

Author's note: *the following is an abbreviated version of my October, 2022 personal memoirs which were written primarily for distribution to my family members*

INTRODUCTION

This short work is a memoir of my life. I appreciated my parents taking the time to write their individual memoirs for the benefit not only of their children, but of their grandchildren, great-grandchildren, and so on. Due to the fact that I didn't have children, I once questioned the necessity of writing a personal memoir, as I would never have any offspring or descendants who would like to know about my life and read the words I'm presenting to you now.

Well, something happened to change all of that! I married Doris Walker on June 1, 2019. We've been married over three years and reside in League City, Texas. Doris had 16 grandchildren when I met her in 2016. They now range in age from 6 to about 23. I've gotten to know the majority of them.

Doris' son Chuck and his wife Amy decided to foster a couple of young children about 2 ½ years ago (a boy and girl who are siblings). They fell in love with the "Littles" as they've come to be called, and became interested in adopting these two. The adoptions took a while to progress, but they were finalized on August 23, 2022. Now, Eyrah (age 3) and Andre (age 4), are officially Chuck and Amy's and are considered our grandkids. We've built up a relationship with both of them over the past couple of years, which means I've been spending time honing my grandparenting skills!

Inasmuch as Doris and I are the only grandparents they'll ever know, I thought it appropriate to write this memoir with Eyrah and Andre in mind. They are obviously not yet old enough to be able to read this memoir and comprehend its contents, although they will be one day. Then they will come to know and understand me much better through this memoir, as I'm sure other readers will.

I've decided to write this not only for the benefit of the Littles, but for others who may like to know about my background and experiences.

MOEBIUS SYNDROME

If you're reading this, you may already be familiar with Moebius syndrome. Understanding Moebius is necessary in order to help you put various parts of my life into proper perspective and better appreciate the challenges I've experienced and, in some cases, overcome.

Moebius syndrome is characterized by impairment of the sixth and seventh cranial nerves, which control lateral eye (side to side) movement as well as facial expression, including the ability to smile, frown, wink, and close the eyes completely. In my case, an MRI has shown that that these nerves are absent. Our faces are "frozen," meaning we cannot show any facial expression; people often feel we have a permanent "blank look" on our faces.

Many with Moebius have speech impediments. My speech is considered good compared to many others with the condition. However, I have a vaulted narrow palate which affects my speech. Also, because I cannot close my lips, correct pronunciation of

consonants such as “b” and “p” is difficult. I find that I have to speak more slowly at times in order to be better understood by others.

Moebius syndrome usually causes considerable facial abnormalities, but they differ from person to person. Many of us have small mouths and small lower jaws. My facial appearance is very similar to many others with Moebius; I consider myself to be roughly in the middle of the Moebius spectrum.

I was diagnosed with this condition back in the 1950’s when Moebius was practically unknown. Medical researchers estimate that there are between two to twenty cases per million births worldwide, but no one knows for certain how many people with Moebius exist. Nonetheless, Moebius Syndrome remains a very rare disorder. Many health and medical professionals have never heard of it.

The majority of children, adolescents, and adults with Moebius syndrome face many challenges throughout their lives. My life has been no exception, as you’ll see in the forthcoming pages.

FAMILY

My father and mother were born and raised in Southwest Louisiana, also known as “Cajun country.” They were from a small town called St. Martinville, which is about 20 miles southeast of Lafayette. Their families, who were of French descent, settled in the area back in the 1800’s.

My parents knew each other from an early age, as they were distantly related. Mom attended a Catholic boarding school following high school and earned a teaching certification. She taught at rural schools in her home area (the first was a one-room schoolhouse with no indoor plumbing) until she married my dad in 1943. Mom left teaching after they were married and worked for the Louisiana welfare department until after World War II.

My dad (also known as “Pop”), interested in military service as well as earning a college degree, received an appointment to the U.S. Naval Academy. He graduated there in 1941 and served mostly on destroyers in the Pacific Theater during World War II. Pop was definitely “in harm’s way” much of this time; his ship narrowly escaped being hit by a Japanese kamikaze (or suicide) aircraft on one occasion! He advanced in rank over the years, finally retiring from the Navy in 1965 at the rank of captain.

So I was born and raised into a military family which relocated every couple of years. More details to follow!

EARLY YEARS

I was born in 1951 at the U. S. Navy Medical Center in Bethesda, Maryland, just outside of Washington, D. C. At the time of my birth, my parents had two little girls, my sisters Anne and Adele (Dee), who were then five and four, respectively.

After the conclusion of the war, Pop returned stateside. He was eventually assigned to military posts with our embassies at Athens, Greece and Beirut, Lebanon for about three years until he and his family returned to the U. S. Upon returning from Beirut in 1950, my dad received an assignment at the Pentagon. Our family lived in Falls Church, Virginia, another suburb of Washington.

When I was born, my parents and the doctors could see that something was not right with me. In the early 1950's, very little was known about Moebius. However, they loved and cared for me the best they could in those early days, as they did throughout my young life. Mom noted in her memoirs that, as a young child, I benefited from exercise and speech therapy.

We relocated to Newport, Rhode Island in 1953 for two years when my dad was given command of a destroyer. Some of my earliest memories are from this period, particularly of a rare northeastern hurricane that struck Newport and caused considerable damage. My dad was not at home with us, but Mom, Anne, and Dee were with me in a bedroom praying while the storm was wreaking havoc outside.

Mom told a humorous story about our time there. She said that they threw a cocktail party one day for friends as well as for some of my dad's officer buddies. According to Mom, I would walk among the guests at our house and finish people's cocktails when they put them down. At the end of the evening, she said I was "staggering around." Shortly after they noticed this, I threw up. The ship's doctor was there; he examined me and said, "He'll be fine – just put him to bed." So that was my first experience with alcohol!

We returned to Falls Church in 1955 when my dad received another assignment at the Pentagon. I began kindergarten the following year at a local Catholic school, which my sisters also attended. It was during this time that my parents took me to the National Institute of Health in Bethesda to be examined regarding my condition. The people there couldn't be of much help, but they suggested I see a plastic surgeon at the nearby Navy Medical Center regarding my drooling problem. This surgeon later performed plastic surgery on my lower face and jaw to restrict my mouth opening, which helped to address the drooling. He was also the person who correctly diagnosed me with Moebius Syndrome.

Because I drooled so much until this surgery, some of the kids in school called me "Doctor Bubbles." This was the first of many mean-spirited names I would be called over the years. "Doctor Bubbles" may not seem offensive, but other names I was later called certainly were! I began to notice how differently I was sometimes treated by others, both at school and other places.

As I grew up, my facial difference and speech impediment made me stand out even more, resulting in some teasing and bullying. I had thought of myself as a normal kid, even though I was obviously physically different. I eventually came to recognize that the differences brought upon me by Moebius syndrome presented challenges that would continue through my childhood and adolescence. In fact, some challenges persist even today!

My younger sister Lucie was born in 1958. A few months after Lucie's birth, my dad was transferred to San Diego. We found a nice home on Coronado Island, across from San Diego. I have some good memories of our time there. I was in second grade and was enrolled at a nearby Catholic school. I remember enjoying San Diego and southern California. The climate there was good, we saw plenty of nice sights in the region, and spent time in the Los Angeles area where we visited Disneyland and Knott's Berry Farm. Unfortunately, our time in San Diego was short (only one year). We were brought back to Falls Church for three more years as Pop had a new assignment at the Pentagon.

Anne, Dee, and I were enrolled at St. James school in Falls Church, the same school we attended previously. I went through third through fifth grades there. St. James had

plenty of nuns on their teaching staff. It was quite an experience being taught by these nuns, who I regarded as good teachers but were very strict and downright scary to many of the younger kids!

As with our time in California, I have many good memories from those years. I was actively involved in Cub Scouts, enjoyed playing in the snow during winters, did quite a bit of sightseeing, and went on a weeklong family summer vacation to scenic West Virginia. I also developed a lifelong interest in the Civil War when my dad took me to the centennial re-enactment of the Battle of Bull Run not far from Washington D. C. in July, 1961. We also visited the Gettysburg battlefield park that same summer with one of our Louisiana cousins who had come to spend time with us.

After those three years in Falls Church, my dad was posted to Ottawa, Canada to serve as the U. S. Naval Attaché to Canada, so we moved there in the summer of 1962. By then, my older sisters were in high school. I was enrolled at a public school in our area which I came to enjoy and appreciate. It was there that I completed sixth, seventh, and eighth grades.

In seventh grade, my homeroom teacher apparently believed I wasn't intelligent enough to keep up with my academic work. She seated me in what we might call a "remedial row" in our classroom. I remember thinking that I didn't really belong there. But to be perfectly honest, I didn't apply myself in school to the extent I should have, resulting in average grades. I was capable of doing better academically.

Those three years spent in Ottawa were extremely special to me. I came to love the country and its people. We went snow skiing in nearby Quebec practically every Saturday during winters, and often went ice-skating. In summers, we'd vacation at a lakeside cottage and go swimming, fishing, and water-skiing. We visited places like Toronto, Quebec City, and Montreal, and took a long vacation trip to Canada's maritime provinces.

MOVE TO LOUISIANA

After 24 years of active duty in the Navy, my dad retired at the end of our tour in Canada.. Subsequently, our family moved to Lafayette, Louisiana in July 1965. Pop was 47 at the time and too young to retire, so he sought employment with our local university, at that time called the University of Southwestern Louisiana (USL), and now named the University of Louisiana at Lafayette. He accepted the position of Director of Student Housing, and worked there until 1977.

My sister Anne was in nursing school in Baltimore, Maryland, so she wasn't living with us. Dee enrolled at USL and married her husband Tony Watt later that semester. So that left just me and Lucie at our new home with our parents. Lucie and I were enrolled at a local Catholic school which at the time included both an elementary and a high school. Lucie was in second grade by then, and I was starting ninth grade.

The four years I spent in high school were very different than my previous school experiences. I was teased and bullied there much more than had occurred in my past. I tried to fit in and be accepted as "one of the guys," but that simply didn't happen, given my "uniqueness." For me, part of having Moebius syndrome meant you may not be accepted or easily befriended by others. After all, I had a facial difference and a speech impediment, and was a bit awkward with my social skills at this time. I was also somewhat clumsy and lacked athletic skills, which caused some embarrassment when I attempted

to play sports, In Ottawa, I received some mild teasing because of this, but it was much worse during high school. It's pretty embarrassing when you're choosing up teams during physical education class and you're almost always the last one chosen. However, I became active in school organizations, including serving as cartoonist for our school newspaper and yearbook. I had been drawing and cartooning since age 5 and apparently had inherited some of Mom's artistic genes. I did some limited dating, but was reluctant to ask girls out for fear of rejection. I was actually very shy then and for years thereafter, but eventually conquered this later in life.

Also in high school, people would tease me because of my speech. One guy even said to me "The less you talk, the more I like you." I also learned from others in later years (and discovered through experience) that some people didn't care to listen or talk to me.

Following high school graduation, I took a six-week European study tour with a group consisting of about 140 students. We visited several countries and saw plenty of historical and cultural sites. It was a great experience and was packed with many fond memories.

During my freshman year at USL, I went through fraternity rush where you attend open houses and meet the frat members. Later, each frat makes "bids" or offers to students to join their fraternity. There was one frat I was particularly interested in. However, I received no bids, which was a huge disappointment to me. When I didn't hear from that one or any of the others, I discussed it with one of my friends, who checked on this and then told me outright that it was my physical appearance that kept me from receiving bids. He wasn't being cruel, just sharing the honest truth with me. In fact, I don't know of any other Moebius adults (either male or female) who were in college social fraternities or sororities. No surprise, I suppose! However, I was actively involved with other campus organizations, and continued one of my high school interests by serving as cartoonist for our college newspaper.

While attending USL, I switched majors a couple of times, and finished with a bachelor's degree in business management in 1974. I did some dating in college, but was still reluctant to approach women or to ask them out.

By my senior year, I was interested in joining the Navy and entering an officers' training program. As it turned out, I couldn't pass the physical because of my extremely flat feet and fallen arches, so that was not an option. One other career interest was in personnel management (later known as Human Resources, or HR). I knew I had to keep my options open, because my future employment was subject to whatever offers employers would extend to me. Whether or not I'd have an opportunity to enter the world of personnel management was uncertain. I was also insecure about job interviewing due to my facial difference, not knowing how I'd be regarded by potential employers.

Following college graduation, I was employed in different positions over the next several years. One of these was coordinating a Federally funded jobs program for the City of Lafayette. This gave me an opportunity to work in what was essentially a personnel position. Once I had that experience, I knew that was the profession I wanted to pursue.

HOUSTON

In 1980, I went to work at the Lafayette area store for a small oilfield supply company based in Houston. At that time, the oil business was booming. I started out working in the warehouse, driving trucks, and making deliveries to customers. I later moved into inside sales. A year later, I received another promotion and relocated to north Houston where our home office was located. In 1982, the oil business took a nosedive and a large portion of our employees were laid off, including yours truly.

Following the layoff, my job search wasn't yielding any good results. After all, the employment market tightened up considerably and I wasn't receiving any decent offers. It may have been during this period of unemployment that, when speaking to a potential employer over the phone, they seemed very interested and asked me to come in for an interview. When I arrived for the interview, the person's demeanor changed as soon as we met face-to-face. There's little doubt that my appearance had surprised or confused this individual. Others with Moebius have reported this happening to them as well.

I had considered pursuing a graduate degree for some time, so I enrolled in the University of Houston's MPA (Master of Public Administration) program. My parents graciously offered me financial support for this. I enjoyed the experience, but had to apply myself and work very hard, as the program required you to maintain a "B" average, something I had never achieved before. By that time, I was 31 years old and more mature than I was starting out as an 18-year-old freshman at USL. I finished the program in late 1984 with a good GPA. After working a temporary job for several months, I landed a position with one of our local governments in their Personnel (now HR) department. I was assigned to a new division which was just starting up at the time. The position involved labor relations, administration of the employee grievance procedure, and other duties and responsibilities over the years.

I later spent time in the Public Works and Parks and Recreation departments and then returned to Personnel. One of my major responsibilities in each of these departments was handling employee disciplinary actions. Most of our employees were dedicated and hard-working. However, there were some who unfortunately displayed unacceptable behavior. This could include poor attendance, fighting on the job, theft, insubordination, failure to follow instructions, and violation of our drug policy, among other things.

A male employee in Public Works presented a doctor's note to his supervisor following a work absence. The supervisor was suspicious of the validity of this doctor's slip, so it was turned over to me to research. Turned out it was indeed a fraud. I contacted the medical clinic, and they indicated that the staff person whose name was on the form was not an employee there, and that a "Dr. Johnson" who allegedly signed the form was a gynecologist. Remember, this was a **male** employee! During a disciplinary hearing, this employee was shocked to hear that the Dr. Johnson he claimed to have seen that day was a gynecologist. This guy was subsequently terminated! So much for a clumsy attempt at providing a fake doctor's note!

I was very happy to be back in the HR field, and generally enjoyed my job through the years. Like many other HR professionals, I had ambitions of "moving up my career ladder" once I had been there a while. I maintained a good employment record and received two promotions in the 28 years I was there. However, many other employees received more frequent, and better, promotions. I felt that my having Moebius syndrome

was holding me back from further advancement within our department. This was implied to me by one of my managers, but I don't know this to be an absolute fact. However, I strongly suspect that this was the case. Other issues I faced in our department were favoritism, back-stabbing, and different types of discrimination. It's a rather long, complex story which I won't get into here.

Perhaps I was naïve before I began working there, but I had assumed that a local government would be more accepting or inclusive of someone who was physically different. Before too long, I sensed that this wasn't happening, at least with me. Also, word got back to me that some people in management would ridicule me behind my back, which was quite sad!

I married my first wife in late 1984. Unfortunately, like many other marriages, ours didn't work out. Following a long separation, we divorced in 2001.

Sadly, we lost Mom (Verne) in 2004; Pop (Roland Sr.) died in 2011. As anyone who has lost a parent will tell you, it was very difficult to say goodbye to each of them. Prior to their deaths, I had travelled back and forth to Lafayette and visited them as often as I could.

MOEBIUS SYNDROME FOUNDATION

I became aware of the Moebius Syndrome Foundation in 1996, and immediately reached out to them. In the next couple of years, I met a few Texas children and their families with Moebius, in addition to a lady from west Texas who had Moebius. I attended the Foundation's 1998 conference which was held near Toronto, Canada (the Foundation holds a conference every two years). We had people of various ages with Moebius not only from the U. S. and Canada but from other countries as well. In particular, I was pleased to become acquainted with about 15 other adults with Moebius who were in attendance. Many of the "quirks," idiosyncrasies, and characteristics some of us share were easily noticed. For instance, due to our small mouths, many with Moebius (me included) have challenges eating, which may be observed by others around you. Food tends to get caught inside our mouths as we chew, so we push the cheek with our hand to dislodge the food and enable us to swallow it properly. This must look quite odd to the average observer. After seeing some of the others doing this and other things, I finally saw myself as others had been seeing me all these years. For this and other reasons, the conference was an emotional, life-changing experience for me!

Beginning with this conference, I began making many good friends, which included other adults with Moebius as well as children and their families. It's been nice to attend conferences every two years and watch the kids grow up and reach adulthood. Doris and I saw some at our 2022 conference that I first met as youngsters years ago. We really are like one big "family."

Some of the Moebius adults began getting together in the summers between the conferences; we enjoyed some fun and camaraderie during these gatherings. We also held many discussions about the challenges we faced and tried to help each other by offering support and sharing our experiences and insights. I continued to attend each conference over the years, and helped coordinate and host the 2004 conference held in Arlington, Texas. Additionally, I served on the Foundation's Board of Directors from 2005

until 2018, and was very honored when they named me an Emeritus Board Member after I had left the board.

RETIREMENT

I retired in 2013 when I was 62. I had grown very unhappy with the way things were going in our department and decided that it was time to move on.

I have tremendously enjoyed my retired life and have been busy with various things I've always wanted to do but lacked adequate time for them when I was working. I took yoga classes, did some travelling, volunteered here and there, enjoyed doing more reading, watched movies, and stayed in shape by riding my bike, swimming, and exercising.

Since my divorce, I had romantic relationships which eventually failed. One breakup in particular was very difficult for me. Relationships (and simply starting one) are difficult enough for "normal" people, but for someone with Moebius syndrome, they can be extra challenging. I dated sporadically and had utilized some online dating sites, which is how I found many of my dates.

Speaking of dating, there's nothing worse than meeting a lady for the first time and feeling that she's not interested in you at all. I could always sense when a lady was disinterested or uncomfortable, or was perhaps wishing she could be somewhere else.

After one of my break ups, I joined my church's singles ministry and began attending their social events regularly. Eventually, I began co-chairing the group, and relinquished that role when I married in 2019. I was also involved with a couple of other singles' groups, and had plenty of fun attending events, dinners, live music venues, etc.

DORIS

I decided to try the Christian Mingle dating website in August of 2016. After all, I wanted to have a good Christian woman in my life, especially if I were to begin a relationship and contemplate marriage. I had been praying for years about finding the right mate, fully understanding that this was on God's timetable and that it may take some time for this special person to come into my life. During some of these prayers, I specified the type of characteristics or qualities I was searching for.

Well, these prayers were answered a few weeks after I began using this site. I connected with Doris by late September via e-mail; our first date was October 21st. Up until that time, we had been e-mailing, texting, and making numerous phone calls, so we were already getting to know each other quite well. Doris had been a widow for a while and was working for a downtown law firm as a paralegal.

I looked forward to meeting her after work in Midtown Houston on the 21st. I always experienced some anxiety on a first date, particularly this one. After all, we had hit it off so well during our various contacts and conversations. I felt extremely comfortable with her and appreciated her down to earth qualities and sense of humor, which was similar to mine. But, I asked myself "What if I like her but she doesn't like me, or vice versa?" and "What if things don't go well tonight?" You simply won't know any of this until you've actually met. I had so many negative dating experiences up until that point, I felt I had to "protect myself" by hoping for the best but mentally preparing for the worst.

As it turned out, everything went well. Doris showed up late because she was lost and that embarrassed her, although I reassured her this was nothing to worry about. I enjoyed our time together, gave her two hugs and kisses when it was time to head home, and called her the next morning. We were off and running! From that point on until shortly before we were married, we saw each other practically every weekend. We lived about 45 minutes apart, so we weren't conveniently close to each other. However, seeing each other regularly was doable, especially on weekends.

We became engaged in January 2019 and were married at her son Chuck's home on June 1, 2019 (Doris had retired the day before). It was a small gathering officiated by Chuck, who is a minister. Because we were very busy after the wedding transitioning and doing various things, our honeymoon was deferred. We took a Caribbean cruise that October and had a great time.

Along with everyone else, we were faced with the COVID-19 pandemic beginning in March 2020. I've understood that one effect of the pandemic was that many couples had serious issues while they were shut in together for months and ended up parting ways. The pandemic was a test for us as well, but we survived it and have enjoyed living more normal lives after the COVID situation improved.

As I write this in October 2022, we have taken five trips this year. You might say we were making up for lost time, as the pandemic had made us uneasy about travelling during the previous two years.

We've come to collectively call ourselves "RoDo" which is short for Roland and Doris. We typically enjoy having a lot of laughs every day, and experience what have come to be known as "RoDo moments." These occur when one of us says or does something funny or goofy, which is usually, but not always, unintentional. Two examples of RoDo moments:

Key Lime Pie Disaster: One day, Doris decided to make a key lime pie for a Thanksgiving celebration they were having at her office. She initially had a hard time finding key lime juice, but finally found some. I was in the kitchen with Doris when she was preparing the pie. Trying to be ever so helpful, I took the graham cracker pie crust which was in the package, removed the top, and then turned it upside down and dumped the crust, which caused it to break into hundreds of pieces! Doris' remark was "and why did you do that?" I had to run to the store to get another pie crust. Doris claimed that my "mistreatment" of the pie crust distracted her, and she put twice the amount of required key lime juice in the pie, which made it way too tart to eat. She then made another pie, which turned out ok.

Drill, Baby, Drill!: Doris and I decided to install handles and pulls on the kitchen drawers and cabinet doors. When we began working on the drawers, which are all about waist high, I asked Doris to bend over and watch me as I placed my drill against the drawer to drill holes for each handle and make sure I was drilling a level hole, and not at an angle. We proceeded to drill almost all the drawer holes, with Doris stooping over to watch and tell me whether the drill was level or not. Toward the end, her back was starting to hurt. Just as we were beginning to drill the last couple of holes, I looked down at the top of my drill, and told Doris "Hey, guess what? The drill has a built-in level!" Of course, Doris was not happy to learn that I didn't need her stooping over all this time, because using the "newly discovered" level would have done the trick!

Doris has been very supportive in my Moebius Syndrome-related efforts and activities. She's assisted at local or state Moebius events held in the Houston area, as well as volunteered at conferences put on by the Moebius Syndrome Foundation in 2018 and 2022.

Doris is a wonderful wife who takes great care of me and kindly puts up with my personal quirks, as well as my "unusual" sense of humor. We look forward to more travel in the future and experiencing other "RoDo" adventures. I am so glad that Doris is my life partner, and that we've made a great life together!

MY LIFE WITH MOEBIUS SYNDROME

What's it truly like living with a condition such as Moebius syndrome? If you were to ask a large number of adults who have it, the responses would vary. Many adults with Moebius have had common experiences that we can all relate to. It is difficult for me to discuss this question with someone who doesn't have Moebius or any facial difference and get them to truly understand what I've been through and how emotional and challenging all of this can be. I've told others that if you could "walk a mile in my shoes," or live my life for a while, then you might begin to understand what I've faced. Even if I sat down with individuals and discussed these experiences for a couple of hours, I still don't believe they'd gain a full appreciation of these struggles and challenges. It's important to me that, upon reading these words, you emerge with a better understanding of my life with Moebius syndrome and how it can affect someone's life in ways you may not even imagine.

I mentioned above that some people didn't care to listen to me when I spoke, and often ignored me. Some people wouldn't make eye contact with me, which to me was tantamount to ignoring me and not including me in a conversation, or not acknowledging my presence. For example, one of my managers would meet regularly with three or four employees, including me. While having discussions, he would always make eye contact with the others, but not me. I felt like saying "Hey, I'm part of this conversation too!"

During my school years, I would often feel uncomfortable standing in front of classes to recite poetry, give a report, or speak about different subjects. I believe this was primarily due to my speech impediment (of which I was very self-conscious), in addition to some teasing or heckling from class members. When I took a speech class at USL during freshman year, I told my instructor that I didn't think I could present a speech, but she pushed me to prepare and give my first speech (we had to give three speeches in front of the class during the semester). To my surprise, I pulled it off, and gained some self-confidence through this class. When I worked in HR, I conducted many training sessions for employees and managers. I always felt some "butterflies" or mild anxiety before speaking, but by and large I did fine when presenting anything to an audience. Eventually, public speaking became a fairly easy thing for me to do. I even taught some college level courses in the evenings.

Some people have acted nervous or uncomfortable when they're around me. I mentioned that this has happened in dating situations, but it's also occurred in other settings such as work and social events. These individuals may have made the wrong assumptions due to my appearance or the way I conduct myself. I believe if they were familiar with my condition and had some understanding of it, this could make a difference

in how I'm perceived and treated. But without that knowledge, many assume that I'm intellectually challenged in some way, or simply view me in a negative light! Also, I've encountered plenty of individuals who were condescending or disrespectful toward me.

From my adolescent years forward, I've been excluded from certain things. For instance, I wouldn't be invited to social events such as parties being given by kids I was in school with, or a group from our department going out to a bar after work may not ask me along. There were several occasions at work when I wasn't invited to meetings that I should have attended.

For me, making friends over the years has been difficult. Once I find and make friends, I make an effort to keep in contact with them to sustain the friendship. Nowadays, my true friends mean a great deal to me! There have been many times in my life when I've felt lonely, wishing I had good friends nearby that I could spend time with.

As far as the teasing and bullying went, there was little of that once I was in college. The majority of the teasing consisted of name-calling and other verbal harassment. There were things said to me regarding my appearance and/or speech that were very emotionally debilitating and which I still vividly remember even today. For example, "freak show," "funny face," and "scarecrow" have been thrown at me. Once, I overheard someone telling his friend, "That guy has a face only a mother could love." I'm sure you're familiar with the old expression, "Sticks and stones may break my bones, but words will never hurt me." Take it from me: words indeed do hurt!

Occasionally, I'll receive dirty looks from people that I don't even know. This always puzzles and saddens me. After all, what have I done to deserve this? I hadn't even spoken to that person or done anything to offend them. One time I was looking at some items in a grocery store aisle when a lady walked by in front of me. When I looked up towards her, she gave me a dirty look. This happened years ago, but I can still recall the look on her face as though it was yesterday; it cut through me like a knife through soft butter! Also, I occasionally receive stares from people when I'm out in public. When this happens, I usually just look back at them, and they'll turn away! I sometimes say "hello," and they may or may not respond to my greeting.

I have a lack of situational awareness, which may be connected to Moebius. I've learned that a few others with Moebius have this as well. Basically, I'm not always fully aware of things happening around me, sometimes failing to read people's facial expressions or attitudes, or picking up on their body language. This helps to set me apart even further when factored in with my appearance, speech, or being physically awkward at times. However, I've managed to improve this situation to some degree.

When I was about 12, I was beginning to develop a dry sense of humor and learned to use it to my advantage. Some people around me, particularly other students or co-workers, seemed to be amused by this, at least most of the time! I found that humor is a good coping mechanism and a way to break the ice and help gain acceptance by letting others know that you're a regular person who can share some laughs with them. I've even managed to keep a straight face when telling a joke or playing poker!

Many others with Moebius syndrome have experienced self-esteem and self-confidence issues. In my case, I'd say my self-confidence has generally been normal, although my self-esteem has taken a beating throughout my life.

Some of us with Moebius have faces that others perceive to be "angry" or "sad." In my case, many people have told me that I appeared sad, or even told me to "cheer up."

One time I reached out to a lady through an online dating site, who remarked that I looked sad in the photos on my online page and asked “Are you sad?” I told her that I’m basically a happy guy, and pointed out that my profile contained a brief explanation about Moebius syndrome. I may have embarrassed her, as I never heard from that lady again!

Having said all of this, I don’t want the reader to get the impression that I’ve received the types of treatment I’ve described from all people I’ve encountered. The vast majority of individuals I interact with from day to day are, at the least, civil towards me. However, it takes just one unpleasant incident to make you feel sad, misunderstood, or mistreated. All I’ve wanted over the years is for others to treat and respect me like a regular person! Most people do, but there are still some exceptions!

Indeed, all of these experiences are my reality. I think it’s important that more people in the medical and health care professions learn about Moebius syndrome. It’s also important that many others outside of these fields learn about Moebius as well. To this end, I’m always willing to share my story with various people from all walks of life, and don’t mind someone asking me about my appearance.

I was approached several years ago by an author named David Arnold, who was writing a book of fiction for young readers. This book featured a central character named Vic who was 16 years old and had Moebius syndrome. David had learned about Moebius and decided to use it in his book *Kids of Appetite*, published in 2016. I agreed to help him with the Vic character, as did a few others with Moebius. Consulting with us paid off, as David did an excellent job in portraying Vic as a typical young man with Moebius.

Another author contacted me early this year about helping him with a book for young readers. As with David’s book, the central character is a teenage boy with Moebius. At his request, I reviewed his book draft and provided feedback. To my knowledge, this book hasn’t been published as of yet.

Recently, Andre asked me why I don’t smile. My nephew Calvin asked me the same question many years ago when he was about the same age. Obviously I couldn’t explain it in terms they would understand.

Upon reading this in the future, Andre will understand. I’d like for everyone reading this to know that I may not smile with my face, but I **ALWAYS** smile with my heart! Additionally, I stress to young people that it is what’s on the inside of a person that is very important, and not just the outside. Another old expression comes to mind here: “Don’t judge a book by its cover.”

PERSONAL REFLECTIONS

I believe that, despite all these challenges, I’ve demonstrated a great deal of resilience which has enabled me to cope with, and often overcome, adversity during difficult periods in my life. To use a popular analogy, life may have dealt me a lousy hand of cards, but I have played that hand the best way I knew how. I haven’t always made the right decisions or conducted portions of my life in the best manner, but overall I’ve had a good life and feel blessed in knowing that. I’m proud of my accomplishments, both professional and

non-employment related. I feel that whatever mistakes I've made or failures I've faced were good "learning opportunities," and not necessarily things to regret.

My experiences with Moebius syndrome have made me more sensitive to others who are different in various ways as well as those with disabilities, whether intellectual, developmental, or physical. When I see disabled folks out and about, my heart really goes out to them! I served for a while on the City of Houston Commission on Disabilities so I could help make a difference to the Houston disabled community, as I feel I've made a difference to the Moebius syndrome community since I became involved many years ago.

When I first considered writing memoirs a few years ago and was not interested in doing this at the time, the fact that I didn't have any offspring was not the only reason for my lack of interest. My life's story contains some sensitive and painful memories, as you've no doubt noticed. I was reluctant to share much of this information. However, I had a change of mind and am content with including these in my memoirs, as doing so has been very therapeutic for me!

I'm very happy with my life today, sharing it with Doris and our little dog Tucker. We're both aging and deal with various health issues, but intend to keep pushing ahead in life. I continue to be an active member of the Houston Civil War Round Table, was appointed last year to serve on the City of League City Historic District Commission, and both Doris and I joined the League City Historical Society. We plan to enjoy spending time with the grandkids, do more travelling, and continue spoiling Tucker!

-Roland Bienvenu