

My Gift

By Jose Sanchez

For all who suffer from the rare and incurable.

Let me preface this by saying I wanted to write this before all my memory is gone.

All names and places have been changed to protect the innocent.

I.

I was born in the summer of 1969 to parents of Hispanic descent. My father was 34 at my birth and went by the name of Miguel Sanchez, while my mother Maria Gonzalez was 29. I was their second child; their first was a daughter named Teresa was born in 1964. My parents wed in 1972 and it was their second marriage. From their first came a son for each; my father's was a junior and still lives in his native Puerto Rico a Caribbean Island and my mother's offspring, who lived with us, was called Julio and both were born in 1960. We lived in Dedham a small suburb of Boston, Massachusetts. My entire immediate family is alive and healthy except for the usual age related illnesses. As for myself I was given one of the more common names of Jose. Our childhood was typical of the times with my father working hard to provide our essential needs while my mother took care of us the first few years and then my older brother Julio took over when I was almost four, as she went to work. We were by no means rich or well off, but in no way did we want for anything. We were middle class, went to public schools, and even had a dog and cat.

Around 1975 or 1976, I can't recall exactly when, my brother began to hang out with the wrong crowd, who introduced him to drugs and alcohol. This would eventually result in his dropping out of high school in the twelfth grade as well as moving in and out of the house upon numerous occasions. Soon after my brother moving back out in 1983 my father decided it was time to move away from the hustle and trouble of city life. So we settled in a small town about thirty miles south of Boston called Stoughton. It was a single family home in a "clean" neighborhood. All in all it was a pretty bland childhood.

My parents, who are still together by the way, loved us equally back then and still do. I can say that now with my maturity but growing up, I didn't realize this. Maybe it was their commitment to providing for our every need or their lack of outward affection but whatever the reason they led by example. It's hard for me to express my admiration for the way I was "taught" but I hope to some day before it's too late. I can't remember the last time I uttered these three words to them or heard them from my parents, I love you.

I began to work at a laundromat at the age of fifteen with my mom, who helped me get the job. I remember blowing my first paycheck on music and clothing, all of about \$75, but after that I began to save.

High school was easy, the studying part that is. I was always able to write the teacher's notes down and recall them quickly. My problem was with my weight. Ok I'll say it I was fat, but most everyone seemed to have the need to point it out! Never an athlete, more of a fan, of boxing in particular; I was woefully out of shape. I used to walk to a nearby store and pick up every magazine on the sport as well as videotaping every televised fight I could. My video collection is still ongoing. The magazines however became less popular as the sport was not as mainstream as others, thus publication diminished. I would eventually donate the collection of nearly one thousand magazines to the International Boxing Hall of Fame. High school was also where I found two lifelong friends, Fred and John. John in particular shares my passion for the sweet science. Although separated by miles we still keep in touch.

II.

However much I excelled in high school, I quickly realized that I was not "college material", so on a whim one day I took a test during my junior year and soon thereafter I was enlisted in the United States Army, but because I was a minor at the time I needed my parents' permission, which they reluctantly gave. Soon after I graduated I was off to basic training, two days before my eighteenth birthday. My primary job was in communications, the irony of which you will realize later. Away from the comforts of home for an extended period of time for the first time was rough enough, but to spend it in the Army at Fort Jackson, South Carolina was almost too much for me. Still overweight, I was an easy target for the Drill Sergeants. I was beginning to think I had made a HUGE mistake!

Eventually I came around realizing that I had made a commitment and I was under contract for a minimum of eight years. Luckily the Army utilizes the buddy system and my buddy, Mario, like myself was just shy of his eighteenth birthday. But the similarities ended there. Mario was a guest of the Alabama juvenile court system for most of his life and he was in shape. Although we lived in eight man rooms, our company was comprised of forty or so diverse trainees and serious infractions were dealt with as a group. The first three days were the hardest of my young life until I slowly came to an epiphany. All the yelling, scrutinizing, singling out, and chastising were for the sole purpose of attempting to break our will. As Mario and I began to understand this the training became fun, believe it or not. We began to do minor "screw ups" just to show the Drill Sergeants that they couldn't "smoke a rock" Army jargon for "break my will". I'm proud to say all of the pushups and punishment we went through didn't "smoke" us!

Although I didn't excel in basic training, as hard as it was, I recall it fondly. Especially the firing range, rappelling off a seventy foot tower while overcoming my fear of heights, and the obstacle course; But being forced into shape was by far the greatest benefit. Job training was in Fort Gordon, Georgia and a whole different experience. We had a few more liberties, such as more time to eat and co-mingle with the female soldiers. Also there were two man rooms with fewer inspections of our living quarters. They were more like college dorms and although separated by floors, co-ed. One of the more important things I learned from my brief experience in the Army was to volunteer for any and all work details for with that came privileges.

After a few months of excelling in my job training and volunteering like a mad man I was promoted to barracks leader and got my own room. Training came as easy to me as in high school. My official job title was Single Channel Radio Operator or to put it in my Sergeant's words and I'm paraphrasing now, "You will be that soldier in front with a radio as a back pack and antenna as a target with a wartime lifetime expectancy of about ten to twenty minutes!" Not a comforting thought but a least an honest one. We still marched alot, had physical training, rifle training, and were told what to do but with respect; after all we were soldiers!

After training from August thru September and graduating third in my class, I received my "permanent duty" orders. I was to report to Fort Sam Houston in San Antonio, Texas. Nervous and excited to put my new skills to work, I reported for duty in mid- December only to learn that most of those skills would not be needed. I was assigned to work at a M.A.R.S. facility, an acronym for Military Affiliated Radio Station which monitored radio traffic thru amateur radio operators, including the Military. Fort Sam was a partnership between Military personnel and civilian workers. Shocked to hear I would be predominantly working under a civilian boss, I asked my military boss why I wouldn't be putting my skills to work. His paraphrased answer was, "Where would you rather be, out in the scorching Texas sun for six months at a time doing more training or in an air conditioned radio station monitoring traffic"? Needless to say I chose the latter!

Permanent duty was like having a regular job; we were on our own for the most part. My wages weren't that great, under one thousand a month to start, but I sent one hundred home to my parents every month and kept the same for myself with the rest going into a my savings. It was up to us to keep in shape as well as our military discipline. My job had no set hours but I was expected to put in a minimum of sixty hours a week. I monitored several stations at once, making sure nothing inappropriate was said or anything that may be a security risk was said. Soon after learning the ropes I became a licensed radio moderator, which meant I could join in on the conversations. Which I enjoyed immensely, talking to people from around the globe was as much fun as it was educational.

Aside from the seldom military drills, living quarters inspections, and physical fitness tests it was like I wasn't in the military at all. Speaking of living quarters, we were in a co-ed building; with females on the first floor and males on the second. The rooms were for two people with one room on each floor for one person. Because of

my volunteering at every opportunity I was eventually rewarded with the private room.

Around February of 1988, I came across another lifelong friend in Bridget, a civilian living nearby. She would soon become like a sister to me; not only because she made it perfectly clear to all within hearing distance that she was not interested in a military man but her heart, outspokenness, and honesty were endearing to me. I can't recall the exact circumstances of how we met, just the time. We still keep in touch, though not as much as we used to. Before I received my gift our letters were as frequent as our long phone conversations. At about the same time I met Bridget, I requested and was granted a three day pass as another reward for my volunteering. So I booked a flight home to pick up a car given to me by my father. I didn't have much time with my family, but it was a refreshing break. I had to leave almost immediately, for I had a long drive ahead of me from Massachusetts to Texas and not much time. About thirty six hours of straight driving and countless caffeine pills later I was back at Fort Sam Houston. I love to drive!

III.

On June 22, 1989 just a few days before my twentieth birthday, my time on active duty was officially over. So I gave Bridget a hug, packed up my car and headed back home, taking my time to stop at some tourist areas since I wasn't in a hurry and I love to drive. Arriving home three days later, sort of a free man, since I was still technically contractually assigned to the Army for several more years. I received my honorable discharge in May 1996. But until then I was considered inactive. After a couple of weeks of unemployment, I began working at United Parcel Service as a part time worker, getting the job by being recommended by Fred's mother. Of which I am eternally grateful. The work was hard and pay was low at the beginning, with only about 15-20 hours a week, I had alot of spare time. But I stuck it out partly because with time came much better pay; however the main reason was their benefits.

Unfortunately my new found "freedom" led me to gain weight, yup I was fat again. I went into the Army weighing 175 lbs. and at five foot seven inches tall, was considered borderline obese. When I was discharged from active duty I weighed a svelte and healthy 143 lbs. but a mere six months later I had ballooned to 187 lbs. One morning after a shift at UPS I was drying off from a shower, I took a look in the mirror, and frankly was disgusted at what I saw. So I put on an old pair of sneakers and set out for a two mile run, which was the regular distance run during my time in the Army. After about a quarter mile I had to stop, out of breathe and cramping badly, I glanced at my stopwatch and was shocked at what I saw. Ten minutes and out of gas! To put some perspective on this, a two mile run had to be completed in less than sixteen minutes in order to pass their physical fitness test, which I had done. On my slow painful walk back home, I set a modest goal to be able to run a mile in ten minutes in a month. After experiencing the euphoria of achieving this goal, I set another and another. Thus began my obsession with running.

Although I was living with my parents at the time and I with little to no debt, my unquenchable thirst to save, (for what I didn't know at the time) led me to search for a second job. The search didn't last long; actually there was no search at all because I went back to working at the laundromat on a part time basis. This didn't last very long because the laundromat hours were conflicting with my hours at UPS, so I quit the job of washing clothes and quickly picked up another job at a women's catalogue store answering phone orders. It was the easiest work I had done so far!

However easy it was, I had to leave it after a year or so since I was considered a temporary employee, unbeknownst to me. That was around 1992 and although still part time at UPS, my perseverance was beginning to pay off. Along with respect from fellow workers came better pay and more hours! I felt that I could relax a bit on the second job hunt for a while. Meanwhile my running had gotten me to a weight of 140 pounds and in the best shape of my life. I was running roughly thirty to forty miles a week and decided it was time to take it to the next level, so I entered a few local road races of different distances and was hooked. Thus began my short-lived but moderately successful competitive road racing career (again, more later).

I also began to hang out with my sister on Friday nights along with her best friend Aida, for a movie or dinner or just to "chill". It soon became a routine until about the middle of the same year when all things changed for the better. Aida's sister Isabel was going through a rough time with her soon to be ex-husband, and her six year old daughter, Rosa, wasn't having it easy either. So reluctantly, it seemed, she asked to join our group. We were surprised that she felt she had to ask, an emphatic yes was our answer. Little did I know what our meeting would come to be.

IV.

One Friday during a casual conversation Isabel mentioned that they were hiring at her job, a direct mail marketing firm. She wanted us to spread the word. Never considered to be a "ladies man", I jumped at the opportunity to spend more time with her; even if at work. The hours were flexible so I was able to work both jobs with relative ease, plus I was falling for her and fast. Meanwhile I had amped up my running regiment to around fifty miles a week; yup I was a "junkie" and was training to run my first of five marathons and to qualify for the Boston marathon (which I came close to accomplishing but never did). I fell for Isabel even more when she attended one of my races. Again I was clueless to her growing feelings toward me. Her daughter was a different story as she was regretting losing her mother's undivided attention; however she slowly warmed up to me. That Christmas my sister gave me a miniature billiards table, to which Isabel exclaimed she always wanted to learn. I shyly agreed, but our hectic schedules kept this on hold.

Meanwhile my friends and I were planning a trip to Atlantic City, New Jersey in mid-June before my birthday. There was a boxing event and I needed a vacation. I mentioned this to Isabel and thank god she reminded me of our "billiards training date". A few weekends, races, and hints I would miss later we took a ride to a nearby bowling alley to give a few tips on billiards, it was an informal date. On that day, June 23, 1993, to be exact, still clueless to all the hints she had thrown my way we headed home. On our way back to her house she asked me to pull over, so I did. "Come closer, I have something to give you," she whispered. As I leaned in, her lips met mine, our first kiss and the light bulb was turned on finally. I'm proud to say we've been inseparable ever since!

Although my trip to Atlantic City with my friends was an enjoyable one, I couldn't keep my mind off of Isabel. Our first real "date" was shortly after my return, we went to a local dog track to try our luck. Even though we didn't win anything, she had won my heart. About three months later we went out to dinner to a restaurant in Sandwich, Massachusetts a quaint little town located in the heart of Cape Cod. A walk along a nearby beach followed and with each passing moment, we became closer and knew there was something special growing between us. Whether a movie date, dinner (my favorite), or just being with each other it was magic to me. Meanwhile I was getting used to working two jobs, winning my age group in races, and saving. Life

was good. That Christmas we exchanged gifts, I gave her a ruby heart necklace and I received a bath robe (which mortified my mother) but I loved it!

In the summer of 1994 or there about I tried my hands at becoming a full time driver at UPS, not quite ready, I settled for driving weekends, as this gave me the opportunity to learn to handle the truck and drive a manual transmission. Also that summer, the three of us took our first vacation together, which became a yearly habit. This one was to Aruba, we had a great time and my relationship with Rosa, her daughter, became closer as well as the one between our respective families. Also in the fall of that year I ran my best marathon in Falmouth also on Cape Cod, my time was just under three and a half hours. Before the end of the year, I paid a visit to my favorite jewelry store at the town mall and after much deliberation I picked out an engagement ring, and put it on lay-away. Yup I was ready! While I patiently paid off the engagement ring and planned the proposal, little did I know what was being unwrapped ever so slowly.

V.

My gift was beginning to reveal itself in ways I either ignored or didn't notice since the clues were so small and slow to make an appearance. At first it was my speech that was affected by such minuscule slurs which were not always there I thought it not to be a concern and attributed it to my running and not hydrating enough. I just needed to drink more and keep up with my hydration. So I dismissed that clue and went along with life.

The spring of 1995 was a tremendous time in my life and also revealed what my constant savings was for. Isabel and I had come to the point in our relationship where we wanted to move in together, but I couldn't see my paying rent for someone else's property. Buying house was thrown about during our conversations more and more, so for kicks we contacted a real estate agent and went house hunting. Now I don't recall the number of houses we had toured but the house we eventually purchased was viewed shortly after the hunt began. It was a single family raised ranch in the better side of the town we were living in. The timing was perfect as well since prices were down and sellers were eager to sell before it got worse. So Isabel and I put in an offer and after negotiating with the sellers, we were first time homeowners, Rosa was excited as well since the house came with an above ground pool! We were to "close" in early June.

After the hunt was over, I made a trip to the jewelry store and made the final payment on the ring. My anxiousness and nervousness wasn't because of doubt as much as it was how and where to "pop the question". The answer came from a co-worker. "How about that beach you're always talking about," he said and the light bulb was switched on once again. During this time I was taking on more driving assignments so that my next go around at becoming a full time driver would go a bit smoother. In May I passed the test and became a full time UPS driver which meant better wages and only one job. So all that was left to make my life complete was to pick a day my love would remember, seeing it was the month of May I figured what better day then Memorial Day.

So on that day in 1995, I took Isabel to the same restaurant on the Cape. Well prepared to get down on one knee and ask for her hand in marriage, the perfect spot being their fireplace in the waiting area. It was too crowded however so I had to think quickly of a "plan b", it quickly came to me that the beach where we first walked

along was a better place. Unusually cold for May, I figured that a short walk would have to do. What follows is a paraphrasing of our conversation:

Me: "Want to go for a walk?"

Her: "But it's cold."

"Oh come on a short one? I'll keep you warm."

"Then you'll be cold, let's just sit for a while."

"Okay, we've been together for some time now," now I'm nervous, "Oh I'll just come out with it, Isabel will you marry me?"

She smiled her beautiful smile and said, "Of course I'll marry you!"

I placed the ring on her finger and of course then went for that walk!

Beforehand, during our dinner, another subtle clue was unraveled and this one I couldn't find a reason for, so I ignored it because of the upcoming event. If Isabel noticed what was happening, she didn't show it. My tongue was beginning to take on a life of its own by pushing food out. Next up was to set a date, which we did pretty quickly. It was to be on December 30, 1995; coincidentally my future in-laws wedding anniversary.

That September I was set to run another marathon, little did I know it would be my last competitive run! I was so exhausted that I completed the half marathon and could go no more. Still unaware of my condition I attributed my fatigue to my hectic schedule. Also, or so I thought at the time, contributing to my exhaustion was the turmoil going on in my immediate family. More specifically my sister had divorced after several years of marriage (the length of which escapes me). She had moved to Florida with her then husband and had since returned home to live with my parents. Also my brother's own marriage was being tested. In November, I think, I ran my last road race, a 5K or 3.1 mile run, I did horribly completing it just under thirty minutes. Though continuing to jog, I didn't have the energy to be competitive and about a year or so later my gift had taken away the first, but not the last, of my interests. My legs had become so uncoordinated; I had no other alternative but to stop running.

Thanksgiving has always been a big deal for Isabel's family, not so much my side, as all of them would congregate at one house and feast. This one was particularly rough for me, since days before I had been involved in a major car accident at work. Unbeknownst to me my gift had been attacking my reflexes as well as everything else it was working on. Thank God no one was seriously injured,

although in trouble I was still working during the investigation in the warehouse. Thinking my job was on line, needless to say my holiday was a solemn one.

Although the conclusion of the investigation in early December resulted in me being at fault, I kept my job since I was a member of the Teamsters union and it was my first offense. I was suspended for three days and couldn't drive for ninety. Relieved I could focus on my upcoming nuptials that were fast approaching. We had decided on a small ceremony with a best man (Fred) and a matron of honor (Olympia) who was my fiancée's sister in law. I also wanted to include Rosa in some manner. To simplify it for our guests both wedding and reception were to be held in the same banquet hall, in different rooms of course.

The day was finally here and I was surprisingly calm. Also surprising was the ceremony itself went on without a problem, with the exception of there being no videotape. During the ceremony I presented Rosa with a gold necklace and heart pendant. The reception went on just as well. Our honeymoon was a Caribbean cruise, gifted to us by my parents. We had a wonderful time. Meanwhile my in-laws Ezequiel and Dina had since retired and moved to their native Puerto Rico. During this time my small (two) but close group of friends were moving on with their lives. John had enlisted in the army; Fred had secretly married and moved to Las Vegas, Nevada which was a shock to us all.

VI.

In May of 1997, to complete our family, we rescued a kitten from a nearby shelter and because of his distinctive coloring we named him Tiger. Life was good except for one thing, my job. Being a stressful job, I decided take on the less stressful position of Air Driver. Not knowing then what I know now -- that stress was a major contributor and accelerator to my condition -- it was a great move. Next up was to get checked out by my doctor, who couldn't find anything wrong, so he referred me to a leading New England hospital. I've been to numerous doctors, as you can imagine, but my last and present neurologist is Dr. David. He has been an immense help not only medically but in gathering information for this story.

Thus began my seemingly endless journey into medical testing. Without getting too technical, medically speaking, I will list the tests I've undergone since my first step. First came the blood tests to look for deficiencies or abnormalities in my B12, iron, ferritin, lactate, pyruvate, vitamin E, white blood cells, hemoglobin, hematocrit levels etc. This is just a partial account of my donating blood, of which I have no idea what most of what they were looking for, so don't ask! The following are the medical tests performed on me at least once though not in chronological order. An EMG, which is basically a muscle reaction test with acupuncture like needles stuck in every imaginable muscle followed by a "small" electronic charge.

The results weren't very conclusive: a minor abnormality in my reflexes. Next was an MRI of my lower spine which revealed a bulging disc unrelated to my condition. A number of video swallowing exams revealed that I had no gag reflex, which didn't account for my tongue's new life. While testing continued another condition was escalating, which I had neglected to mention before. In the early stages of my mysterious illness I had begun to involuntarily bite my inner cheeks, lips, and tongue to the point of drawing blood.

My personal life was no better. Work was becoming more and more difficult due to fatigue and slower reflexes, but to use military jargon I had to "carry on". My delivery customers began to notice my worsening speech as well. John had returned from the Army but our friendship was rocky due to a misunderstanding on my part. Fred had his own life in Vegas, and letters to Bridget had become less frequent due to my uncontrolled hand movements. Phone calls to her as well were seldom if at all.

My in-laws Dina and Ezequiel along with their other children Alfonso, Aida, and Israel were aware of my declining health but had their own trials. My mother,

Maria, blamed herself, as all mothers tend to do. My father was angry and didn't comprehend how or why so many doctors couldn't pinpoint a diagnosis. My sister, Teresa, was like my in-laws. My brother, Julio, now single, was like my father but to a lesser extent. My other brother, Miguel Jr., was out of the loop since he rarely kept in touch. My wife, Isabel, and daughter, Rosa (now a teenager), just wanted a definitive answer; like myself. It was now the turn of the century approximately five years after receiving my gift and it was still a surprise. And so the tests continued.

A small bowel biopsy to test for something called Whipple's disease revealed nothing. The next one involved me urinating into a container for 24 hours to test for Wilson's disease. Followed by a genetic test for Huntington's disease, and then a spinal fluid test which revealed absolutely nothing, and then moving onto a negative muscle biopsy. A blood smear showed to be inconclusive because the method of processing the smear was incorrect. I didn't know what the preceding diseases were just that I did not have them. Moving forward with an MRI of the brain and of the cervical spine both came up normal.

As my health continued to deteriorate during the year 2000, tragedy struck my family. While in Puerto Rico, my father in law after several months of severe stomach pains paid a visit to the hospital. Moments later he was diagnosed with terminal pancreatic cancer with only three months to live. For better healthcare and to be closer to his children, they moved in with us. After months of unsuccessful chemotherapy, hospice was called upon. The end was near and came six months, not three, later. My mother in law still lives with us.

After a brief bereavement leave I went back to work. A few days later, while driving my wife's car to work, I was t-boned by a car that ran a stop sign. My wife's car was totaled, but I was alright. 2001 had begun bad and would end the same. With my reflexes slowing rapidly; I was driving my UPS vehicle back to the hub in late November, I think. After hitting a patch of black ice, I was unable to react quickly enough and slammed the vehicle into a tree. My driving career at UPS was over; my job however was safe as long as I worked split shifts, five p.m. to nine p.m. and three a.m. to seven a.m., to be more specific. I had no choice and for the next several years did just that.

VII.

With my reflexes now slower than a sloth's, it was hard to keep up with the fast paced work environment, but I did. Speech was completely taken from me next, followed soon by eating solid foods.

My incessant biting had gotten so bad that I was lit literally drooling blood and even considering having all of my teeth removed. But not yet, at first I carried a face cloth in my mouth, unattractive yet effective. Next my wife made a sort of tooth blocker with cloth, again effective. The problem was I had to remove it to take my pills and drink my meals. As I was now on a liquid diet taking my nutrition in through a straw. Finally taking a piece from my favorite sport of boxing I began to use a mouth guard. Eureka! A straw could be threaded through the breathing hole and pills could be manipulated through the guard. Problem solved, for now.

With my condition slowly worsening and frustration growing, a blood test came up positive for the "Kx antigen", which I have no idea what it is, just that I didn't have something called "McLeod syndrome", which is one type of neuroacanthocytosis. Finally a breakthrough as my gift was unwrapping itself. Further blood test for the protein "chorein" revealed very low levels of "chorein" compared to blood samples from unaffected subjects. This, in plain English, meant that I most likely have "chorea-acanthocytosis", a specific type of neuroacanthocytosis. Not as definitive as I would have liked, but a diagnosis nonetheless. What is "chorea-acanthocytosis", well the best way I can describe it is Parkinson's, Lou Gehrig's, and Muscular Dystrophy wrapped in one package of which there is no cure, of course.

Though diagnosed in 2008, all throughout my testing ordeal was my trial with prescription drugs. Initially I was given the pills for specific symptoms such as my uncontrollable muscle movements and biting as well as lack of coordination. Some medicines worked for a period of time and then became useless; most didn't work at all. The primary goal was to, at the very least, slow the progression of my disease. I don't recall the exact year I found out that my disease was progressive just that it was early on.

My medicinal ordeal was to be introduced soon after. Those that worked with limited success or none at all include Sinemet, Mirapex, (for depression and as a sleep aid, worked but discontinued) Reserpine, Zolpidem, Scopolamine, and for my excessive drooling Atropine (which actually works but not often used),

Levetiracetam, Keppra, Carbamazepine, Carbatrol, Mirtazapine, Seroquel, and Tramadol. Those that have worked in slowing the progress are Amantadine (three taken daily), Clonazepam (five taken daily), and Levoxyl (one per day for an unrelated thyroid condition).

After being diagnosed with the incurable "chorea-acanthocytosis" came somewhat shocking news. So rare is my disease, with a maximum of about two thousand diagnosed cases worldwide, there was little if any funding for research. Left to experimental treatment alone, I decided to try to regain some of my speech. So I sought the help of a social worker from the same hospital who referred me to a speech therapist. After a month and a half of extensive sessions there was no use my speech was gone.

Following years of struggling to keep pace at work and months of soul searching, I came to the conclusion I could go no more. With help from the Teamsters union, I looked into early retirement due to a disability. After eighteen years of seniority at UPS I qualified for a reduced pension and retired at the age of thirty- nine. Later in the year I was awarded Social Security Disability. So unemployed for the first time since I was fifteen, I took to driving to local malls to stumble around to waste my time. Only to realize that my condition had battled back with a vengeance and taken what reflexes I had left. Driving became hazardous not only to me but others as well. So by January of 2009 I had voluntarily given up my driver's license.

While this was going on, we had sold our home for close to fifteen years and begun the arduous process it takes to build a house. At first our plans were to construct a one-level handicap accessible home, for safety reasons there were to be no stairs. An in-law was added later but before the building had started, for Aida who had since divorced with two daughters. During the construction of our new abode, to save money we moved into an apartment, crammed but homey. My first and hopefully only taste of apartment living was a short one, it lasted just under a year.

My gift was not done giving, however as my "now living by its own rules" tongue had begun to force my mouth guard out of my mouth; my biting worsening by the moment, I was forced to make a decision I had been ignoring for some time. My wife and I had been pondering the radical move of having all of my teeth pulled. To pay for this procedure we appealed to my wife's health insurance. Though a routine surgery, my condition had to be taken into consideration, the dentist wanted the operation to be in the hospital and for me to be kept overnight for observation. My

neurologist Dr. David, who was in agreement, wrote the insurance company on the necessity of such a drastic procedure, however they deemed it "not medically necessary", thus denying our request. Nevertheless, on March 3, 2010, I had all my teeth removed.

The good news was that I no longer had to worry about chewing the inside of my mouth into hamburger meat and no more visits to the dreaded dentist, which had begun to be painful due to the aforementioned biting. The bad news was that until my gums were completely healed I would still be on a liquid diet. The healing process took less time than expected, only about three weeks instead of the six that I was told. Once healed I started my transition to eating solids slowly. Being on a liquid diet for some time now, I was unsure how my stomach would react. So yogurts and ice creams or foods with a similar consistency were the norm for the foreseeable future.

As my stomach became accustomed to the change, which much to my surprise was a little while later. Happy that I could eat just about anything, as long as it could be cut into small pieces to avoid choking, my menu was to expand tremendously. In the beginning, while still in control of my arm movements, I could feed and hydrate myself. Although I still used a straw to drink, I was a fool to believe I had conquered one aspect of chorea-acanthocytosis. But as I soon found out all good things must come to an end or so I was coming to believe it was that way for me. About three months after losing my teeth, I lost my independent eating. So uncontrollable my arm movements had become, I couldn't hold a utensil in my hand without it falling to the floor a number of times. Drinking wasn't much easier as spills became the norm rather than the exception.

Though not the first time or the last the suggestion of a peg (or feeding tube) was mentioned. After all I had given up or lost in this never ending war, I wasn't ready to surrender the ability to nourish my body orally. So my ever supportive wife had become an extension of my hands, all the while holding down a full time job for the duration of our now over sixteen year ordeal. Other members of our household help as well.

Now drinking through a baby bottle and adapting to being spoon fed, my gift was feeling ignored. To be noticed again it attacked the ability for me to open my mouth voluntarily, forcing my wife to almost literally pry open my jaw. But the fight isn't over for me just yet. This not being my first act of outward aggression towards my diseases, I realize that there will be retaliation on its part. What it will be I'm sure

to find out soon enough. However, as long there is a breath in me I vow to fight back. The more public this little known disease becomes, my hope is that more proper diagnoses will be made leading to better research.

VIII.

By now you're probably wondering why I've been calling what has taken so much from me a "gift". Allow me to quickly review what I've lost to chorea-acanthocytosis in no particular order and certainly not all inclusive. First was my ability to communicate verbally, then I was unable to write legibly. With my legs failing to cooperate along with my stamina, I was forced to give up running. I lost the power to chew food and drink from a glass. I've surrendered the capacity to independently feed myself as well. The privilege and freedom of getting in a car and go anywhere was gone. My active employment ending at a young 39 years may be enticing to many, but not to me. Also every one of my teeth have been pulled. Again the aforementioned is not everything but the major losses have been mentioned.

Now what have I gained or should I more appropriately say what I've been "gifted". I can still walk, however slow I may be, and personal hygiene is still on my own. My heart and will are stronger in denying my condition any type of victory. My wife and I have an unbreakable bond. Also the knowledge that I can adapt to much adversity. And lastly, but not all, I have been given the gift of time. The time to pursue my dream of being involved in my favorite sport, boxing.

I couldn't box and being an announcer was out of the question. But I could still type, though as slow as I am, and offer my opinion on the sport. Given a laptop by my wife I decided to take action. So I wrote an article on a recent fight and by recent I mean around March of 2009 or thereabouts, after a few revisions the final product was ready. A few websites I had been following for years had their contact information online. After much trepidation, why I really don't know, I took a shot and emailed my article to about five or six sites, with fingers crossed I waited for a reply.

Weeks and then months dragged on without a response, I sent it out again but this time I included a note. Though my recollection of the contents of the note are sketchy at best, its context aren't. In it I stated my condition and its limitations; then emphasized the few abilities I had left. I also wrote about the years of interest I had in the sport, since 1980, and my willingness to learn how to write on the sport. Without any experience as a writer/reporter, my hope was that this addition to my original email would spark interest.

About a week or so afterwards I was shocked to receive a response from the editor of a website based out of San Francisco, California. As I began to read his reply my disappointment was setting in; he wrote that although he was not looking

specifically for someone to report on the sweet science, he was in the market for a person to record the results of major weekend fights. If I was interested to reply with a sample of my work on the prior weekends fights. I was elated and began immediately on my response, to my eternal gratitude he enjoyed my straightforward approach and I was "hired".

At first I wrote the results of bouts on television and when given the shot to report on live events, I couldn't believe it. The only problem was I had no way of getting to the event. Also I would need some assistance in setting up my computer. Anyhow I applied for two media credentials to a fight card in a nearby casino. When I was approved my wife who accompanied me, though she is not a boxing fan by any means, and sometimes my sister would help me get set up. After I was settled in they'd go and gamble as I sat in press row, most of the time situated at ringside.

I was in heaven to say the very least. It wasn't long before the next live event came along, though not soon enough for me. New England has had its number of champions, nonetheless it is not considered a hot-bed of boxing activity. The few fight cards that are held I try to attend. Don't get me wrong I had been to a handful of fight cards, as a fan however. Never as a reporter, until now, let alone seated at ringside. However few cards that are promoted in this area, to my dismay, was putting undue fatigue on my wife and sister, who were both working full time jobs. A little disappointed, I understood, and began to pick what cards to go to.

With the majority of my work being done through the internet, I was familiar with the numerous social networking sites available. Since being diagnosed with chorea-acanthocytosis, I was compelled to search for old friends. It wasn't long before one search in particular caught my eye. Actually it was an article of mine on the weekend's boxing results that sparked an old friend's interests. As his curiosity got the better of him, he decided to write a comment on said article. I don't remember his exact words so once again I will paraphrase. "Is this the same Jose Sanchez I hung out with years ago?". I was a bit skeptical as well as cautious when I read the comment, since the internet carries with it its own pitfalls. My response was to ask basically the same question, not expecting any reply from the stranger. After a couple of days my expectations were proven wrong!

The ensuing days provided the answer, as the both of us asked questions only close friends would know the answers to. Much to my surprise the inquisitor was my no longer estranged friend John, who I hope was as happy as I was to have

reconnected. There was only one problem, I needed to know the reason why we had become so distant. To my recollection it was a mistake on my end. John had swung by our old house (the first) to say hi and hang out. The circumstances that follow are sketchy but I will do my best. I believe it occurred during a family reunion after my father-in-law's wake. As is customarily done, the immediate family congregated at our house for recollection and comforting, when the doorbell rang. I excused myself as I noticed it was John at the door. Hindsight being what it is, what I did next was just plain rude, as I greeted him outside the door I may have shut it on our friendship. It was cold out but I didn't want John to feel uncomfortable in the house, which was packed with people he didn't know. While we conversed I should've noticed the feeling he had was that of an unwelcome guest. While listening to his explanation of our rift, I understood why.

After we were reunited, I mentioned that I was looking for someone to help me out with my transportation issues. Coincidentally he had been writing letters to Ring Magazine, one of the few remaining reads, and had his own blog linked to a page located on the same social website in which we had reconnected. Though he lived about an hour or so drive from where I lived, I asked if he wanted to help me out. To sweeten the pot, as if I had to, I let him know about the seats we would usually get. So the first event we made it to was a for a world championship belt televised on cable and though not seated ringside, we were elated just being there.

John brought his laptop along so that he could right his own report for his blog. We've gone to several cards since and continue to do so. John, now with his own press credentials, has developed a website that is doing quite well. As for myself, with the control of my hands dwindling rapidly, typing has become a bit of a challenge. Determined not to give up, I type slowly while taking short breaks until the pain subsides and then begin again. Years ago I made a silent promise to myself denying chorea-acanthocytosis the chance to define my life and although it has laid claim to numerous small victories, I am still here and willing to go into battle.

Several years have passed, more than fifteen, since the first of my symptoms appeared and yet there is no reasoning as to why. What I do know is that without a widespread outbreak of this insidious disease, no effort will be made to find out what causes it, let alone any type of treatment or cure. Unless those of us affected by any type of neuro-acanthocytosis including patients, family, friends, medical staff, and

acquaintances (as few in number we may be) speak out by any and all means we are capable of. Until then our seemingly endless fight will rage on.

END