



**Rancho Los Amigos**

*Post-Polio*

**Support Group**

Newsletter - June 2017

## **The Lasting Legacy**

**By Terry Wiens**

I often joke that I grew up with about 30 mother figures and one father. The hospitals of my childhood were the employment domain of the female worker, which contributed to so many mother-figures. With the exception of your doctor, who you may have seen an hour or two a week (unless he was hanging over you with his surgical mask on) or a janitor somewhere, everyone in positions of influence were women.

Physical therapists, nurses, teachers and any other staff that had direct care duty with us would often entertain us with a story like “The Little Engine That Could” while we were undergoing treatment. I was nine years old and my physical therapist had made my mantra “I know I can”.

We were surrounded by nurses, saw our physical therapist two or three times a day and teacher four to six hours a day. Even with surgeries you couldn’t escape those teachers.

It was not uncommon to have a nurse on one side of my bed giving me a shot of Demerol and my math teacher on the other giving me my home work for the day. We may have been lying around but we didn’t just LAY around. We were expected to produce, and that was the strategy to build survivors. The numbers were just too high to ignore so there was a lot of effort put into making us adaptable and independent. It might have been a hospital but, in those days, it was also our home. We were expected to be part of the “treatment” team.

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Like any home we all had our weekend chores. I spend more weekends, outside of recreation time, scrubbing black wheelchair tire marks off the hallway floors after racing up and down all day. Or you spend a couple of hours sterilizing bedpans and urinals with a nurse, and there was always a story. After all, a 25 year old nurse couldn't sit there and discuss their wild weekend (if) with an 11 year old, and small talk can be difficult with a questioning 11 year old. Instead they would tell you a story. The stories weren't just distractions but themes meant to instill confidence and survival.

It got to the point where you chose your Saturday chore based on the staff person involved. There were no computers and minimal TV, so a big part of our entertainment was staff stories. Whoever told the best stories had the most volunteers helping out. Generally the stories would have a moral lesson, often referred to as parables, and were meant to help build character. They weren't just time fillers but thought generating "I will survive" type of thing. At the time I never doubted survival, why should I, I was surrounded by my family, the other polio kids.

What they didn't know at the time was that the future held "post-polio syndrome". What nobody had anticipated was the appearance of this condition 30 to 40 years after the fact. How could they? Up to that point, life span following the onset of polio was pegged at 25 to 30 years. Improvements in healthcare, technology and community acceptance changed that drastically.

So fifty somewhat years later I have now made peace with "post-polio syndrome". I spent almost twenty-five years in denial because it wasn't convenient for people around me. The 90's turned into a very scary time for me and an almost self-loathing began to overcome me. I was losing physical abilities, experiencing increasing pain, had a creeping soft depression deep inside me, and nobody I could really discuss it with at the time. People came to me to discuss problems, I didn't burden people with my issues. Not a good time in my life, but then nobody had talked about the depression aspect of post-polio. I thought I had fought and won that battle so to have it slowly invade my life has created my own parable.

Let me tell you a revised version of "The Tortoise and the Hare". In my version we will name the Hare "polio". Post-polio would be the tortoise as the legacy of polio.

Polio hits you with the speed of the Hare. All of a sudden it's there, has its way with you, moves on and poof it's gone. That probably explains my early nightclub days behavior. Yeah that's it, I wasn't fickle, I was traumatized and therefore spent fifteen years acting out. I can live with that.

In my mid 30's I began experiencing migraines bad enough to create vomiting. That was a

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signal to head for the hospital. Due to the late onset of these migraines my doctor decided further examination was probably warranted. There were all kinds of work-ups, expensive medical tests including a muscle biopsy. I began to realize the snapper on the tortoise was just over my shoulder in the guise of post-polio. I moved into a state of denial and minimized the whole thing.

I did attend a couple of post-polio support groups and, to be honest, judged it from an elitist perspective versus health concerns. I was coming from a place of privilege without even realizing it. I had a good job as a mental health therapist and was very familiar with support groups. We ran them everyday at the hospital. My experience with this support group struck me more as toxic and I wasn't prepared to stare that tortoise back down. To accept it scared the shit out of me and made me look weak (or so I thought). I had a family circle where you didn't discuss your feelings, so it was easier to just swallow them; an action I would have encouraged any of my patients NOT to do. However my family didn't function that way, expressing feelings was bunk and the expectation was, don't talk about it, either act on it or shut up about it.

Unlike the Hare that went through you quickly that damned Tortoise takes its time. I was probably in a state of denial because it was so easy to justify an aging body than face up to something you have worked hard to avoid. But still that Tortoise came.

The harder you work to stay ahead of it the more ravaging it is on your health. The more you deny the further into a depressive pit you can sink. Poor mental health will tear physical health apart and that was happening regardless. It has only been in the last eight years that I have come to grips with that Tortoise.

I made a very conscious decision in 2008 to walk with the Tortoise rather than try to stay ahead of it. Acceptance was my starting point and now I am rebuilding a life based on post-polio. I have had enough people ghost me over the years with the explanation that I am too emotionally draining and I have to accept that. I have to stay focused on my emotions and ignore this "you get the best parking spots" attitude (and yes I hear that a lot).

That Hare died a long time ago. The Tortoise is here until the end so I need to embrace it, not fight it. In keeping with my history I will make the accommodations I have to in order to have some type of quality. I cannot expend any more energy (fatigue is an issue) worrying about how emotionally draining some think I am. Time to move on...and that's my parable.

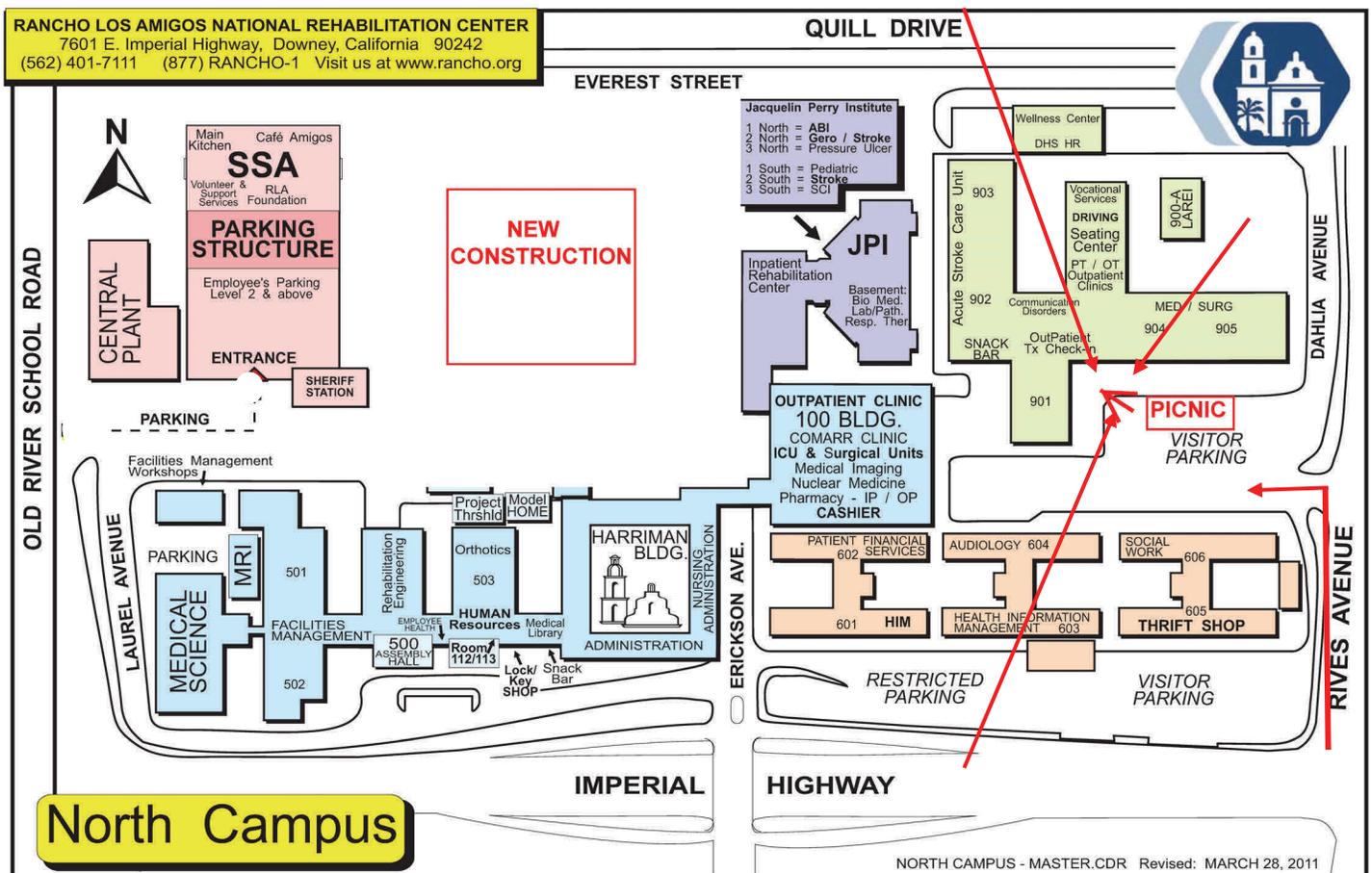
*Terry Wiens lives in Canada. He writes about polio, disability in general, and on many other topics that interest him. You can follow him at: <https://terrywiens.com/>*

# Rancho Los Amigos Post-Polio Support Group - Annual Picnic

## Saturday, June 24, 2017 2:00 p.m. to 4:00 p.m.

At Rancho Los Amigos National Rehabilitation Center, in front of the 900 Building

**Enter Rancho from Rives Avenue** - Please see map below. If you need additional directions or more information, please send an email to: [polio1953@gmail.com](mailto:polio1953@gmail.com)



Please join us for this fun time.  
The Rancho group will supply all the food and beverages.  
You bring an appetite and a friendly smile.  
You will enjoy yourself, and we will enjoy seeing you.  
Bring a family member or friend.