

FACES:

The National Craniofacial Association 1-800-332-2373

What is Moebius Syndrome?

Moebius Syndrome is an extremely rare condition which typically affects the sixth and seventh cranial nerves. These nerves affect the face and eye muscles and cause facial paralysis. Characteristics of Moebius Syndrome include:

- impaired ability in infants to suck
- inability to follow objects with one's eye -- instead the child turns his/her head to follow
- lack of facial expression
- crossed eyes
- inability to smile

Why did this happen?

Moebius Syndrome is caused by underdevelopment of facial nerves. Researchers believe that there is a genetic cause, but have not yet been able to identify it.

Will this happen to children I have in the future?

The chances are very small that other children will also be born with Moebius. However, there appears to be an increased incidence of Moebius in children of parents with Moebius.

What kinds of problems could my child have?

In addition to the physical characteristics common to Moebius, your child may have the following problems:

- delayed crawling and/or walking due to low muscle tone
- respiratory illnesses due to low muscle tone
- speech problems

- hearing problems caused by fluid in the ears
- limited movement of the tongue
- teeth problems
- sensitivity to loud sounds
- sensitivity to bright light

Will my child need surgery?

- Strabismus (crossed eyes) is usually correctable with surgery.
- Nerve and muscle transfers have been successful in recent years in providing some ability to smile.
- Though not surgical in nature, children often benefit from physical and speech therapy to improve their gross motor skills and coordination, and to gain better control of speaking and eating.

New advances in procedures to improve and correct problems associated with Moebius are continuing. Be an advocate for your child!

How do I get help for my child?

Your child should be treated by a qualified craniofacial medical team at a craniofacial center. Currently, FACES has information many of these teams. This is by no means a comprehensive list of all the craniofacial teams. Please contact FACES for details.

Am I alone?

No! There are many families and organizations who will be glad to talk with you and help you with information and support. Don't forget books, videos, and websites. The listing below will get you started.

FACES: The National Craniofacial Association
P.O. Box 11082
Chattanooga, TN 37401
(800) 332-2373

email: faces@faces-cranio.org

website: www.faces-cranio.org

We provide financial support for non-medical expenses to patients traveling to a craniofacial center for treatment. Eligibility is based on financial and medical need. Resources include newsletters, information about craniofacial conditions, and networking opportunities.

Moebius Syndrome Foundation

Vicki McCarrell

P.O. Box 147

Pilot Grove, MO 65276

(660) 834-3406

e-mail: info@moebiussyndrome.org

website: www.moebiussyndrome.org

Excellent Resource!! This network has a very informative newsletter and an address list of over 850 families who are willing to provide support. They have bi/ yearly conferences and all of the most recent research developments and information.

Children with Facial Difference: A Parent's Guide.

Written by Hope Charkins, MSW.

Excellent resource for parents to help them cope with medical, emotional, social, educational, legal, and financial challenges presented by facial differences of their children. *Look for this book at your larger bookstore chains or amazon.com.*

Available at: www.Amazon.com

National Health Law Program
1444 I Street, NW - Suite 1105
Washington, DC 20005
(202) 289-7661

website: www.healthlaw.org

Provides extensive information on health care laws affecting families of children with special needs.

Helpful internet sites:

<http://smile-surgery.com>

Smile-Surgery.com describes the features of facial paralysis and their personal effects. It outlines the treatment which is provided by The Toronto Facial Paralysis Group.

Dr. Ronald Zuker at the Hospital for Sick Children in Canada is the one who successfully developed the technique of muscle transplantation. If you are considering "smile" surgery, you should call his office for any referrals. He or his assistant, can be reached at (416) 813-6447