Hunt for the Elusive Cure

Gigi Mericka

Imagine being told for 23 years that you have a deadly, incurable, neuromuscular disease, only to discover one day that you do not. I lived for years with a diagnosis of ALS, also known as Lou Gehrig's disease, anticipating only living 3-5 years. This quirky miracle of sorts has come about through an odd combination of medical misdiagnosis and advancing medical discoveries.

I am 55 years old now, when I was about 19 years old I began developing several baffling physical symptoms. My hands would cramp up for no reason, my legs grew stiff and tired very easily, in turn causing me to trip and stumble. Maybe it was the crazy dessert diet I concocted to lose 5 pounds from my midsection, though I only weighed 110 pounds! In a search for answers I spent the next two years journeying from doctors to specialists.

I began with a primary care doctor. I requested that he run a blood test to see if possibly I was suffering from some form of arthritis. However, at my next appointment, he briskly informed me that my tests all turned out to be negative. “What else could it be?” I asked waving my left hand in protest that revealed a fist filled of fingers that no longer worked. "I don't know what could be causing your problems, but it's not arthritis," he insisted hurrying out the door to perhaps a less troublesome patient. He seemed unconcerned that a previously healthy 19-year-old had lost an obvious motor function. Next I sought out a chiropractor who blamed my physical troubles on mismatched legs, compounded by an unusually twisted spine. Then I went on to an orthopedic surgeon who was certain I was suffering from inflamed cartilage of the knee. When the drugs the orthopedic doctor gave me didn't help I saw another orthopedic surgeon who, lucky for me just prior to scheduling surgery to correct misaligned tendons, was interrupted by his physical therapist who asked if he could also examine me. The therapist told the doctor that he was sure that my problems were not structural but neurological. I began physical therapy immediately and was then referred to a neurologist.

At the time I had no idea what a neurologist was; within a few minutes of sitting in her waiting room I realized that it wasn't a good place to be. Everyone had a sad face with sad story to match. Once inside the room, the neurologist stuck me several times with needles, called an EMG, and completed a muscle biopsy. Weeks later, she called me back to her office to share her results and enlist me into the ranks of her other sad faced patients. The news she claimed, was both good and bad. Yes, I did have a myotonic muscle disease but it was not like the kind you see on those *annual television telethons*. She said that I wouldn't get any worse until my mid forties then I probably would need a

cleaning lady. Finally, she sharply admonished that I keep in mind that the world doesn't stop just because *I have* a muscle disease. Well isn't that strange I silently fumed, doesn't she realize that her medical revelation just caused my world to stop?

And after that day my world continued to stop. My fiancé didn't believe the neurologist's slow progression diagnosis and after consulting with a family doctor friend who had never examined me he became convinced that I was suffering from some sort of terminal illness that my family knew about but were not telling me. He began to feel depressed, moody and even became abusive a couple of times. Once he even had the nerve to say to me, "how could you do this to me, ruining our marriage plans." Finally, as a parting gift, he made an appointment for me with another neurologist at a major hospital out of town. It turned out that the next doctor didn't know any more than the last and although this neurologist couldn't put a name on what I had he was certain that it was caused by some sort of a genetic defect caused by, let's see, my father and mother's brother's baldheaded genes. My poor father was depressed for months thinking he had passed on some genetic defect to me but he did agree with the previous medical prophecy that I probably wouldn't get any worse for decades to come.

Two months later I experienced a rapid progression of paralyzing problems. I had moved to Arizona to continue my college, hoping that a warmer climate would be helpful for my condition. Instead, I found myself leaning on a cane to get around. Sensing that I was in real trouble I came up with the idea to call one of those telethon clinics. This time, the doctor at the Phoenix Arizona Muscular Dystrophy Clinic really took interest in my case and promised me that he would get to the bottom of my troubles. After several more blood tests, spinal taps, a myelogram, and yet another muscle biopsy he very somberly broke the news that I had a terminal illness called ALS/Lou Gehrig's disease. However, because I displayed some atypical symptoms, my young age, my lack of reflexes, and thankfully no upper motor "bulbar" problems of speech and swallowing he wanted me to get a second opinion from a major medical institution. I was referred to Scripps hospital in San Diego, California. While there I made the rounds, from specialist to specialist as each neurologist sent me on to their esteemed colleagues for second, third, and forth opinions. All were hoping to find something that mimicked ALS and could be treatable. Sadly, they could not find anything else. As a last-ditch effort these doctors referred me to a man they respectfully referred to as "the grandfather" of all neurology. At first, he was convinced that I did not have ALS but rather something that mimicked it. The doctor got my family and I very excited by the promise that I could be included in his upcoming trials with what was sure to be the miracle drug of the early eighties, Interferon. Months later when all his tests were complete, this end of all expert had to concede with the others that there was no cause for my symptoms other than ALS. The worst part of this news was his delivery. First he sent an impersonal letter, then when I visited him in person he added insult to injury by refusing to look me in the eye when he abruptly told me there was nothing further that he could do and that I was excluded as participant in the interferon trials. He went on to say that I did indeed have ALS with the dire prognosis of living three to five years and that modern medicine had nothing to offer me. He left me with the caution that I shouldn't waste my money on any quack cures. Given that I didn't

have long to live, why would I want to save my money? Why not try anything? And so try everything I did; within *some* reason of course.

My family and I turned to the the alternative health world. I followed organic food diets and took food and vitamin supplements that were considered vital for the proper functioning of the nervous system. It's funny, 20 years ago the same things the orthodox medical community scoffed (the importance of food and vitamin antioxidants, omega-3 fatty acids, and lowfat and whole-grain foods) medical science now recognizes as having important disease fighting properties. Many folks thought my family and I and the alternative doctors we would see (the good, the bad, and the crazy, along with a couple of criminals) were all pursuing unrealistic health hopes. We were actually putting into practice health principles that were ahead of our time. In addition my father, a former Golden gloves boxing champion and trainer, put in a swimming pool and developed a daily exercise regimen for me to follow. I did not succumb to the standard three to five years death sentence ALS victims are given. Instead, my condition progressed much slower and I was still able to stumble around with my cane and walker for about eight years before needing a power wheelchair to get around.

Every time I had any type of swallowing difficulty brought on from colds or allergies, I was tormented with the fear that I was developing the ALS bulbar symptoms (loss of speech, eating, and a quick death). It was around this stage of my illness that I finally came to terms with my disability. I believe that when someone becomes disabled, there are stages of grief (anger, embarrassment, etc.) and eventually they must psychologically work through such truths if indeed that person ever wants to become a productive member of society again. My truth: “Yes, I probably will never walk again, but in the meantime I'm still alive.” I had two choices: allow myself to become bitter over my physical losses or try to become better regardless of my health. Ironically, Dr. Kevorkian and his so-called death with dignity suicide option was beginning to be a popular choice for many physically disabled during this time in Michigan. Instead, I opted for another route and became a Christian turning my life, health, and future to a more knowledgeable power than myself. I also decided to play the hand that I was dealt and move on with life even if that meant having to rely on a wheelchair to get around and eventually the help of others just to get out of bed in the morning. Maybe a cure would come my way; maybe not but I wasn't going to let myself be cheated out of anything more life had to offer.

So I lived my life. I completed college and earned a bachelor's degree, started a career as the Resource Director of a nonprofit, served as Program Manager for an access to recreation initiative which helped in the creation of Michigan's first and only publicly owned accessible treehouse, worked in marketing and public relations, as well as became an advocate for people with disabilities. Two of my proudest advocacy accomplishments included working with other advocates and state legislators to get the Michigan Medicaid buy-in legislation passed which allows people with disabilities to continue working without losing their health insurance. I also came out the winner in a very stressful three-year lawsuit which, after several appeals, resulted in a statewide ruling that now protects people with developmental disabilities from being denied services they are entitled to under the proper interpretation of state and federal definitions. Many people with

disabilities would consider themselves “accidental advocates" becoming one out of necessity when forced to stand up. Ironically it is often against those social agencies that were established to help us not to serve as stumbling blocks.

Gigi with her former director Dave and coworker Debbie at the annual fundraiser for the St. Clair County Community College Foundation

Just before turning 40 and for the next three years thereafter, my immune system went haywire. I developed several autoimmune problems: hypothyroidism, tubular renal acidosis with potassium wasting deficiency -at times leaving me so weak I couldn't feed myself and struggled just to hold my head up, as well as an extraordinarily high rheumatoid factor. The last two conditions were discovered just weeks apart in the early Spring of 2002 after I requested my gynecologist do some blood studies. He also wanted to get to the bottom of my development of an autoimmune kidney problem. I sought to educate myself and investigate the newest intruders of my body by surfing the Internet for health information that I would in turn, share with my doctors. Most times, my suspicions were confirmed through the help of my doctors and the various blood tests.

Another interesting twist in my story took place around this same time period when I was struggling with these additional health problems. In the spring of 2002, my pastor asked me to give a testimony before our church of 300 attendees on how God had been faithful to me throughout the 20 some years that I had lived with Lou Gehrig's disease. My pastor's mother had died of this same disease when he was a young man and although he had known me for several years he told me of this only minutes before I was to give my testimony. He he had purposely avoided talking to me about this subject until that very moment because of the intense grief that he had felt over his mother passing away when she was a young woman – too soon for her time. On the other hand, I was also a young woman, who defied the odds and remained alive; why was that? Pastor Mike said that it was a freeing moment for him to finally be able to share his thoughts with me. In turn I received my own blessing shortly after sharing my testimony. The following week, after waiting 20 plus years, the answer as to why I was still alive was finally revealed. I did not have ALS and probably never did! What began as bad news, developing the above

mentioned autoimmune health problems, was in fact what that lead to my life-changing diagnosis.

Frustrated by my recent blood studies again showing I had severe autoimmune problems I decided to take matters into my own hands and faxed them all to my neurologist who practiced about 60 miles away in the Detroit metropolitan area. Even though I only saw my neurologist, Dr. David Simpson, every one or two years at the Detroit Muscular Dystrophy Association Clinic, I knew him to be a very sharp M.D. who seemed to thrive on problem solving and working with oddball cases such as myself. After reviewing my blood work, he agreed that all of these diseases could not be coincidental and told me to come back to clinic to see him immediately. Prior to the appointment, I remembered reading 10 years eariler about some neurological disease on the Internet that mimicked ALS. In fact, I had even undergone a specialized antibody blood test for this disease years prior with an associate of Dr. Simpsons which at the time revealed that I tested negative for this treatable disease. The day before I was to see Dr. Simpson I discovered amongst some of my old medical records that same article I had printed out from the Internet. The article made reference to a disease called **Multifocal Motor Neuropathy** and as I reread this article I was amazed that symptoms of this disease matched every symptom that I was experiencing. The article also referred to this masquerader of ALS as being an autoimmune disease in nature. So the next day when I saw Dr. Simpson the first thing I did was mention the article. His face turned ashen and he immediately ordered a nerve conduction study and EMG. Normally the clinic is jammed with patients but on this particular day there were hardly any patients and he and his interns performed the tests immediately. I've never prayed so hard in my life.

My new tests showed that I did in fact have Multifocal Motor Neuropathy. Dr. Simpson said that because of medical advances that were unknown 10 years ago, EMG readings and even blood tests that once were believed to be consistent with an ALS diagnosis now reveal distinguishable differences between the two diseases that only highly trained specialists are able to properly interpret. However, from everything I read the proof in the diagnosis would come if I responded to the treatment, which he ordered to begin immediately. Everyone at the clinic was excited for me, including Maggie Segal, the MDA patient coordinator. It reminded me that whether I responded from the new treatments called IVIG or not, I was still ahead of life by no longer having the death sentence of ALS hanging over my head. Later, Dr. Simpson personally apologized to my family and me for not having discovered the correct diagnosis sooner. I appreciated his humble sincerity and we all agreed that receiving this news was certainly better late than never and that we just needed to proceed on the potential treatment. Dr. Simpson warned me that because I had gone untreated for many years, the treatments may not be helpful. The treatments were scheduled for the following week and would take place at my home by registered nurse. There was a major glitch with my insurance company and the treatments were going to have to be postponed. I was furious and got on the phone speaking to one person after another- I had been waiting over 20 years for this treatment and would not stand for wasting any more time! Just a few days before my nurse was scheduled to arrive we were given the go-ahead by my insurance company and IvIg company. I had also gotten back on that Internet and discovered some medical journals

that talked about the disease. On *medpub* I read the most exciting news about a woman in South America who had, like me, been misdiagnosed for nine years and forced to use a wheelchair.nYet soon after her first treatment she was able to walk. Other articles describe how 80% of patients responded to the treatment. The anticipation my family, friends, and I felt was tremendous. I prayed that my body would respond like the woman in South America. I told everyone I was sure I would be one of the 80% who would get something. And get something I did; on the last day of five days of infusions, about midafternoon, while I was relaxing and reading a book, the most powerful tingling sensation of strength began moving all over my whole body. Soon after this surge of strength over took me, I was able to flex my calf muscles, pick up and grasp a piece of paper, lean forward in my chair, turn on and off the water faucet, and open the back door myself as well as slightly move my left arm and hand. Things I had not been able to do in over 10 years.

For the next few months I continued to improve physically and had a medical port installed in my chest for easier intravenous access. Shortly after the port was installed, I became so dizzy my head would not stop spinning, I felt weak and my heart pounded incessantly. My treatments were causing anemia. The treatment that was supposed to cure me was instead making me sick. My neurologist temporarily stopped the IV IG treatments and a hematologist began treating me with Procrit along with iron pills. Eventually I was able to start the IV IG treatments again with a lower dose and lower monthly frequency. I had come to accept the fact that if I was to ever get cured this way, it would just take a lot longer. A friend told me, *slow is better than no*. In my case it has been more than 20 years since my disability began so any positive progress gained I viewed as a reversal of the unfortunate.

It's now 12 years later, and my hoped for cure has not materialized to the extent I had dreamed about, but the IV IG treatments keep me going stamina wise and have restored more mobility to my hands, for which I am thankful. If I skip the treatment or go too long I can actually feel the strength wearing off. It's like some sort of strange magic potion- except you can't drink it and it doesn't make you beautiful! In the meantime, I remain on the lookout for that elusive cure, choosing to live my life to the fullest in spite of whether or not it ever materializes.