Excerpts from *Not Just Polio* The Autobiography of Richard Daggett

(May 1954, Rancho Los Amigos) My tracheostomy was closed, I went to occupational therapy every day, to the pool three times a week, and I was fitted for a pair of leg braces, one long leg brace (KAFO) and one short leg brace (AFO). I could stand and walk a little without braces, but the braces added stability. In June I received my own wheelchair. For several months I switched back a forth between using the chair and walking, increasing my walking time until I no longer needed the wheelchair.

Once I could get up I started writing a journal. I didn't write every day, just whenever I felt that something happened that was worth recording. I had to learn to write with my right hand because my left hand wasn't strong enough to hold a pencil. I wrote a short poem about my new leg braces:

These are my braces, They set me free. But, these are my braces, They are not me.

> Without my braces, I sit in my chair. Without my braces, Life is not fair.

But, put on my braces, And I'm just like the others. Put on my braces, And I run like my brothers.

> Well, not exactly, I'll have to admit, no. Well, not exactly, 'Cause I had polio.

Polio Déjà vu

The years from the late 1950s to the early 1980s were my best physically. I walked well, if stiffly, and had a high level of function. I needed help with some tasks but was fairly independent. However, because of reduced pulmonary capacity, I didn't have the energy to work all day, every day. A regular nine-to-five, five-days-a-week job was not possible. This is one reason I volunteer with many organizations. I can pick my hours and tasks.

My left hand was most affected by polio, but the middle finger had some strength. It could flex and hold weight. I'd use this finger to hook onto a belt loop of my pants as I pulled them up. One morning in the early 1980s, as I sat on the side of the bed getting dressed, I discovered the finger wouldn't work. This was probably my first noticeable symptom of what we later knew as post-polio syndrome.

Post-polio syndrome, or the late effects of polio, affects many polio survivors. My problems started thirty years after my initial recovery period. It was almost as if my warranty ran out. I still functioned reasonably well but noticed loss of strength and I was tiring more easily.

I had season tickets to the Downey Symphony concerts. I always set in the balcony because I had a better view of the entire orchestra. Climbing the stairs had never been a problem. Now, when I reached the top, I'd have to pause a few seconds and catch my breath. At first I thought this was because I was getting older.

Late in June of 1984, I felt I was coming down with a cold. With me a cold usually has three stages: several days of congestion and discomfort, three or four days of gradual improvement, and another week to get back to normal. This cold, or whatever it was, just did not respond to my usual treatments. I went to a doctor in our new HMO and he did a very brief examination. He said I was just tired and I should go home and rest. If I had taken his advice I'd probably be dead. I felt miserable, and knew enough about pulmonary issues to realize something wasn't right. I made an appointment to see my friend Elaine Layne, the Nurse Practitioner on the Pulmonary Service at Rancho. She advised that I have my CO_2 level and other blood gasses checked.

Given the way I felt, it didn't surprise me that my CO_2 was elevated. What did surprise me was that it had shot through the roof. My CO_2 had been running between 50 and 55 mm Hg, and this is somewhat higher than the normal 35 to 45 mm Hg. Now it was 80! My blood oxygen level had fallen dangerously, too. Obviously, I was not getting adequate ventilation. July 11, 1984, I once again became a Rancho Los Amigos in-patient.

For two weeks we tried several non-invasive respiratory options. I just couldn't seem to tolerate them. Even using a chest respirator full time didn't seem to help. To compensate for my reduced ventilation I was given oxygen, but I knew this was not a good long term solution. Administering oxygen will help with blood oxygen levels but it can mask CO_2 retention, and this can be fatal. After much thought, I decided that another tracheostomy would be the best choice for regaining my pulmonary health.

The prospect of having another trach didn't frighten me. I have several good friends who still function well with trachs after more than thirty years. If our vision is less than perfect we wear glasses. If our hearing is impaired we get hearing aids. To me, it was not such a huge leap of faith or logic to get help when my breathing became compromised.

On the other hand, having a trach would mean I couldn't wear a tie. It may sound odd, but this was my only real psychological hurdle. I really enjoyed wearing a suit and tie. I looked better, and I felt my disability was less obvious.

This decision to have a trach was not made in a vacuum. For several years the doctors had kept a very close watch on my CO_2 levels. This was coupled with a borderline vital capacity of about 1,100 milliliters, approximately 24 percent of normal. Having made the decision, I was sent to surgery on Monday morning, July 30, 1984. I was relieved to learn that this tracheotomy,

unlike my original one thirty-one years before, was going to be done under general anesthesia. I didn't look forward to a repeat of my 1953 experience with trach surgery under local anesthesia.

I awoke after surgery with a number 8, cuffed trach. This type of trach has an inflatable "cuff" that closes off a person's airway, above the trach, to prevent any leakage of air through the nose or mouth. It also prevents a person from talking. The doctor explained that he had to remove quite a bit of scar tissue left over from my 1953 trach. It required several stitches to help keep the tissue tight around the opening.

Three days later I was back on the ward, and after two more days the stitches were removed. A size 6 trach with no cuff was put in. Without the cuff I was able to talk again. The type of respirator I was using had multiple hoses and it was difficult to move without pulling on the trach. This was very, very uncomfortable.

In the middle of August, the bulky, multi-hosed respirator I was using was replaced by a much smaller, portable, single-hosed positive pressure volume ventilator (PVV). This was a great improvement. I could move much more freely. I was also given some time off the respirator. I was encouraged to sit on the side of the bed and take a few steps. After more than a month in bed I felt pretty wobbly. The first two or three times the therapist recommended that I use my respirator as we walked. I found this cumbersome and asked to try walking without it.

To my real relief I had no trouble making the adjustment, but it took several days before I felt very steady on my feet. I'm sure that the weeks I spent lying in bed had a very debilitating effect. Still, each day I walked a little farther down the hall.

This was the time of the 1984 Los Angeles Summer Olympics, and the television coverage of this event helped to break the monotony. In addition, a segment for the television series "Highway to Heaven" was being filmed right outside my window. This added a little extra diversion.

I was discharged exactly eight weeks after being admitted to Rancho. The new trach and the weeks in bed, coupled with some of the late effects of polio, caused some changes in my life. I couldn't stand in the shower safely, both because of my increased weakness and because of not wanting to get the tracheostomy wet. The trach made it more difficult to cough naturally, but it facilitated mucous management mechanically. I couldn't cough it up very well, but I could suction it out of my airway if needed.

I reduced my activities to compensate for my lower energy level. I was probably pushing my limits anyway, since for many years I had been very involved with a variety of church, civic, and disability-related organizations. I've tried to be more selective and conserve my energies for those things that I feel are most important. I try, but I'm not always successful. I have a very hard time saying no to projects that I feel are worthwhile.

In addition to the tracheostomy, to assist my breathing, I have returned to a wheelchair. Actually, I never used a chair very long from the beginning. My current chair is electric, and tilts, reclines, and does the dishes (not really). I can still stand to transfer, and I could probably take a few steps, but it would not be safe.

> *More of my journey can be read in my autobiography. Contact me at:* <u>*Richard@polioassociation.org*</u> and I can tell you how to get a copy.