Rancho Los Amigos Post-Polio Support Group

Newsletter - April 2011

# "A Special Olympian" - My Polio Story

By Luis Mata

Recently I read an article about the early experiences of people diagnosed with polio. Most of the people interviewed were diagnosed with polio as teenagers. My experience was totally different because I was a toddler when diagnosed with polio and the social, cultural, and linguistic circumstances of my hospitalization and rehabilitation were not similar to theirs. Disability was not a barrier for me because I was able to achieve my life's goals and dreams through proper support and resources.

I was born in 1946. When I was fifteen months old I became ill with a high fever and was rushed to a nearby hospital where the doctors soon diagnosed my illness as polio. I was quarantined for an extended period of time. My family does not remember how soon after the diagnosis I was placed in an iron lung. They did not receive information about my condition and were not allowed to see me due to lack of information on how the virus was transmitted. I have vague recollections of being in the iron lung. Maybe God wanted to save me from the pain and suffering that I probably went through, especially not being able to breathe on my own. As a baby being isolated inside an iron tube and not having the embrace of my parents, my body and mind were not stimulated to feel and act normally enough to remember events.

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From the stories I have read and heard from polio survivors, I can imagine how being in the iron lung must have felt - the tremendous pressure on my chest and lungs struggling to breathe. As I grew older, I have vivid memories of lying in this machine with only my head protruding out from one end of a huge silver tube. I could move my head and was able to look through a mirror that hung right above my face. The people I could see were dressed in white; the women were probably nurses and the men in white coats were probably doctors. I remember the nurses more than the doctors because they would talk to me and make loving gestures with occasional baby kisses. I do not remember anyone else, maybe because no one else was allowed to visit me.

The next phase of my recollection was after I transferred to another hospital, Valley Baptist Hospital in Harlingen, Texas. From the information I gathered from family members, no one had ever been allowed to visit me during the early stages of my diagnosis. They recall visiting me, but just being able to see me through a large glass window without the ability to touch or talk to me. I remember being placed in a large room with other iron lung patients. After surviving in the iron lung, I was weaned off the machine and placed in a large dormitory with other children. Living in this dormitory I interacted more with the other children. However no one from my family was allowed to visit yet. As I reached the age of 4 or 5 years old, I remember my aunt Maclovia and my sister Frances coming to visit me. My aunt always brought me Fig Newton cookies and Dentyne gum.

It was during this time that I was introduced to my first braces, crutches, and daily therapy that taught me how to walk. I remember the pain and crying I experienced each day as I was forced to strap on my metal and leather braces. After every session, I recall being embraced by a Hispanic nurse, probably the only one who helped to calm me down. She would massage my fatigued legs and sore arm pits from the use of the wooden crutches. She and I bonded and she soon became my family for the remaining months that I was in treatment at Valley Baptist Hospital. This nurse became for all intents and purposes my surrogate mother. I remember the day I was discharged to my natural family - I cried and cried because I was being taken away from the only mother, the only family, and the only home I ever knew. The new home and family that I was about to experience were completely opposite from what I had known for all of my childhood.

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I was born in Mercedes, Texas a rural community with a population of 3,500 people. During the 1940's era the town was segregated. Spanish speaking town people lived, shopped, and went to school on the north side of town. English speaking town people lived, shopped, and went to school on the south side. Being of Mexican decent, my family lived on the north side of town. My parents emigrated from Mexico and were married in Mercedes, Texas. I am the youngest of their thirteen children. My dad, mom, and the elders of our family spoke mostly Spanish. My brothers and sisters, because of their schooling, were more prone to be bilingual. My dad was able to learn some English because of his job as janitor at North Ward Elementary School.

All the members of my immediate family lived in one house, except for my eldest sister Josefa who was married and raising a family of her own. Our house did not have indoor plumbing or gas for heating. To heat the house during the winter my dad would build a bonfire outside and bring in the coals. A huge tank of butane was placed outside the house to provide the fuel for stove cooking. A well constructed outhouse was built in the back yard that everyone used as our bathroom. Near the outhouse were corrals for our pigs, cows, chicken coops, and cages for rabbits. About 10 yards from the north side of the house were cotton fields and orange groves.

This was a totally different environment from the one I left at the hospital. It was as if I had moved from one country to another - different language, different foods, and different accommodations. Above all, the people looked and acted one hundred percent differently from the people at the hospital. Most of the time, I did not understand what they were saying, because I only spoke and understood English. I was unable to communicate with my mom and dad. My first bed at home was a large crib. A five year old in a crib - what a sight! My dad and mom feared that if I were placed in a regular bed I might fall out and hurt myself. Nevertheless, I slept in the crib and cried myself to sleep, lonely and homesick. Only time would heal these wounds.

As I began to understand the love that my parents and family had for me, I started to evolve as a small member of my beautiful family. My dad, Refugio, would pick me up with his weathered and calloused hands, place me on his lap and talk to me. At that point I started to know the love of a father. My mom, Amalia, would

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massage my legs with olive oil, pray and sing to me as only a mother could. The food she prepared did not compare to the hospital food; it was wonderful. My mom's love was overwhelming. She was not only my mom but my teacher. There was a set of Encyclopedia Britannica in the living room which she used as a guide to teach me the alphabet and numbers in Spanish. My mom listened to the radio daily and would have me repeat words in Spanish as we heard them from the broadcast. I grew to love all my family members - my brothers and sisters, my aunts and uncles, and the great number of people our family called friends. The hospital became a distant memory and ironically, I would cry every time I had to go to the hospital for a checkup. I always felt that my family would once again abandon me and I would never see them again.

Growing up with my braces, always wearing short pants, white high top shoes and crutches, was clearly different from the other kids. I got accustomed to my look, and more often than not, the kids accepted me. Most of the time the adults didn't; they probably thought that I might spread the deadly virus and kill them. As an example, my family was Catholic and wanted me to attend the Catholic elementary school in town. I vividly remember my mom and dad taking me to meet the nuns - probably to see if they would let me enroll in their school. As we left the meeting, I could see the disappointment on the faces of my mom and dad. Of course the nuns rejected me, probably not wanting to deal with a kid who was handicapped. My parents knew that I was upset because I sensed the negative attitude of the nuns. Then my mom talked to me, assuring me that everything was OK and that I would be attending the school where my dad worked. Oh, what a mistake that was!

By the time I was enrolled at North Ward Elementary School, I was only speaking Spanish, and the teachers were constantly spanking us for not speaking English. I often had to write 100 times on the blackboard "I will not speak Spanish at school." Additionally, my dad, being the janitor at the school, became overly protective. At recess I wanted to run around and play on the playground equipment. But when the recess bell rang, he made sure he was at my classroom door with a chair plus milk and cookies. His son was not to play with the other children because he might get hurt and break his brace. If I got to school before the morning bell rang my dad would lock me in his janitorial room until the bell rang. I can picture that room from top to bottom. I could probably draw every single

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square inch of that place. One day I was so mad when he locked me up that I decided to eat his lunch. I must have eaten two or three chorizo and egg tacos that my mom prepared for him. Speaking of snacks, I was the only kid at my school who had snacks for morning, lunch, and mid-afternoon; no one else in school got them. My dad was wonderful.

After I finished first and second grade at North Ward, I was moved to another school across the street. I felt free not to be under the watchful eye of my dad. I ran around and got into trouble like a normal kid. No one treated me like a kid with polio.

The day after graduating from high school I moved to California to live with my brother Gonzalo. I think this new phase of my life had a deep impact on the individual I was to become. For several years I worked for the Desert Sands Unified School District in Indio, California as their community liaison for the first Head Start Program in the region. Most of the children came from migrant families who picked the crops in the Coachella Valley. It was during this time that I met Cesar Chavez and became a committed supporter for the Farm Workers Union. I worked in those offices after my regular work hours. I also joined their picket lines out in the fields in the early morning hours around four and five o’clock. I still remember that at times I was the only one who could run the mimeograph machine, and in the process stained my hands and clothes with purple ink. My employer at Desert Sands School District objected at times for my participation but did not really say too much about it. No one ever said anything about my polio; I was accepted for who I was as a person.

I left Indio in 1968 to finish my college education at Pomona College in Claremont, California. Pomona College is part of the seven institutes of higher learning that together comprise the Claremont Colleges. Once I completed my formal education I decided to work in different political campaigns but always serving the Farm Workers Union, whether I lived in Michigan, Ohio, or Texas. We organized picket lines in front of stores that were selling nonunion grapes, tomatoes, and lettuce.

In l973 I returned to California and accepted a position with the Claremont

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Colleges Chicano Studies Center as a counselor, assisting students adjust to college life. This experience led to being named Center Director/Regional Director for the League of United Latin American Citizens (LULAC) National Educational Centers. I served LULUC for four years until I was appointed to serve in the City of Los Angeles Mayor's Office, coordinating services for people with disabilities. This was the first job that really brought to the surface and acknowledged my disability. It was not a negative but a positive outlook as a person with a disability. I was in a sense, a role model for other people with disabilities. They saw first-hand that a person with a disability was able to succeed in education, a career, and ultimately in our society. I was rewarded in the 1984 Olympics by being named "A Special Olympian" for my work and commitment to helping people with disabilities fulfill their dreams and aspirations. This award was also acknowledged in a full page advertisement in the Los Angeles Times newspaper.

After completing my tenure with the Mayor's office in l985, I accepted a position to develop and manage a health promotion/disease prevention agency representing various medical and allied health universities. I secured various operating grants of more than three million dollars; I created several 'model' community programs, employed fifty people and helped countless adults, teens, and children improve the quality of their lives. I retired from the agency after 26 years of service as President/CEO.

My life's work is included in this article to demonstrate that persons with disabilities, like me, exist in our country and throughout the world. A disability is not a barrier. With proper support and resources it is possible for us to accomplish our life goals and dreams.

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# Support Group Meetings

## Post-Polio Support Group of Orange County

Saturday, April 9 --- MOVIE ***The Final Inch*** (<u>Polio Eradication</u>) 2-4PM

**<u>SUNDAY,</u>** May 15 --- **<u>Dr. Perlman on Research</u>** 2-4PM

*Please note **<u>Sunday</u>** meeting date for the May meeting*

Saturday, June 11 --- <u>Van Conversions</u> 2-4PM

Meetings are in the Villa Park Council Chambers
17855 Santiago Blvd
Villa Park

Take Katella to the East from the 55FWY. Go North on Wanda. Right on Santiago. Immediate left just past the Wells Fargo Bank. The council chambers are straight ahead.

| For information, please call: | | |
|---|---|---|
| | Marte Fuller | 562-697-0507 |
| | Marilyn Andrews | 714-839-3121 |

## Rancho Los Amigos Post-Polio Support Group

Saturday, April 23 —- Open discussion

*This is Easter weekend, but many of us will meet for this informal session*

**<u>Sunday, May 15</u>** —- A joint meeting with Orange County to hear **Dr. Perlman**

*There will be no Rancho Los Amigos PPSG in May*

Saturday, June 28 —- Annual Picnic

For information: Diane at 562-861-8128 or Richard at 562-862-4508
or e-mail us at: RanchoPPSG@hotmail.com

The Rancho Los Amigos Post-Polio Support Group has many interesting programs planned for the remainder of this year, and some informative articles being prepared for our newsletter.

In June, we will have our annual picnic. An announcement, with a map, will be printed in the June newsletter. Also in June will be one of Mary Clarke Atwood's excellent reports. She will be reporting on Dr. Vance Eberly's presentation to the Rancho Los Amigos Post-Polio Support Group. Mary writes informative reports about our speakers, and also about presentations to the Post-Polio Support Group of Orange County. Our two groups work together in many areas.

We are planning a presentation with a psychologist who can give us some tips on coping with the physical changes many of us are facing. When we are faced with physical changes, it can also bring psychological adjustments.

Sometime this summer we will show another informative film about the polio experience in other areas of the world. This film includes contemporary and historical interviews and film clips.

All of our meetings are open to family and friends. We encourage you to bring someone with you to a meeting. Although we are a post-polio support group, polio is not our only topic, and polio does not define us as human beings. We have fun as we learn from each other. If you haven't been to a meeting in a while, please plan to join us soon.

Remember!
Life is a
Rollercoaster.

Enjoy the ride