Testimony of a Polio Survivor in México

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I was one of many kids in the thousands of children who were brutally attacked by poliomyelitis during the epidemic outbreak of the virus between the years of 1951 and 1952 in México, this was the most terrible outbreak the country remembers in which some children survived and sadly many, many others died.

I still remember the stories my mom used to tell me once I was grown up of the never ending days and nights, the anguish and desperation of a single mother seeing her daughter suffer from the highest fevers as my little body would stop little by little all movement, as she would hold me in her arms she felt as if my



body was made out of gelatin, not knowing what was going on with me and as I was deteriorating due to a virus of which doctors knew little of, my mom's anguish and uncertainty grew at the same time the virus would continue its course greatly affecting me.

Many doctors came to check me but it was a great pediatrician who finally came to right diagnosis, Poliomyelitis. Little was known of the virus, nobody knew the fundamental principles of manifestation which made it difficult to diagnose Infant Paralysis promptly. Symptoms would be confused with those of pneumonia, pulmonary edema or an intestinal angioedema.

When the virus had done the most damage I needed an iron lung as my own lungs were collapsing. The iron lung was needed urgently to be able to survive but finding one wasn't easy, thankfully I was fortunate to have all my loved ones who put their best efforts to work and overall I thank God for giving them the means to be able to get one.

Since then my mother and I began a battle that lasted for 18 years with intense medical attention, surgeries, long hours of physical therapy and a lot of pain. Aside from suffering because of the disease, I also suffered emotionally due to

other people's rejection for fear of contagion, so I lived isolated from everything and everybody. In spite of that I grew up being secure of myself and extroverted because of my mother's attitude and moral values. She taught me to accept my new reality as a life experience, unlike others around me and not like an adversity, this gave me the opportunity to develop myself intellectually and emotionally increasing my perception and sensibility of my other senses that perhaps I would not value under other circumstances. I knew that I was physically different but I had other values and capabilities that helped me evolved and I owe this to my Mother, wherever she is, I am and have been her life's greatest achievement.

Pain was always my companion and still is. I had a childhood filled of emotional disparity, grew up among toys, orthopedic apparatuses, crutches and devices. I remember being in bed for a whole year due to a surgery, that year the opportunity to be child and live as such was denied to me, I had a total of 32 orthopedic surgeries.

With courage and enthusiasm I overcame adversity in my teenage years, being able to make my dream come true "Dancing at my Sweet 15 with no apparatus" was my biggest accomplishment, I will never forget that sensation of freedom, dance and walk without a single device and life ran its "normal" curse between studying, doctors and fun.

I became an orphan at age 19, I lost part of me, the person who gave me daily encouragement to live, to understand and to know that I could accomplish anything I put my mind to, I lost my greatest supporter and I had to learn to continue on this road alone. At age 22 I took a very wished for trip to Europe which helped me to increase my knowledge in arts as I had graduated as Bachelor of Art History. I abused my leg by walking too much which caused damage to my left knee and as soon as I returned to México I went to the doctor and once again the ghost of the polio was back in my life, I had to decide whether to have a rigorous surgery or an experimental one on my leg called osteotomy, I chose the later knowingly the risks involved one of them being the probability of being able walk again was slim.

The surgery was successful but there were obstacles that I had to face, I was in a coma for a month, walking was extremely difficult but I did it with the help of

physical therapy and during that time I met the love of my life with whom I still share my life. I married an extraordinary man who accepted me for who I am and my physical appearance did not matter. We built a family together, we have two daughters who are our most precious treasure and once again the Grace of God came into my life allowing me to be a mother since it is very difficult to conceive and to give birth.

The years went by and suddenly 20 years later the affliction came back. One morning like any other I started to walk but I couldn't, for 6 years I went to every doctor I knew, every doctor recommended by somebody else and I got no answer to what was happening. The back, knee and sciatic pain was taking over my body little by little, it was a nightmare that I could not wake up from, as the pain increased I was losing muscle strength in my leg. It has been the most depressive and disheartening time of my life in which I had several other surgeries of different nature but the surgery that I wanted the most and was anxiously waiting for never came.

During that time, I was clinically dead twice caused by the anesthesia during the surgeries, the agonizing pain in my joints followed by weakness on my arms and legs that evermore would disturb my mind, the pain in my back, in my spine and my sciatic would incinerate me.

I would execute all my activities under tremendous burning pain y I would take huge doses of medications that would prevent me from seeing things clearly, they would strain and weakened me more, as the fatigue increased I would not understand why, as last resort I went to a pain management clinic, this helped temporarily because regrettably it all came back after a few months, the neck and back pain was increasing daily, it was a critical situation with no way out.

It was until 1999 as I was browsing the internet, I came to know of a syndrome called Post Polio, I found a lot of information on it but I was unaware whether or not I was suffering from this syndrome. I had the fortune to travel to the US in 2000, I was diagnosed with Third degree Post Polio Syndrome. I was diagnosed by Dr. Carlos Vallbona at TIRR Hospital, he was specialist and researcher of Post Polio from Baylor Collage School of Medicine in Texas.

The Post Polio Syndrome came back like a ghost 20 years after I had the osteotomy and again the fight started once more. Since 2000 after being

diagnosed to the date, I have dedicated myself to investigate everything related to Post Polio Syndrome and I pledge to myself a goal, I planned to create an organization to spread the knowledge of the existence of Post Polio Syndrome, to help achieve the building of a new clinic to treat post polio patients (Clinica Integral de Post Polio) to help other people who would surely were suffering from PPS and probably did not know it and to provide medical information and provide names of international specialist on PPS, with that intention Asociación Post Polio Litaff, A.C. APPLAC was born and it works hard and loving every day to accomplish all the objectives required in México to be able to receive and get the proper health rights that every person with a disability according to the Integral Law for People with Disabilities.