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### A JOURNEY WORTH TAKING

It is an awesome reality to know that for the rest of my life, every time I lay my head down to sleep, I will do so with a respirator mask strapped to my face. It is a fact that at times seems overwhelming but, most of all, it is a fact of my life.

It is also “a day at the beach” in contrast to the chaos that was my life eight months ago. The days for me were difficult. I felt spacey, off balance, somehow not firmly grounded in the world, either physically or mentally. It was as if I did not have enough breath to cry, laugh, sing or yawn.

I always felt a lump in my throat.

The challenge of teaching was impossible. The biggest effort I could handle was trying to concentrate on a 30 minute TV program. One night, I actually felt a sense of accomplishment at being able to follow an hour-long episode of Northern Exposure.

The nights were endless and frightening. Sleep was short and restless, always with a vague sense that it was dangerous, even with oxygen, to abandon my-self to sleep. I constantly struggled with the feeling that it was all in my head. I needed to snap out of it. Nevertheless, there was a powerful and hunting sense that something was terribly wrong. Life could not be this painful. I knew I could not, would not go through life feeling this unreal, this estranged from myself. I had to find “me” again.

The events that led to this “not me” place in my life were years in the making. I had been aware of Post-polio syndrome since the mid-80s; however, I was experiencing no major problems. In the late summer of 1990, I remember feeling more exhausted than usual. On my return from a vacation in Canada, I fell asleep and woke up 24 hours later, not having moved or changed position from where I landed when I arrived home. On returning to work, I found myself falling asleep any time or place I could. I would even lie on the front seat of any car and rest for 20 minutes before getting the energy to drive home!

When the fall semester started at the college where I teach, I had a closed-in feeling that there was just no air. Finally, one weekend, I went to the emergency room. I did not feel sick in the normal sense of having the flu or pneumonia. I just could not push my way through the day any longer. The blood gases showed respiratory failure. I was put on oxygen and hospitalized. The specialist, who was called in as a consultant, took one look at my chart and told me that I should quit my job and resign myself to being on oxygen for the rest of my life. To put it mildly, I was NOT a happy camper!

Like the true overachieving post-polio person that I am, I returned to work with oxygen in my car, my office and the Health Service at the college. By November of that year, the blood gases were improved and I was on oxygen only at night.

I found a pulmonologist who was willing to work with polio survivors, although she had little experience with the population. In December, I went to the Post-Polio Clinic in Ann Arbor, Michigan. Dr. Fred Maynard, at the clinic, was adamant that I see Dr. Oscar Schwartz, in St. Louis, Missouri. Dr. Maynard offered to phone Dr. Schwartz immediately and make arrangements for an evaluation in St. Louis. Part of me wanted to just go and worry about the details later but the procrastinator in me won out and I decided to wait and go during spring break. By that time, I was back in the hospital with life-threatening pneumonia. I had waited too long and the price was high. I did not attempt to go back to work this time as I was on continuous oxygen for the next several months. Eventually, I was off daytime oxygen but I did not bounce back. I continued using oxygen at night but restful sleep was not restored.

The day I was taken off oxygen I felt I had gotten a little piece of my life back but I wanted more. I called Dr. Schwartz's office for information. To my surprise, he returned my call a few hours later.

After several calls and much indecision on my part, arrangements were made to fly to St. Louis in mid-summer. Getting through the day consumed every ounce of my energy. How would I ever get to St. Louis and survive?

I was admitted to St. Mary's Health Center in St. Louis for a 24-hour observation. Sleep was monitored by what seemed to be a zillion straps, belts, meters and gadgets. The results of the overnight study were clear, I had severe hypoventilation during sleep. It was explained to me that when my polio damaged diaphragm muscles relaxed with sleep, breathing became so shallow that the oxygen decreased to 50 percent of normal and carbon dioxide soared as exhalation diminished throughout the night. In short, I was experiencing respiratory failure every night.

The next step was to be admitted to St. Mary's for a longer stay so that a ventilator with a face mask could be tried. I was willing as I would try any-thing at this point to get a night's sleep. It was obvious that a night on the ventilator, if I could tolerate it, would supply the necessary support for breathing adequately through the night. I was skeptical, however, that this would have a carry-over effect to help me through the day. Dr. Schwartz and the staff were most supportive, explaining that giving the respiratory muscles the "night off" by letting the ventilator take over their function for eight hours, would enhance day time breathing. As much as I wanted to believe that relief was in sight, it all seemed rather impossible to me.

It was at this point, that a young man, Jeffrey, who had been using the ventilator for a year, arrived for an annual check-up. He was just what the doctor ordered! There is nothing like a kindred spirit for comfort and assurance. Jeffrey related that at one point he stopped driving as he no longer felt safe on the road. Now, after a year on a ventilator at night, he had taken a group of students from the college where he works on a trip to Brazil! He was light years away from where I was but I was starting to believe I could make the same journey.