

Forward Face

A Newsletter Serving Patients & Families With Craniofacial Disorders

Winter 1993

Volume 4 Issue Number 1

Beyond Face Value

Moebius Syndrome

By: VICKI McCARRELL

The pediatric neurologist comes to see you in your hospital room after the birth of your baby. You know something is wrong -- your baby doesn't suck -- he's losing weight -- he can't breast feed -- he takes two hours to get two ounces of milk from a bottle. But you're not prepared for this. The neurologist says it is Moebius Syndrome. Your baby will never smile, never have facial expression, never blink his eyes, never move his eyes laterally.

Your baby is sentenced to a life with no SMILE. Imagine the shock. You've heard of lots of birth defects, you pray during your pregnancy your baby won't be one of the statistics, but here he is -- with a syndrome so rare no one you talk to ever heard of it -- or ever met anyone else with it.

You spend the first few months of the baby's life trying to keep him alive. If you're one of the lucky ones, you can make the bottle hole big and hold his lips together with your hands to

force milk down him, hoping he doesn't choke. If you're not one of the lucky ones, you feed your baby via a gastric tube through the nose, or worse yet a G tube. It takes months for him to get enough muscle strength to hold his head up alone. Even more months for him to turn over and eventually begin to do the "army crawl." More months, or years, for him to walk.

Through all you wonder how many other parents and children are going through this. You sneek peaks at your baby all day long, hoping to catch his first smile. It never comes. Slowly, you realize it never will. You wonder how other children, other adults, will treat him. You begin a search for other families affected by this rare occurrence.

When you finally find the wonderful organizations like About Face, Faces, Forward Face, Let's Face It, NORD, and publications like the Forward Face Newsletter, you realize you're not alone... your baby is not alone. You revel in the

ability to communicate with other parents whose children cannot stand the sun because they can not blink, nor squint to keep the light out of their eyes. You discover that most Moebius children have swallowing problems, malformed tongues and weak muscle tone. You also realize that some Moebius children have it much worse.

Some Moebius children have missing limbs, fingers, toes, or webbed fingers and/or toes. Some Moebius children

have club feet, or small limbs. Some Moebius children don't walk until they are 4-5 years old, if at all. Some Moebius children have respiratory problems or hearing problems.

All Moebius children have one thing in common, they do not have the 6th and 7th cranial nerves. The nerves to the face which control facial expression and allow one to blink and move the eyes laterally.

Continued on page seven



To Ireland...Hope and Acceptance

By: BETSY OLD

On March 16, 1992 James Brown was born in Belfast, Ireland. He was born of an ordinary delivery but with an out of the ordinary syndrome called Treacher Collins (see: FF Newsletter Summer-Fall '91). James was given a tracheotomy within a day or two and a tube was inserted into his nose to aid in feeding. James was also born with a cleft palate which makes feeding extremely difficult. Doctors in Ireland admitted to knowing almost nothing about James' condition and even less about how to help him.

Luckily, James has an aunt and uncle living in the U.S. who started to do some research into Treacher Collins. His Aunt Dottie called Betsy Old of Forward Face in April of 1992 asking for educational materials to send to James' family. This contact began months of networking and phone calls. As the months progressed, James was not gaining weight in a normal manner and his parents were becoming increasingly concerned. James' doctors in Ireland still did not know what else they could do for him.

Continued on page eleven