

the functioning facial nerve to the effected side can be performed. However, in bilateral cases such as Moebius Syndrome, there is no functioning facial nerve available. The surgical options in these cases are a local muscle transfer procedure or free muscle transplantation. Local regional muscles such as the temporalis of masseter can be used to restore facial movement. Either of these muscles of mastication can be moved maintaining their innervation to restore movement of the upper

lip and commissure. Retraining and practice is necessary to get the maximum benefit.

A newer procedure is microvascular muscle transplantation. This involves moving a muscle from another part of the body along with its nerve and blood supply. The nerve and vessels to the muscle are reconnected with the aid of a microscope. The muscle is oriented in such a fashion as to provide motion to the upper lip and commissure.

In each of these procedures the family needs to

have realistic expectations of what can be accomplished. If successful, these procedures can provide tone to the upper lip and commissure at rest, with muscle action that can produce a smile. Fine movements of variation in expression are usually not possible. However, these procedures can make dramatic improvements in the mask-like facies of Moebius Syndrome. They provide the potential benefits of facial animation with improved social interaction.

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## Beyond Face Value

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The ability to smile sets man apart from other animals. People with Moebius Syndrome do not have this ability. They have the same feelings, emotions, needs, wants and desires that we all have, but they do not show it via facial expression.

As the mother of a 2 1/2 year old boy with Moebius Syndrome, I have learned to read his emotions without the benefit of his facial expression. I know when he is happy, because he opens his mouth and laughs out loud. I know when he is sad because he cries, and I know when he is mad, because he throws things or yells just like any other 2 year old.

Despite what many of us are told, these children are bright, intelligent, fully functioning human beings who happen not to have the ability to communicate via facial expression. They usually need speech therapy to help them approximate sounds made with the lips, such as B, P, F, V, M, and W. They work very hard to over-

come the weak muscle tone they are born with. And, from the day they learn to walk, they run.

It has been a little over a year since I began the search to find other families with Moebius children -- or adults with Moebius Syndrome. I found 80 others throughout the US and Canada. More mothers call or write every week. Along with Lori Thomas, we publish a newsletter, "Moebius Syndrome News," four times a year. Lori has a 4 year old daughter with Moebius Syndrome. Actually, there are seven children and one adult here in the Los Angeles area with Moebius Syndrome.

Networking with others affected by Moebius Syndrome is vitally important to those who have children with Moebius Syndrome and adults with the syndrome. The ability to share information, ask questions, and get suggestions on how to deal with crossed eyes, choking, drooling and cruel comments from unknowing strangers are

imperative to a parent trying to cope with Moebius Syndrome.

The most important gift we can give our children is that of love, self confidence and a strong self image. We can't shelter them from cruel remarks from unknowing strangers and we can't live their lives for them. We can, however, let them know that they are beautiful even though they cannot smile. We can tell them daily how important they are, how wonderful they are, and that they have an important mission in life -- to educate others about the need to look "beyond face value."

*To have your name added to the "Moebius Syndrome News" mailing list, please write to:*  
Vicki McCarrell  
6449 Gerald Avenue  
Van Nuys, CA 91406

