

Many Faces of Moebius Syndrome



eBook Collection of Stories from the Moebius Community
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www.manyfacesofmoebius.com

Press Release – Moebius Syndrome Awareness Day 2015

The Many Faces Of Moebius Syndrome (www.manyfacesofmoebius.com), the Moebius Syndrome Foundation (www.moebius.com) and the Moebius Syndrome Research Trust (www.moebiusresearchtrust.org) are proud to announce the 5th Annual Moebius Syndrome Awareness Day which will be celebrated worldwide on the 24th of January, 2015.

Moebius Syndrome is an extremely rare congenital neurological disorder which is characterized by facial paralysis and the inability to move the eyes from side to side. Most people with Moebius Syndrome are born with complete facial paralysis and can't close their eyes or show facial expressions. Limb and chest wall abnormalities often occur with the syndrome. Respiratory problems, speech and swallowing disorders, visual impairments, sensory integration dysfunction, sleep disorders and weak upper body strength may also be present.

People with Moebius Syndrome are of normal intelligence, although their lack of facial expression is often taken to be due to dullness or unfriendliness. It is estimated that there are only between 5,000 to 10,000 cases of Moebius syndrome worldwide.

Last year's Moebius Syndrome Awareness Day was a resounding success and saw participation from every continent on the planet – the main focus was to create awareness via the media, and dozens of news stories hit the headlines, wound up on the airwaves, and blasted off into cyberspace via various print, TV, radio and social media news publications!

Family, and the importance thereof in the lives of individuals who have Moebius syndrome is the focus of this year's Awareness Day. "It is a tribute to the many families around the world who are often the unsung heroes of our lives" says Tim Smith, President of the Many Faces Of Moebius Syndrome, who himself has the condition.

"There is no substitute for a loving, supportive family - whether that family is biological, or our worldwide Moebius Family. Knowing someone is there to support and fight for you when the going gets tough makes living with Moebius Syndrome a little easier" says Vicki McCarrell, President of the Moebius Syndrome Foundation.

Moebius Syndrome Awareness Day is held annually on the 24th of January, the birthdate of Professor Paul Julius Moebius, the doctor who first diagnosed the disorder in 1888. Please join the Global Moebius Syndrome community and take part in one of the many family gatherings taking place on January 24, 2015. We encourage you to proudly wear purple, and do some of your own research to educate yourself and others about Moebius Syndrome. We appreciate your support and look forward to the biggest Moebius Syndrome Awareness Day ever!



Smiling with our Hearts

Foreword

The global Moebius community has grown tremendously over the past several years, and as a matter of such, has connected many people and families that would not have been connected otherwise. In some cases, adults with Moebius have lived 20, 30, or 40+ years and have only recently met another person with Moebius. Our mission is to raise awareness and understanding of Moebius Syndrome, and to help other families along their journey as they come into the Moebius family.

We hope you enjoy this first installment of our e-book, and welcome you to share this with others to further our mission of awareness and education about Moebius Syndrome.

Thank You.
-Rebecca Maher



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Epilogue



Life with Moebius Syndrome – by Vicki McCarrell

When my son Sean was born on August 8, 1990, he and I began a journey that would change the course of our lives forever. After an uneventful pregnancy for which I'd prayed for over 30 years, Sean came bouncing into my life. There was one hitch, he was born with Moebius Syndrome, a very rare neurological disorder which can affect any of the 12 cranial nerves – but almost always the 6th and 7th. With those nerves missing or incomplete, babies can't blink their eyes or move them laterally and they have no facial expression – they can't squint, frown, grimace or smile. Unfortunately no one told me that because of the facial and tongue paralysis babies with Moebius also can't suck. . .

I took my little guy home from the hospital and decided he'd be fine, but soon I was scouring the shelves of stores looking for the perfect nipple because I was spending hours trying to feed him to no avail. I called every mom I knew to ask how long it took their baby to drink a bottle of milk and they said, 'just put it in his mouth – he'll know what to do.' It didn't happen. In desperation, after Sean's 10 day check up when the pediatrician sternly told me I had to feed my baby because he'd lost too much weight, I went home in tears and burned a bigger hole in the nipple with a darning needle. I was NOT going to lose my baby! I held his cheeks shut for him and suddenly he began to chew on the nipple – he was eating for the first time in 10 days.

Time went on, Sean was nearing his first birthday, and as I marveled at my little guy's tenacity, I kept wondering how many other moms had the same problem feeding their babies that I'd had. I wrote to NORD searching for others who had children with Moebius Syndrome and they sent me a list of craniofacial support organizations – including AboutFace. In July 1991 I received the name and number of another mother who'd also been searching, and she lived only 4 miles from us in a suburb of Los Angeles.

I called Lori Thomas that same day and we began a lifetime friendship which ultimately changed the world for people with Moebius Syndrome and their families. She invited Sean and me over to meet her then 3 year old daughter, Chelsey. I was amazed. Sean and Chelsey could



have been twins. They had the same Moebius 'look' – bright eyes which didn't blink, the same little triangle mouth, and the lack of smile that forced them to show happiness through their actions and body language. Chelsey was running around, eating apples and potato chips which was a relief to me, because Sean did not have the upper body strength to walk at that point and he was still eating pureed foods. (He did begin walking at 19 months and began to eat solid foods at age 3.)

After a couple of months, while the kids played, we put together a small newsletter, sent it to all of the craniofacial support organizations and we became a 'real' support group. Over the next few months we were flooded with phone calls and letters from families who had children with Moebius as well as adults who each thought they were the only one in the world who couldn't smile. In 1994 Ken Koke, the father of a baby boy with Moebius in Toronto, suggested that he develop a Moebius Syndrome website, and our list of people with Moebius continued to grow.

We hosted our first Moebius Syndrome Conference in Los Angeles in 1994 and people from 26 states and Canada came to hear doctors and other professionals speak about Moebius Syndrome. Families networked and information kept flowing. Moebius doesn't only affect the face – it can also affect the hands, feet, arms, legs, respiratory system, can cause club feet, choking, dental problems, eye problems - the list of issues grew.

We now hold conferences every two years and attendance grew to 400 at our last conference in 2014, with attendees from 10 countries. It's hard to imagine what life was like even 40 years ago for people with Moebius Syndrome. They were alone, had no information and no support. Paul Julius Moebius, MD, an Austrian neurologist, had published the first case study of a man with facial paralysis in the late 1880's. Thanks to the Internet and our ability to reach people throughout the world via our newsletters, there are now Moebius Syndrome Foundations and support groups in Canada, England, Holland, Spain, Italy, France, Germany, Sweden, Brazil and Peru.



It hasn't all been easy. Sean had strabismus surgery at age 13 months, dental surgery at 3 ½ years to repair 16 decayed teeth because of Moebius, and at age 6 he developed hydroa vacciniforme, an extremely rare allergy to the sun (unrelated to Moebius). He has an amazing inner strength, is now 24 years old and has a Bachelor's Degree in Broadcast Journalism from the University of Central Missouri. After a few years as a broadcaster and board operator for an FM radio station in central Missouri, he now lives in Chicago where he works and takes classes at The Second City honing his skills in improv and comedy writing.

Life with Moebius Syndrome has its challenges – but we're not alone; and that's the way it should be. . . We smile with our hearts!

Vicki McCarrell

President

Moebius Syndrome Foundation

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Where it all Began – by Tim Smith

I was born on May 20th 1963 in Alexandria, Virginia. In those years if a child was born with a deformity, impairment, or disability they were automatically labeled as being retarded and the parents were informed that if they lived they would need constant care and supervision.

After my birth the doctors didn't give me more than a few weeks to live. They had no clue what was wrong with me. They suspected my deformities were caused by over the counter diet medicine my mother took before finding out she was pregnant. She was never told differently and carried the blame to her grave.

I couldn't suck on a bottle or move my eyes. They said I just stared into space when I was sleeping. I had to have IVs in my feet because it was the only place which they could get the needle in. A nurse whose name I never knew took it upon herself to try and feed me with a spoon. There was no other way. When she got off of her shift she would come in my room and take turns with my mom, dad, and grandmother at feeding me.

I made it past two weeks, but the doctors were not very optimistic. They said I probably wouldn't survive more than a couple of years and if I did I wouldn't be right..... I remember very little during those first few years other than I went to the doctors more than I went any place else. My parents did everything they could to make sure I got the best medical attention they could afford. During those times you couldn't get medical insurance for children who had serious problems. My parents paid for everything with the money they made. My dad worked for the Washington Gas Light Company and in those early years my mom did typing work.

My mother taught me how to read when I was four so that I would be ahead of the curve when I started school. I remember in first grade we had a huge copy of "The Little Red Book", which sat upon an art easel. Everyone would take their turn reading it. When it came to my turn I would read it perfectly. Unfortunately the teacher couldn't really understand me and



since my eyes never moved she assumed I was just copying what the other kids had said. Almost every week my teacher and the principal would take me to the class for the special ed kids and say "Tim wouldn't you like to be in this class with others like you?" Each time I would say "no." My parents fought the school system tooth and nail to keep me in normal classes.

Eventually a compromise was reached. The school system told my parents they would allow me to stay in normal classes if I passed a series of tests which measured your aptitude and skills. They said if I didn't pass the tests I would have to be moved into other classes because I would be a disturbance to the other children. I remember taking the tests but I don't remember what they were about. I scored above average on every test. The person who conducted the tests became my parents ally and shortly after that the school system backed off.

Because I looked different and couldn't speak clearly, and because I did some very stupid things I was often teased. I remember being in 4th grade and some of the kids wanted the teacher to ask me a question just so they could hear me answer it and when I did they would laugh. The teasing continued through elementary school. Back then I was a wimp and whenever someone teased or hit me I would go running home crying to my parents.

My medical condition never got any better or worse. I once heard my doctor tell my mom that he didn't expect me to reach adulthood, but by then I was used to that type of talk so it never bothered me.

When I was in seventh, and eighth, grade I became friends with certain people who were popular and I was accepted by association. Plus I finally learned to behave a little better. :) Unfortunately when I was in eighth grade my father died of pancreatic cancer so my life started to take a turn for the worse. My father was my idol and inspiration. Somehow my mother managed to pull me through it and I continued to do well in school.

During the summer between ninth and tenth grade my mom lost a five year battle to cancer. My sister, my brother, and my sister in law, continued to live in my parents' house but I was a pretty lost soul. I didn't finish high school because I couldn't get up early and once I did



get up all I wanted to do was watch TV.

I got my GED when I was 18. I actually got in before my class graduated in 1981. To me the test was very simple and I didn't think I missed much not going to school. I drifted for a few years. Had a few adventures. Got into a little trouble here and there. My fear of going to prison kept me out of any major trouble.

I didn't actually find out I had Moebius Syndrome until I was in my 40's when someone I knew discovered it by going through my old medical records. I thought I was the only one out there alone in the world. When I finally reached out to others with Moebius a whole new world opened up for me. I met a lot of good kind and caring people.

Looking back it's been a pretty good life. I've had some fun times. I've gone on some great adventures. I've stared death in the face and beat it. I've made some great friendships which have lasted for decades. I lived, I learned and I've loved.

I am not sorry that I have Moebius Syndrome. If I could change it I wouldn't. Everyone wants to be a unique individual. Everyone wants to be part of something special. I was lucky I was born into a group of very special people who I proudly call my friends and family. If it weren't for me having Moebius syndrome I don't know if I would have made it through those teenage years after my parents died. Having Moebius Syndrome made me a stronger, better, and wiser person.

"Course heading Captain?", asked Mr. Chekov.

"Second Star to the right and straight onto morning!", replied Captain Tim.



Resilience Defined – by Rebecca Maher

“Failure to thrive”.... Three words which I will never forget. Thank goodness I didn’t know what the term really meant back then, or perhaps I had repressed it at the time. When Jessica was born it just seemed like one issue after another – first there was no red reflex in the eyes, then there was the short pinky fingers, then there was the problem latching on and the lack of weight gain, the crossed eyes and of course the asymmetrical cry. No answers to “why”, no diagnosis, only more questions.

Losing weight with each passing “new baby checkup”; “Are you feeding her when she wants to be fed? She should be gaining weight by now” I was asked and told at each doctor visit. “Are you kidding me?” I thought... I’m practically walking around with an open shirt trying to feed this baby. All the while I carried a sense of guilt that I had done something wrong, or that I failed at bringing this cute little baby into the world. Nearly at the end of my rope of patience and frustration, I asked a pivotal question; “Isn’t it possible that she’s not absorbing what she’s taking in?”

“We can test for that” the doctor said. After a “reducing substances” test was complete, we found that Jessica had a malabsorption of carbohydrates and a severe lactase deficiency... lactose intolerant. Thanks to some Lactaid drops and a baby scale, we began our journey of growth. After four weeks, her baseline weight was a mere 4 lbs., 13oz. I’ll never forget. I was told to weigh her once a day, but in true resilient and determined Moebius Mom fashion, I weighed her after every feeding, at least five or six times a day, maybe even seven. From that point on, every pound she gained was a celebration for us. Another phone call to the in-laws and another phone call to the grandparents! Prior to those test results she was literally withering away. When I should have been basking in the glow of new “mommy hood”, I was in problem solving mode.

At five months, the call came... “This is what we think it is” said the pediatrician. I’ll never forget those words, or where I was at the time of that phone call. “Finally, some answers” I thought. So began our journey as a Moebius family.

Back in 2001 there was very little research, and hardly any physician I spoke with knew about Moebius Syndrome. Since they couldn’t really tell us anything we didn’t already know, I set out on



my own personal mission to educate – anyone from neighbors, to church friends, therapists – even the random strangers or checkout people at the grocery store who stared at my beautiful baby too long. After several months of doctor visits, my approach was *this is what I've tried, and this is what we are doing at home. What else can you tell me that I am not already doing to support my child?*

Then one day in 2002 I was looking on the internet to see if there was anything new in the area of Moebius Syndrome – any news or research. I checked out the Moebius Syndrome Foundation's website and was awestruck... A conference was in the works for that summer! Decision made, on the spot.

Another pivotal moment. Our first conference helped us connect with other families and it gave us a sense of optimism for the future. That was our first time meeting other families with Moebius children and we felt completely at home. There was a tremendous amount of information shared, and I think I filled up two notebooks during the conference. I asked for conference materials and shared those not just with the pediatrician, but any other doctor or therapist we saw after that. I felt empowered for the first time in a long time, just as many other families have, thanks to that first conference. Since then we have been to all but one conference (due to the arrival of Jessica's little brother).

Over the years Jessica has continued to amaze us. She is smart, funny, charismatic, *very* talkative and absolutely LOVES her Moebius family! In fact, she talks so much that you might not think she ever had any speech challenges. The reality is that she had an amazing speech pathologist that taught her how to truly communicate... "Speech Janet" as she will always be known.

While Jessica has had her challenges early on, she remains a strong, independent and smart young lady. She deftly handled middle school bullying and is admired by teachers for standing up for herself. High school will be our next challenge, but I look forward to her reaching her long term goal of getting into Harvard University. She absolutely can do it.



Everyday Moebius – by Tara N. Lewis

I'm a hero to Dr. Who fans, a guardian against weeping angels. I can't blink.

I don't miss as much of the world. At least the parts I can see clearly.

I can win any staring contest, except with my cat.

I look young for my age and probably will longer than most people, I won't get many wrinkles.

I have partial facial paralysis.

I have Moebius Syndrome. I have had Moebius Syndrome for 36 years, but I did not know until recently. I was misdiagnosed, or rather my pediatric neurologist, all six of them and a consult of 50, could not quite figure me out. I'm not sure why, perhaps because I have limited facial expressions, or because they didn't know enough about Moebius at the time.

Growing up I was different and I knew it. I was bullied, I was teased, and people stared at me. Children still stare at me. Some people assume that I have limited intelligence because of the way I look. I've always had to hide from the sun, wearing dark sunglasses, pain from the light. I love cloudy days. I was horrible at sports and too weak in my upper body strength for gymnastics. I have this fantasy about being a runner, or someone who jogs, but I'm rubbish at it. In elementary school I had to run on the slow team in gym class; but I can dance! I always had trouble seeing the board in school, but I hated wearing glasses. Despite that I managed. I found ways to circumnavigate my limitations.

Growing up I thought that I was the only person to have these issues and I've often wished I could be "normal". Oddly, not everyone realized I was different, although I still find it difficult to make eye contact with those I don't know, or have recently met. This is my insecurity, this is my fear that people will know I am different.

My parents never acted as if I was different, although they knew I had needs that other children did not. They pushed me to be confident in my abilities, to be independent, to help



me find my limits and not accept them. Despite lacking some depth perception and not having the ability to use both eyes simultaneously I can paint and draw; I was an art major in college.

I have had other successes, I have done many things in my life, so far. I went to graduate school, I worked at Disney World, I joined AmeriCorps, and I found an amazing job working as an administrator at a university. I still have difficulty acknowledging my limitations, but I'm learning that sometimes you have to ask for help, or help others to understand. So here I am, 36 years never knowing what was "wrong" with me, never meeting anyone like me, until now.

Writing this I do not even know if my previous experiences have been similar to others with Moebius Syndrome, but I know the pitfalls and I know what the positive aspects have been for me. I know that everyone has their struggles, has met their limitations, and either tries to push past those limitations or uses them as an excuse. I know that I am no longer alone; that there are others I can share my experiences of living with Moebius Syndrome.



Here and Gone – by Kay Von Willingh

*"I'll lend you for a little time a child of mine," He said.
For you to love while he lives, **and** mourn for when he's dead.*

*I cannot promise he will stay, since all from earth return,
But there are lessons taught down there I want this child to
learn"*

*But should the angels call for him much sooner than we've
planned,
We'll brave the bitter grief that come and try to understand." by Edgar Guest*

Many years ago, when I first read the words of this poem, I could not begin to comprehend how these same words would one day bring meaning to my life. Wesley Von Willingh from Paarl was born on 25 August 1989 and diagnosed with Moebius Syndrome, Hydrocephalus and Poland Syndrome. From the age of 3, Wesley developed seizures and together with acute Hydrocephalus, resulted in his sudden passing 22 July 2007.

Before this tragic day, our life and family moments were as special and normal as any other family. We regarded him to be 'normal' and treated him the way we treated our other two 'normal' children, but it will be senseless of me to talk about his passing without sharing the joys he brought, and how we journeyed from there.

With his initial diagnoses at birth, I shut myself off from the world, refusing to see him or hold him. Instead, I prayed, cried and perfected my negotiation skills with God, whom I couldn't allow to get off lightly. After all, I told Him: if you entrust me with this special child, give me the courage to cope, the love to hold him and protect him and the determination to never give up on him, and that day, a three-some pact was sealed.

Wesley survived against all odds, and up to the age of 13 years managed a hassle-free VP Shunt which had been inserted when he was 4 days old. I recall a further conversation with God when I thanked him for giving Wesley to us but telling him how I longed to hear him say "mommy".



His development was noticeably slower than other babies but a friend who cared for him since the age of 9 months would give me a rundown of his daily activities when I fetched him after work. She recalls how he would turn his head as cars passed the house, attracted by the sounds he heard. When he was just a few months old my sister sent him a Fischer Price CD player, with nursery rhymes. His favorite was Twinkle Twinkle little Star, yet, when we changed the CD to Baa Baa Black Sheep, Wesley objected with what could only be described as an early toi-toi (an African way of objecting to unhappiness by means of chanting or dancing). He displayed a strong rhythmic sense and he showed his appreciation for music by thumping his feet to the beat...especially when we turned the volume down.

In true Wesley fashion, at the age of three, 23 July 1993, bypassing the crawling stage, Wesley could walk, talk, and pretty much caught up with his peers reaching each and every Moebius milestone.

He astounded us all when starting to converse in full sentences in both official languages and as he progressed through schooling, often had to assist his older sister with her Afrikaans essays. Wesley loved this, being placed in the spotlight by his peers and praised by his teachers. His excellent vocabulary, together with his good sense of writing, won him a competition when writing an essay about being the President for one day. He was gob smacked, but proudly boastful.

Like many other teenage boys, he loved the attention of girls and soon started dreaming about his first date out with a girl. I use to enjoy his excitement, but cautiously warning him against the 'butterflies' he would feel and always to remember to treat a girl with respect and care. His response was as spontaneous as he was: "Mommy, no need for lectures, I know my place".

But Wesley's dream of going on his first date was to remain a dream. Undoubtedly soon after his passing I was angry with God. I would wake up in the middle of the night in conversation with God which often ended in a spiritual fight I just couldn't control. Are we supposed to remain Godly and accept loss? While everyone assured me that they knew where Wesley was, that he was with Angels and that God knew best, I wasn't prepared to accept this as I enjoyed my fights with God too much. Maybe I was even thinking I was getting back at Him




for stealing my son, but in time, and this period was hard, painful and bitter, I realized that he remained in my heart, this time, engraved on every bone of my body.

What would go through your mind if you were told that the only best thing would be to have the respirator turned off? Those words, will I ever forget that day? It was Sunday, 22nd July 2007 and as much as what we were avoiding the doctors, it was inevitable for us to be called to a separate room where the news of Wesley being brain dead was relayed to us.

Like within any family, there were mixed feelings. My husband at the time and my eldest daughter felt we should give it time, that it was too rushed. With deep emotions, hours of consultation with a panel of doctors, confusion and fierce sadness, we agreed to have the machines turned off. That afternoon, with family and friends surrounding Wesley, we said our goodbyes. The room was filled with a sense of peace, love and spiritual warmth when we witnessed his final goodbye and I, rightly positioned, caught the glimpse as his eye directly looking at me, opened as if he was saying: “don’t you worry Mommy, I will be with you forever” when soon after, the beep was silenced – his lamp hath burned to the end!

I don’t remember much of his funeral and weeks to follow remains a haze, but I’ve realized by sharing my story and talking about Wesley helped my journey of healing and acceptance.

Greater are we who had him in our lives, even if it was for a shorter time than what we so selfishly wanted. 



The Journey of Christopher – by Grandma Virginia

My name is Virginia Villarreal and I am the proud grandmother of Christopher E. Rodriguez. Christopher is a very special little boy because he changed our family when he was born and has opened my heart. His parents were very young when they became pregnant with him. His dad, Jose and his mom, Mariela were both under 18 years old when he was born. They have cared for this beautiful child with so much love and devotion. They are wonderful parents and I am very proud of them. Mariela, his mom gave me the information that I am sharing with you here.

At 25 weeks of the pregnancy the first ultrasound showed that he had Gastroschisis and he was born at 36 weeks on December 3, 2009 and weighed 4lbs, 9oz and was 17 inches long. He was given test to see if he had any other problems and one of the tests showed he had Cystic Fibrosis but a better test was taken and it came out negative for CF. He had tests done on his chromosomes and they found that he had a deletion on chromosome 17 and 15. He also was had low muscle tone and needed physical therapy.

After he was born his intestines were put in a silo so that they could slowly start going into his stomach little by little and a week after his birth he had surgery to close him up. He had been getting his nutrition through an IV until he was two weeks old and they nursing staff began to bottle feed him but he could not finish his bottle because he could not suck and they found out he was aspirating the milk so they stopped the bottle feeding and started feeding him through a tube in his nose. When he was almost two months old and still was not able to suck on his bottle it was decided to have a G tube put in. Christopher had to wait a few extra weeks to get the G tube surgery to give him time to heal from a previous surgery and when he was almost 3 months old they did the G tube placement surgery and a week later he was finally able to go home from the hospital.

Because of his low muscle tone he didn't begin to walk until he was two. Christopher was not diagnosed with Moebius Syndrome until he was almost 2 years old by his ophthalmologist at Texas Children's Hospital. I had taken him to Texas Children's Hospital after the ophthalmologists at Lyndon B. Johnson Hospital in Houston Texas had told Mariela that



Christopher was legally blind. At Texas Children's Hospital he was tested and she was told that his vision was perfectly fine but that he could not move his eyes laterally because he had Moebius Syndrome.

I myself as his grandmother knew nothing about Moebius Syndrome until Baby Tre passed away and I recognized Moebius in one of his pictures; I commented on Baby Tre's page that Tre looked like my grandson. Since then Tre's mom, Yanet and our family have had a wonderful relationship and it has brought us so much knowledge and hope from joining pages like Many Faces of Moebius Syndrome. Through meeting and talking to others that have children with Moebius or people that have Moebius I've been able to learn how to interact with my beloved grandson.

Christopher has had a long journey from the time of his birth until now. He is 4 years old and in those four years he has grown so much and has taught his family so much. He is in school and he is feeding himself now. He still has his G tube but he eats on his own. He still doesn't talk but that boy can hum. He loves humming and with the constant loving care of his parents I am sure he will become a wonderful and productive young man.



Growing up with Moebius – by Roger Kreil


It is hard when you have to grow up not like everyone else. When people don't know what you have, they make assumptions. Even to this day, people wonder if I am retarded. Kids sometimes stare at me in public because they don't know what I have. When I was in kindergarten, I remember one of the kids saying as we were sitting around eating our lunches "Roger's handicapped! We don't like him!" That hurt really bad.

When I was in my first year of Grade One, I thought that I made some friends. But they were just kids who wanted to tease me. They would say to me "Roger, what's your name?" They wanted me to say my name wrong so that they could laugh at me. I was held back in Grade One because I didn't have any friends. Then, I made one. His name is John and he used to read to me in Grade Two. Other kids used to read to me as well but we connected and the other kids didn't connect with me as well.

In Grade Four, a girl told me that I was the ugliest kid on earth. I yelled back as she climbed the stairs "You are the ugliest kid in the universe!"

In Grade Five, a new kid came to school. He bullied me for five years for various reasons.

In Grade Seven, he told me "You are fat! You're ugly! You wear glasses! And you're cross eyed!" So bullying is a big factor for people living with Moebius Syndrome. Kids need to know that we have feelings just like they do.

We may not have facial expressions to show how we are feeling but we still feel it. And it hurts when they tease us for our inabilities. As soon as more people realize this, we will have easier lives and not have to worry so much about bullies. Hopefully, the kids who have Moebius Syndrome will not have to go through as much as we older Moebians went through. 



The Pain or the Pancake? – by Shelby Kennedy

If, like me, you're a bit of a social media hound, you probably stay up-to-date on the latest Moebius happenings by following the various Moebius Facebook groups. I don't have to tell you how great it is to be constantly connected to the people that best understand your hopes, fears, struggles, aches and pains, and, let's be honest, intermittent feelings of what can only be described as 'general social awkwardness'. Our cool community (I almost said 'little community', but it's not that small anymore, is it?) is an amazing blessing for which I am extremely thankful. We are strong and beautiful; our hard work carves out the foundation on which a better world is built.

All that work can really wear you down sometimes, though. I've noticed that a lot of people post about frustrating experiences interacting with people outside the disability community. (Oh 'normies', when you gonna learn? Ha!) Others are looking for encouragement as they try to motivate themselves into jumping over the emotional hurdle known as dating. Yikes! Some days you're on top of the world, but others... well, you're whatever people say is the worst thing in the world. Maybe the word that would accurately describe your lowest low hasn't even been *invented* yet.

Navigating life's challenges is hard. As my college friends and I loved to remind each other (at the most emotionally sensitive times, of course): '*Life is hard. Have a pancake.*' As we live and exist in our minute-to-minute lives, dealing with new people and making the best of awkward situations can feel overwhelming and teeth grind-y. However, if we step back from our problems and ask ourselves why we react to events the way we do, it's easy to see that life is all about making a simple choice between the pain and the pancake.

Example: A few days ago I was riding the bus into DC. It was early, I hadn't slept much the night before, my blood sugar was low and I probably had a hangnail. You know, whatever. I wasn't at my best. I was sending a text message and became aware of what I perceived to be the guy next to me staring at my arms. (For those who don't know me, my arms end at the elbow—in other words, I totally have short little t-rex arms.) I gave him a stare that I reserve especially for my fellow riders of public transport and sighed audibly. I really wasn't looking for



that sort of attention right at that moment. The guy looked away and didn't look back the rest of the ride.

As soon as I got off the bus, my brain started kicking me. What if he was just looking out the window? Was it *really* that big a deal that he looked at me? He could've had any one of a million reasons to be looking that way; why did I have to ruin *both* our mornings over something so flippin' trivial? If I'd just chosen to ignore it or—GASP!--be friendly, I wouldn't be overanalyzing my questionable behavior now. I had doomed myself to feel bad. I missed my chance at the pancake.

All this talk about forming relationships and my own joys and frustrations got me thinking about how I try to interact with people I've never met before. I'm kind of a stunted extrovert: I love meeting new people, but that joy comes along with the funny little caveat that I can't feel too intimidated by said people. If I feel intimidated, which seems to happen somewhat often, I really clam up. I wait for someone to talk to me before I'll join a conversation. We all know how well *that* tactic works. I might have a million billion conversation starters bouncing around in my head, but I really have to fight myself to strike something up. It's weird! Maybe you know what that feels like, guys.

Anyways, I feel like my problem comes down to an imbalance in what I like to think of as the 'two levels of faith' in any relationship you and I will form throughout our lives. First, we have to have faith in the person we're meeting: We have to remind ourselves that this person doesn't know us, but *because we have faith that most of the people we meet in this world are good people*, we will treat them kindly and without suspicion. We'll assume that they'll treat us like a human being, too. Basically, we have to give everyone the benefit of the doubt—at least initially! If you're good to someone and they beat you down in return, you'll know not to get fooled twice. If you're rude to them or ignore them right off the bat (insert my bus example here) you've beaten yourself up before they even had the chance!

Secondly, they need to be able to have faith in you. You need to listen and be respectful of their feelings. It's that whole 'put your best foot (or any other similarly-purposed appendage that you have, haha) forward' rule. You have to show them you're capable of having a relationship with them. One of the sentiments I heard echoed by several lecturers at the



Moebius Conference was that people with disabilities have to be *more* socially adept than their able-bodied peers. It's so true. We'll be proving ourselves for the rest of our lives, but the rewards are so great. We can't afford to give up!

I deliberately chose to use the word 'faith' because of its spiritual connotation. Making a friend—especially for people like us that can feel pretty excluded from certain social norms like shaking hands, giving someone a smile, etc.—can and should feel like magic, or a miracle, or whatever word you want to use to convey that something truly amazing has happened.

My hope for the future is that able-bodied people will always 'assume competence' when encountering people with disabilities. My hope for us *all* is that we'll 'assume faith' in others over the course of our daily lives. I know that I'll stumble now and then along the way, but I plan on eating a lot more pancakes (literally and figuratively) in the future. We smile with our hearts!



A Moebius Poem – by Joan Fleitas, Ed.D., RN

There's a giggle in my belly
There's a smile in my soul
In my dreams I can talk clearly
Any my nerves I can control.
But in real life there's a problem.
You can't see beneath my skin.
So you look just on the surface
and you notice I can't grin.

My face can't make a smile
and it's hard to close my eyes.
I was born with Moebius Syndrome.
What a name for a disguise.

'Cause I am not this syndrome
I'm a me that's much like you
Though I may look slightly different
and I may at times seem blue.

Some people think that laughter
must show right on your face,
but if you lived with Moebius,
you'd know that's not the case.

So teach your heart to listen.
It will hear what you can't see.
We will have the greatest friendship
If you stick around with me.



Why I Can't Smile – by Jessica Maher

Know how sometimes you get the feeling that you can't do something your friends or classmates can do? I feel that way every day because I can't smile. Let me explain.

I was born with Moebius Syndrome which was caused by a loss of blood when I was a developing baby. That loss of blood caused the nerves for my face to form the wrong way, and because of it, I cannot smile or move my lower lip very well. When you're a teenager, or a grown up, you can't get Moebius Syndrome, you have to be born with it. When you are born with Moebius Syndrome you could have one or more of the following features: clubbed feet, missing fingers and/or toes, crossed eyes, and you cannot smile.

Moebius Syndrome affects me by the way I talk and smile. Because the nerves in my jaw and lower lip do not work well, I have a hard time making "P" and "B" sounds and I cannot move the corners of my mouth to smile. Some Moebius kids cannot feed at a young age and they take longer to develop physically. Thankfully I can be physically active in sports like basketball, soccer, and karate.

I also express my emotions differently than other people: because my face is stiff, you might think I have no emotions. Although you can't see it on my face, I DO have intense emotions inside when I am under stress, such as when I'm taking a hard test or when people laugh at me. But, while Moebius Syndrome may stop me from physically showing my emotions, it does NOT stop me from being pretty.

I am special, not just because I can't smile, but because I am rare. I am nearly one in a million because Wikipedia estimates there are only 2-20 cases of Moebius Syndrome per million births. In fact, you may never meet another person with Moebius in your entire lifetime. Although I am very unique, I've met other children with Moebius, just like me. My friends Dominique and Elizabeth support me because I can talk to them about my feelings and they will understand. I can trust them not to blab to other people about my secrets and personal feelings, and I know they would never make fun of me because they are my mirror image.

I hope you enjoyed my writing, but I have one small request to ask... Please don't laugh if you see me or my other Moebius friends, just think: "she is a little bit different, but she can feel as happy from a compliment or just as wounded from harsh words as anyone else." We smile with our hearts!




A Conference Memory – by Jessica Maher

My name is Jessica Maher, and I live just north of Tampa, Florida. The first time I walked through the Moebius Syndrome Conference doors in 2002, I felt like I was the only one with Moebius Syndrome and I did not know anybody, but I soon found many friends. As the years and Conferences have gone by, I have met so many people with Moebius! It is nice to know I'm not the only one with Moebius Syndrome. I learned that many people around the world have Moebius Syndrome too.

My favorite part about having Moebius Syndrome is that people recognize you. People recognize you the first time they see you and never forget your face! When I went to my first school, I was kind of scared, because I didn't know anyone, and nobody in the entire school had Moebius Syndrome. One out of 800 students to be exact – that was rather strange to me.

At the Moebius conferences, I have many friends that look just like me! Sure, everyone is different, but we all share the same challenges and face the same fears. I have many friends, like Domonique, Mandy, Madison, Elizabeth and Samantha that I am excited to see in my "own environment".

I waited two long years to see all of my Moebius friends again, and I hope everyone enjoyed the conference this year just as much as I did! And... If you are ever in Florida, please come and visit me! 😊

My advice to kids with Moebius: If you are ever in a situation where you are with people older than you, just be yourself. If people don't like you for who you are, then don't be offended. Just think... they don't know the "real me". Tell them – "Don't judge a person by their face". 😊 



Why Moebius Syndrome Awareness Day is Important to Me

Moebius Syndrome Awareness Day is very very important to me, not just for my daughter but for everyone who has it, especially here in the Philippines. Moebius Syndrome Support Group Philippines members are very active to spread awareness not only for this day but every time we have opportunity to spread the word. We are very proud that we have many supporters when celebrating Moebius Syndrome Awareness Day. -- **Maridel Carapatan**

Moebius Syndrome awareness is important to me because like many others, I was not aware it even existed until January 27, 2011. The day my daughter was born was the most amazing and life changing day for us. We had never heard of Moebius Syndrome and had NO IDEA what it was. I was given papers and Dr's explained it but I was so confused. For days I researched and dug into it and stumbled upon sites such as these where people shared their experience and I was able to meet other families. Moebius syndrome awareness means informing people before they have a chance to judge someone based on their looks. It means making sure others know what this syndrome is and making people take a second to step outside of the closed minded worlds we all have once lived in to know about the unknown. Many people do not know about its and probably never will unless they or someone they know is faced with it. I want people to know what it is because it does not define a person. My daughter is a smart, funny, full of energy 3 year old who just so happens to have Moebius Syndrome. At first glance, sure she may be different but her personality is big and her heart is bigger. --**Lila Papp**



Having a Moebius Syndrome Awareness Day is very important to me as it offers a great channel for learning about a very little known syndrome. I am grateful for the knowledge and compassion this site and group have allowed me to gain. I am a runner and belong to the www.whoirun4.com group, a group that pairs runners with buddies who have various limitations or disabilities. I was looking for a compelling reason to run and not only was I paired with a fantastic buddy, Ozzie, but he happens to have Moebius Syndrome and so my quest for knowledge began! Ozzie inspires me and motivates me daily and he truly smiles with his heart (has captured mine as well). [#irun4ozzie](https://twitter.com/irun4ozzie) I will wear purple with pride on January 24th.

--**Jean Fielding**

Moebius awareness is important to me because of my grandson Dallas Walker. He's an amazing lil guy. He never ceases to amaze me with all he has accomplished and keeps figuring out ways to do more and more. It's important to make more people aware because when he was born I had never even heard of Moebius Syndrome. These groups have given me a better understanding. --**Aline Masters**

Having a Moebius Syndrome day is very important to me and my family because it lets a lot of people aware of this. When my son Tony, was born, 20 years ago, I had no idea what Moebius Syndrome was. I was given the phone number to Lori Thomas. This changed my life. She told me what to look forward to and opened my eyes to our family, the Moebius Syndrome family. With her knowledge and kindness we learned a lot. If it wasn't for her and all the people who have been affected by Moebius Syndrome, either having it, has it, or knows someone who does, I don't know where we would be right now. We had to educate everyone in our area, including doctors, family, teachers etc, about this. Now that we have an awareness day, it gets more attention. The foundation has grown so much since my son was born. The more we can get the awareness about Moebius Syndrome is better. Now that it is all over the internet and



facebook, people who need to find out about this can find all the information easier and specially find other people who have this in common. We are all family in our connections with the Moebius Syndrom Foundation. We are all here to help each other with support and even friendship. So the more we can do to raise awareness of Moebius Syndrome, the more connections we can make, and we can let people with questions know all about us. I am so gratefull for everyone that I have met or talk to from the foundation and people I have met on here that is connected by Moebius one way or the other. This is the best group of people I have ever been involved with. That's why I say we are all family. --**Becky Burdick**

Moebius Syndrome Awareness Day is important to me because almost four years ago I met my best friend; she has Moebius Syndrome. We met at church, she's shy-like me, but I noticed that other people were not talking to her. We became friends, she is one of the sweetest souls in the world! Literally, she would give somebody the shirt off her back! Throughout our friendship I've seen how people treat her or take advantage of her generosity, I think in large part because they do not understand her and don't know what Moebius is. Any disability, physical or mental, is no excuse to treat somebody differently! I believe that if more people were aware of and knew what Moebius was, they would no longer see just a different face, they would see the smile within. --**Amanda Michels**

Hey you out there! DO YOU KNOW WHAT MOEBIUS SYNDROME IS? Neither did I until my granddaughter, Jessica, was diagnosed with this very rare syndrome 4 years ago. What did you say? Moebius syndrome? What is that? I googled and for the first time in my life I realized that there are people walking on earth that can't swallow, Blink their eyes or can't SMILE!!! Something that everybody else just take for granted. Therefore having an annual official awareness day to tell and show people all this will make the explaining to everybody staring at Jessica because she is "grumpy" that she actually can't smile with her little face, she is actually smiling with her heart, a lot easier. Please join me in support of all the people with Moebius



Syndrome by wearing purple on January 24th, the official Moebius Awareness Day. Share and like this as by doing this you'll actually spread the awareness all over the world and if that action makes only one person aware of this syndrome it makes the world a better place for people living with the syndrome. Thank you and keep smiling with your face if you can (and if you can't – keep using your heart!!) --**Marina Vosloo**

Moebius Syndrome Awareness is important to me because: I once met a young lady with Moebius Syndrome, and to tell you the truth, she was so beautiful I did not notice that she was affected by facial paralysis. I remember when we would go out, the stupid's would ask her "what's wrong" or tell her to "smile." I watched her handle every ignorant statement with class, dignity, and grace and watched her develop into a brilliant legal mind. I never told her, but she was the one who gave me the strength to explain the burn scars on my face with pride and joy, and to not be held back from any aspiration. Since I've known her, I've never known a prettier woman, or a woman who actually smiled more! Although the the official day was yesterday, Moebius Awareness is important to me everyday! --**Nikki Lynn**

Moebius Syndrome Awareness Day is very important to me and my family because our son was born with Moebius syndrome and he is our world. Every single day Dallas proves to all of us that there is nothing that can ever stand in front of him and he achieves every obstacle he attempts. I hope that our little boy helps others keep their mind open and understand that there is nothing that can stop you if you put your mind to it! --**Cheyenne Kevin Walker**

Moebius Syndrome Awareness Day is important to me for many different reasons. First, knowledge of this rare condition is limited amongst the general public, and as a result, there is little tolerance or compassion for those who have Moebius. We are singled out, mischaracterized, misunderstood, taunted, sometimes even worse. It is my hope that knowledge of this rare condition promotes tolerance. Second, I want the youth who are affected with Moebius to know



that they should NEVER put their dreams or aspirations anywhere near the sidelines! You are different for a reason, and people will remember you, so use it to your advantage and pursue your goals! Don't let anyone tell you no! You can have a professional career AND have Moebius! Finally, Moebius Syndrome Awareness Day is important because it is a way for all of us to connect. We're not alone, not the only ones who have experienced cruelty as a result of having Moebius Syndrome. Network and reach out to those in your area! --**Chelsea Walker-Gaskins**

Our beautiful daughter Kara was born with Moebius Syndrome this past summer. Moebius Syndrome Awareness day is so important to me and my family. For me, it's a way of coping and accepting what is...with such a large spectrum of severity, Moebius syndrome has talk me to appreciate every moment I get with not only Kara, but our other daughter Luna. We are so blessed to have her in our lives and I am looking forward to gaining new friends all around the world who share this same situation. I want my friends and family to see that too which is why Moebius Syndrome Awareness day is so very very important:) --**Tara Buie**

WHY IS HAVING A MOEBIUS SYNDROME AWARENESS DAY IMPORTANT TO ME? It is important because people make judgements about me that are not true. I want everyone to know that I am just like them. And if anyone else is born in my area with Moebius Syndrome, I want his or her life to be a little bit easier than mine at least. I should hope that the kids in his or her school will be nicer and more understanding to him or her than they were to me. So Moebius Syndrome Awareness Day is important so that people will understand that I am not the way that I look and kids born with it in the future need to be accepted quicker than I was. --**Roger Kreil**

Having a Moebius Syndrome Awareness Day is important to me because all the people can find out about this Syndrome. Having Moebius Syndrome doesn't mean you can't achieve your dreams, you can, like all the others, you may just have to fight more to make them come true. It's important that people have knowledge about Moebius Syndrome and this is the best



way, having an Awareness Day so everybody can see that even if you look different, even if you can't smile and show your emotions you can do it with your heart and that is the best and most honest one. --**Anna Maria Exposito Underhill**

My daughter was born in 1977 when there was little or no information on Moebius Syndrome. My husband and I had to go through genetics study as well as my daughter. There was no rhyme or reason they could give, except that the synapse in the brain either misfires or didn't develop. Back then I was told she would be a vegetable and require 24 hour care by THE NICU drs. Our genetics dr sent me 100 cases studies that had been done at that time. Over 80% were very intelligent but we're treated as severely retarded because she couldn't speak, and she always had the "MASK" face her expression never ever changed. Autumn Lee Kunkle was born on April 2, 1977 and passed away on April 16, 2002 her 25th birthday. She walked, she could feed herself, she developed her own way to communicate with us to make her needs known to us. We all enjoyed and loved her very much and miss her every day. --**Evelyn Williams**

I have a friend with Moebius Syndrome. When born their face is paralyzed where they can not move their eyes from side to side. Some have paralyzed smiles where they can't move their lips. If you can take time out and look up to see that not everyone has the perfect smile, but they do have the biggest hearts. She is such a beautiful girl at heart I'm lucky to have her as my friend. She always brings a smile to everyone from her family to her friends like myself. She is going to college exploring her dream as a writer and be on the radio. She has become such a success and that because of her family. You go girl!! --**Linda M. Walsh Rutherford**



My nephew Dallas walker has Moebius Syndrome – he is strong, independent and determined. I feel there needs to be more awareness so programs can be available to help these families. I love you Dallas, your Daddy fights for our country and you are his hero. You're mine too ...Cheyenne Kevin Walker...love y'all to the moon and back. --**Robin Fox Thorson**

Moebius Syndrome Awareness is important to me because I was once told by a great man, a man just like Hannah and many of you, Mr. Tim Smith, that Hannah was his inspiration for the beginning of it all. I appreciate that she helped with this motivation and amazing thing that you have accomplished. I thank you Tim for helping us and making it important for us to remember our own that have passed. It helps us grow. It teaches us how to live life when gets to us. Good or bad. So again Tim, you did it again. --**Katie Penycate**

Moebius Syndrome Awareness day is not just important to me, but to the entire Moebius Syndrome community. It's days like this that make sure the knowledge is spread, and reaches the right people. Hopefully with more Awareness days, we won't have any more people like my little sister have to go to multiple doctors, hospitals and live 2, almost 3 years without a diagnosis. I have never heard of Moebius before my sister's diagnosis, but I hope to change that in the future. --**Kiesha Kusch**



Epilogue

Why Awareness Matters – Anonymous

Dear _____,

I've wanted to say this on so many occasions however I always felt it better to just keep it to myself and hope that you would eventually come around. I've hoped for years that you would see beyond my child's seemingly expressionless face and see the beauty within her. I hoped you would see how she lights up the room with her stories, see how funny she can be, and see how smart she really is... But sadly I continue to be disappointed. I don't think you realize how you look when you stare at her... Or how a seemingly innocuous comment can hurt; "Can she wipe her face? Whenever I try to take a picture she always looks like she has stuff on her face..." You might not think anything of it, however every time you say something like that, it offends me.

You don't see it because you are blind on a couple different levels... blind to the fact that she is a remarkable human being, blind to the fact that she is unconditionally loved by me and her immediate family, as well as her many friends. You look at her and say things like "can it be fixed?" Or you look at others in the Moebius community and pity them... why? You have no idea of anyone's "story". You have no idea what's involved with a smile surgery. You have no idea if somebody is happy, sad, or needs help. You have no idea how successful so many people with Moebius Syndrome really are. You have no idea because you have never truly taken an interest in the greater Moebius community.

You are one of the many reasons for which I continue to raise awareness – Please do some reading, watch some videos, and take an interest in the greater Moebius community. There are so many wonderful, smart, funny, clever and very happy people within this incredible “family”. I ask you to educate yourself so that you can better understand, and treat members of the Moebius community with the love and respect they deserve.





*We smile
with our hearts!*

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