### My child has just been diagnosed, what do I do now?

First, don't panic. You will experience all kinds of emotions and you may feel very alone. With a rare condition it is difficult to find others who truly understand what you are feeling. Educate family and friends and allow them to participate in the process of understanding with you.

**[Click here to receive an information packet. We also have t-shirts for babies and young toddlers.](#)** Plus, you can always [email us or give us a call.](#)

Join one of the Facebook groups set up specifically to provide conversation and support. [Find our groups here.](#) You will be able to talk with other families of children with Moebius syndrome, ask questions and get the support you need. Remember, you are not alone!

### What is Moebius syndrome?

Moebius syndrome is a non-progressive rare neurological disorder that is present at birth and affects the cranial nerves that control facial expression and eye movement. It primarily affects the 6th and 7th cranial nerves, meaning that people with Moebius syndrome are unable to smile, frown, raise their eyebrows, grimace, move their eyes laterally or blink. Their eyelids may not close completely when blinking or sleeping, which can result in dry or irritated eyes. Weakness in the facial muscles may cause problems with sucking and the ability to feed, an early symptom that arises with newborns. [Read more here.](#)

### **How common is Moebius syndrome?**

The causes of Moebius syndrome are unknown, although the condition probably results from a combination of environmental and genetic factors. Researchers estimate that the condition affects 2 to 20 per 1 million people.

### **Are there treatments available?**

There is no cure for Moebius syndrome but there are [treatments available](#). Children with Moebius syndrome usually benefit from physical and speech therapy to improve their gross motor skills and coordination, and to gain better control over speaking and eating, as well as occupational and sensory integration therapies. Infants may require special bottles (i.e. Special Needs or Pigeon Feeder) or feeding tubes to maintain sufficient nutrition. Strabismus (crossed eyes) is usually correctible with surgery.

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 that surgery, nerve and muscle transfers to the corners of the mouth have been performed to provide an ability to smile.

### **What research is being done?**

Research into the cause of Moebius syndrome has increased greatly in the last ten years. The first [Moebius Syndrome Foundation Scientific Conference](#) was held in 2007 in Bethesda, Maryland, funded by grants from the National Institutes of Health (NIH) and the Moebius Syndrome Foundation. We continue hosting these events every two years, preceding the Moebius Syndrome Foundation Conference.

The NIH has announced a collaborative effort amongst a team of researchers at Mount Sinai School of Medicine, Boston Children's Hospital and the NIH, that aims to characterize the clinical phenotype of children and adults with Moebius syndrome and associated congenital facial weakness disorders and use genetic studies to identify disease-causing genes. [Click here to learn more](#).

### **What is smile surgery?**

Smile surgery is also known as a functional muscle transfer. This operation takes muscle from another part of a child's body (usually the thigh) and grafts it onto the corners of his mouth, giving them the ability to smile. This is not a "cure" for Moebius syndrome, but it does assist in restoring a smile. It is important to note that the procedure is very time-intensive and involved, taking up to twelve hours for one side of the face. Ask your treating clinician if smile surgery is an advisable option for your child. Free consultations are available at the [Moebius Syndrome Foundation Conference](#).

### **How can individuals with Moebius communicate without facial expression?**

Facial expression is critical for those in any situation - children in school, adults in the workplace or other social settings. This is one of the major challenges for those living with Moebius syndrome. Using body language and tone of voice are ways to enhance expression. A speech language pathologist can work with those who need help communicating.

Dr. Kathleen Bogart, a member of the Moebius Syndrome Foundation Board of Directors and an adult living with Moebius syndrome, has studied communication and done several studies on this topic. [Click here to read: Communicating without the Face: Holistic Perception of Emotions of People with Facial Paralysis](#).

*Have additional questions? [Give us a call or send us an email](#). Or join one of the [Moebius online groups](#) and just ask! Our community is active and always willing to answer questions and share advice.*