

KANSAS

Connection



Volume 13 ♦ Issue 6 Post-Polio Newsletter for the State of Kansas August 2006



MY THIRTY YEAR JOURNEY WITH POST-POLIO SYNDROME

Elva Suderman, Editor

Kansas Connection

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The first ominous entry in my journal reads: "Experienced first paralysis of legs from exposure to cold on a zero degree day. A very frightening experience since I could not walk unassisted until legs warmed up. Had no explanation at this time for paralysis."

This was the first entry relating to post-polio syndrome in an outline I wrote of my polio history before applying for disability benefits. The year was 1974 -- long before information about PPS was readily available.

My purpose in writing about my personal memories of dealing with PPS is to urge others to write about their polio days. It is important to keep our history alive for the next generation. Also this is a way to share my memories with family members, some of whom only know me as a Aunt Elva, a person who has always been in a wheelchair.

In 1980 I used a collapsible cane for the first time on a trip to Israel where I did extensive walking. Of course I only used it to conserve strength when walking longer distances. On shorter distances I folded the cane as I thought I did not need it. I was still in the "I can do it" way of thinking and had not heard of "conserve it to preserve it." In 1983 on a trip to Jamaica I again only used the cane for longer distances. I still had many things to learn.

In 1982 I along with four other partners purchased the small church-owned printing business where I had been working for many years. This acquisition involved many extra hours of work setting up a new corporation and assuming management responsibilities.

During the following years I experienced increased fatigue, difficulty walking in cold weather, loss of muscle strength and a decrease in ability to balance. In 1984, ten years after my first symptoms, I read a short article regarding something called post-polio syndrome in the April 23, 1984 issue of *Newsweek*. I was overwhelmed with the information as my symptoms precisely matched the criteria written in the article. From that very moment, I knew that I had post-polio syndrome.

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SUBSCRIPTION RENEWALS

All subscriptions to Kansas Connection were due on March 1. There are a number of subscribers that have not paid their subscription fee this year. We have extended credit for a number of months but cannot continue this indefinitely. Please send your renewal payment to the above address.

WICHITA PPSG

The speaker for our August 19 meeting will be Dr. Gary Dick, Certified Practitioner of Structural Integration Roling from the Center for the Improvement of Human Functioning. He will give a demonstration of treatment for pain. According to information found on the Internet Roling® Structural Integration promotes well being by enhancing the body's pattern of organization. It balances the body in gravity and enables participants to function at successively higher levels of efficiency and ease. The meeting will be at 10 a.m. at the College Hill United Methodist Church, 2930 East First. Please join us for this informative meeting. ~ Wayne Larsen

MANHATTAN MESSAGE

We had a great June family picnic with 19 attending. The weather cooperated and we had lots of delicious food. We appreciate Paul and Laura Lee Cross arranging for us to use the Green Valley Community Center shelter. It had

several advantages over our former locations. Our next meeting will be August 23, 11:30 – 1:00 at the Seniors Service Center. Hope to see you there! ~ Donna Alexander

CENTRAL KANSAS POLIO SURVIVORS SUPPORT GROUP

We're certainly getting some variety in the programs at our first Saturday of the month meetings! At the well-attended July meeting Bill Mallonee, a neurologist with the Hutchinson Clinic, spoke briefly, and then answered lots of questions. Mallonee was very open and understood that we're all different and therefore need different treatments. At the August meeting we showed the movie, "Warm Springs." The movie, which was first shown and produced by HBO, chronicles the trials and tribulations of Franklin D Roosevelt from the time he contracted polio at 39 through the founding of the Warm Springs rehabilitation clinic in Georgia and his subsequent return to politics.

The meeting on September 2 will have another change of pace. Sue Harris of the Whole Person Health Center in Canton, MA. will talk about alternative treatment methods, including giving an acupuncture demonstration. She is a graduate of K-State, and her post-graduate training includes study at Beijing University for Traditional Chinese Medicine and the Japanese-Chinese Friendship Hospital. Sue led workshops at the Post-Polio Conference in St Louis last year, and is the sister of Jean Graber, one of our members.

Our meetings are always on the first Saturday of the month at 10 am in the Conference Room B/C on the lower level at Hutchinson Hospital. Survivors, families, and caregivers are all welcome. For more information call Sherry at 620-708-4101, go to <http://members.cox.net/poliosurvivors> or email poliosurvivors@cox.net ~ Sherry Hayes

FROM THE EDITOR

After writing a few paragraphs a week, I finally finished my "Journey" article. It is difficult to share my personal feelings and experiences but I hope this inspires some of you to write about your polio history. Thanks Linda D. for your editorial help and inspiring me to continue writing.

A reminder that you can find some excellent articles at <http://www.postpoliobrangers.com>

Little did I know at the time that I had come to a fork in the road in my life's journey. This new path was littered with boulders and thorns but also with roses and beautiful meadows. There was no way to turn back so I started down this new path.

In 1984 I started using a cane full-time on a trip to Santa Fe and then continued using it full-time. At that time I thought this was a big adjustment and did not know that this was just the start of many more changes to overcome in the future.

On a trip to Wisconsin in the summer of 1984 I experienced for the first time loss of emotions from "hitting the wall" fatigue. When traveling in the past I had always gone from early morning to late at night so why couldn't I continue doing this? The next day I felt better and had no problems for the remainder of the trip.

In 1985 I started looking for information about PPS. There was no Google Internet search engine at that time so this research presented quite a challenge. Finally I read about a polio support group meeting in Topeka, the first support group in Kansas. I drove a 200-mile round trip to attend one of their meetings. This was the first time I met anyone with PPS and it was a great feeling to know that I was not on this journey alone. I purchased a small booklet about PPS and subscribed to a two-page newsletter published by the Topeka group.

In fall of 1985 I attended the first meeting of a small group of polio survivors in Wichita. This was the beginning of the Wichita PPS Support Group and I have attended ever since. When writing a 20-year history of our group I estimated that I have driven about 15,000 miles attending meetings since each meeting was a 100-mile round trip. This group of friends has become a very important part of my life and I have learned so much from them.

In order to prepare for new technology, I took a computer course at our local college. This was very helpful when I switched two small corporations to computer accounting.

In 1985 I realized I had to make some different arrangements in where I lived. At my condo I had a detached garage and had taken some bad falls on icy sidewalks. My timing was just right as a builder wanted to build a duplex with an attached garage and I could help with the design and interior décor. One of the things I wanted included was a walk-in shower and a wide door into the bathroom. The duplex is located across from a small park where I have a great view from my study and kitchen windows. I consider myself so fortunate to live in a central location where I can "wheel" to the public library, downtown and college campus. My city has put in curb cuts for all streets that is helpful.

In 1986 I went to a doctor at the Menninger Foundation in Topeka in search for help with the intense burning pain that I was experiencing in my ankle and foot. The only advice I got was to slow down – something I was not very good at doing.

Finally in 1987 I had to make some major lifestyle changes that proved to be very helpful. To conserve energy, I started working a few less hours, discontinued going home for lunch, and instead rested at noontime on a recliner. My office co-workers were enormously helpful by running errands for me so I could remain at my desk. This

was also the year I adapted my style of dressing to keep warmer by wearing slacks instead of dresses and skirts. Any exposure to cold including air-conditioning made my legs weaker.

In 1987 I was unable to go shopping or walk more than a block or two due to loss of

muscle strength and fatigue. My support group friends helped in my decision to purchase a scooter. I looked at mobility scooters at a large medical supply store but before a salesperson came to help me, I was already gone. I viewed scooters as big, ugly and cumbersome. I certainly could not envision myself using one.

A few weeks after this aborted shopping trip, a friend went with me to look for scooters at a different shop and I purchased my first Fortress 3-wheel scooter. This acquisition involved the even more expensive purchase of a new van and a hydraulic lift to put the scooter into the back of

I was amazed the first time I rode my scooter down the block to my parent's home. For the first time in almost 40 years I could look up and around me; I could enjoy the sight of the beautiful trees and enjoy the scenery.

the van. I was amazed the first time I rode my scooter down the block to my parent's home. For the first time in almost 40 years I could look up and around me; I could enjoy the sight of the beautiful trees and enjoy the scenery. In the past I always had to keep my eyes glued to the sidewalk to avoid tripping.

Among other changes, I stopped singing in our church choir as I was only able to stand for a few minutes. I also had two bouts of a painful frozen shoulder and was in physical therapy for several months each time to correct this.

In 1989 the burning pain that had previously been confined to my ankle and the bottom of my right foot – the better leg – spread rapidly to a large area above my knee. It was very difficult to walk or to drive a car without pain. At this time I went through a spell of deep depression. I purchased an electric wheelchair for indoor use and also started using forearm crutches for walking short distances as the cane was not giving me enough support. Some other changes made were to have a higher stool installed in the bathroom together with grab bars. I use a high stool with rolling casters in the kitchen so that I can sit while cooking. I also rearranged the kitchen cupboards so that items I needed most frequently were in the lower areas.

Accompanying each of these transitions, I went through a period of grief, denial, and then finally acceptance. I can relate powerfully to what a friend of mine, a college professor, wrote about her own experience with her early polio years. She writes, "Where along the way did I learn to be ashamed of being disabled? Why did I expend so much energy pretending I was not disabled? My self-conscious, not OK feelings continued into adulthood. Only when I finally discarded my old negative thinking and substituted positive, healing thought patterns, did life become Only when I finally discarded my old negative thinking and substituted positive, healing thought patterns, did life become so much more joyful and authentic." Unfortunately it took many years before I was able to accept her level of positive thinking.

It was difficult for some family members to understand my new problems. Why did I not host the family Thanksgiving dinner? Why did I stop hosting the annual birthday celebration for my father? After I quit working casual acquaintances

would ask about my work. When I told them I had gone on disability benefits, they would say "But you look so good," implying that I could still be working. I'm really not certain how a person should look if they are no longer working but is nice to hear that I am looking good.

The most difficult transition was in 1989 when I had to start using my scooter both at work and in church. The first Sunday I drove my scooter into the sanctuary was the defining moment when I finally admitted that I indeed had a significant disability and that I would never walk down the aisle again to sit in my favorite pew. After a few minutes I was ready to go home saying I just cannot do this but I also realized that if I gave in the next Sunday would be just as difficult. So in spite of many tears, I stayed until the end of the service. And, yes, the following Sunday was much easier. Incidentally I did walk down the aisle one more time and that was at my father's memorial service. It was my way of honoring him for the many years he had been a support for me. Several years later the church shortened some pews so that I could be a part of the congregation again.

In 1990 I sold my portion of the company stock as the stress of management was becoming too difficult. When possible, I tried to reduce my working hours. To cut down on fatigue, I hired a cleaning lady who also helped with the laundry. It was such an indulgent feeling to come home to a clean house after a hard day at work. I continue to have help with cleaning.

In 1991 I had to discontinue playing piano as my arms became too tired. For a few years I played an electronic keyboard until even this became too difficult. In 1992 I was starting to have difficulty doing repetitive work such as stuffing envelopes without arm fatigue. Also on days of intense burning and pain, it was difficult to concentrate on detailed accounting work and to maintain a cheerful voice on the telephone with customers.

My fatigue and endurance continued to worsen along with pain and muscle twitching in my legs and arm. In March of 1994 I made the decision to apply for disability retirement and retired in April after working almost forty years. The company had an open house for me on my last day of work and many friends and customers stopped by to wish me well.

In my summary statement that I included with my disability application I wrote: "Have reduced all activities to a minimum and can find no other ways to conserve strength except to discontinue working. It is imperative to save enough strength to remain independent. Stress and over-exertion continue to worsen the symptoms of post-polio syndrome." My doctor provided a detailed report of my PPS symptoms to include with my application. Forty-five days later I received notice that my disability claim was approved. Great news!

After retirement, a new phase of my life started. Finally I had the luxury of turning off the alarm clock and having two cups of coffee with my



breakfast while reading the newspaper. I checked out books from the library and spent hours reading. I also enjoyed

going out with friends for coffee and having friends over for lunch.

I had always dreamed about retiring early so that I could do volunteer work. The first summer I was asked to edit a new cookbook sponsored by the ladies of our church. This was something I enjoyed as I could work at my own pace. I also did some volunteer work for the Red Cross Blood Bank.

Six years ago I agreed to edit *Kansas Connection*, a monthly ten-page post-polio newsletter for the State of Kansas and spend many hours searching for articles. Last year I volunteered to do the monthly local senior center calendar and also started attending some of their special functions. Yes, I finally admitted that I am a senior citizen.

In 2001 I had arthroscopy surgery on my left knee for a torn meniscus. Several months later, after pain set in again, I had a gait study done. The recommendation was that I get an AFO brace on my right leg. I argued that this did not sound logical as it was my left knee that was hurting. They however said that if I would brace the right

leg this would protect the left knee that I have to lock with each step. Reluctantly I followed their advice and now years later, I have had no pain in the left knee. Sometimes it does pay to listen to the doctors.

Four years ago, after my electric wheelchair wore out, I got a Jazzy powerchair and a Bruno Curbsider lift for my new van. Since I could no longer use my scooter for outside use due to back problems, I had a ramp added to my deck. I also purchased a three-inch memory foam mattress topper that has been very helpful in reducing pain.

Last year after having some daytime breathing problems my doctor, a general practitioner, arranged for me to get a sleep study. This showed that I had 70 muscle twitches per hour and that I was only getting stage one and two of sleep. I am now on a bi-pap for night and it has improved my breathing and fatigue problems.

My family doctor and I have worked in partnership for years managing my PPS symptoms. He is very willing to read articles that I give him about PPS and to prescribe needed medical equipment or medications. At my last office visit we discussed the partnership arrangement we had and that we would continue working together.

Several years ago I spoke at a District Rotary Convention giving the history of polio and sharing my polio story to help them raise funds for their Polio Pals program. After this I also presented my story to some smaller Rotary groups and our local senior center. Even though I find it difficult to speak in public, I feel it is so important to let people know what affect polio had on many of our lives.

Last year I experienced some intense burning in large areas of my body. Also at the same time I had back pain in the sacroiliac joint. My doctor ordered a series of physical therapy treatments but these did not help. I am now taking Gabapentin (Neurontin) and this has reduced the burning and back pain to a more tolerable level.

Some of the highlights during these years were being able to attend three International Post-Polio Syndrome Conventions in St. Louis. For the past six years I have attended the Bransongoes reunions held annually in Branson, Missouri. This group started with a small group of friends who

met on the Internet. This year there were about 75 in attendance. Much of the time is spent in the large hospitality room visiting, eating and just having fun together. The friendships made during these get-togethers will last a lifetime. One of the hotel's employees said to me on the last day that the staff always looks forward to our stay there. He said that in spite of some of our difficulties we certainly knew how to have a good time. I am so thankful that I am able to drive to these activities by myself.

Another highlight last year was when my family hosted an open house at my place for my seventieth birthday. They recognized that this was an important milestone in my life.

At this time I am only able to walk a few steps each day and must limit my physical activities. I need ten or more hours of bed rest each night. Unfortunately I am unable to take naps and must rely on Ambien to help me sleep at night. I also take several rest periods during the day. At times I deal with overwhelming fatigue – both mental and physical – that can last for a number of days. Facing an unknown future is at times difficult but with God's help I will continue on my journey.

A quotation that I read recently states: "Despite the horrors of catching the polio virus as youngsters and the impact on our lives, despite discovering many years later that it held new horrors in store for us – it occurs to me (repeatedly and with great thanks) that few such devastating illnesses allow so many of its victims full, normal lives of great accomplishment for so many year in between." I thank God for the things I have been able to accomplish and for the great network of polio friends from around the world. □

About the Author: *I was raised in a rural family of four children by parents in rural Kansas and attended a one-room school for eight years. I contracted polio in the fall of 1948 at the age of thirteen and was totally paralyzed from the waist down. Three months later when I left the hospital I was wearing a long leg*



brace on one leg and a shorter brace on the other, along with crutches. As so many polio survivors did I was determined to conquer this illness. By the time I started high school less than a year later I had discarded the crutches entirely and used only a short leg brace. After graduating from business school, I began working at age eighteen and worked continuously for the next forty years. At the time I went on disability benefits, I was an accountant/office manager for a small printing company.

During these 40 years I traveled extensively throughout the USA visiting all but one of the 50 states plus many places outside of the U.S.

ONE PSYCHOLOGIST'S PERSPECTIVE ON THE POLIO EXPERIENCE: SOME THOUGHTS ABOUT MEMORY – PART 1

MARGIE HULL

I have been thinking lately about the important role that memory has played in my experience of acute polio, and later in post polio. I would like for the next few articles to explore some of the ideas from psychology that might help us to use memory as a positive force for our well-being. This time I'm thinking about the way memory helped me in three different stages.

The first stage occurred during those first months in the hospital. In the beginning, at age eight, when I was in solitary confinement—excuse me, *isolation* -- in an iron lung, unable to visit my brothers and baby sister and seeing my parents only for brief visits, I found myself with long stretches of time to think. Without TV, even radio, certainly not laptops, I learned to recognize every swirl in the ceiling that might be recognized as a horse, cat or person's face. But I also spent a lot of time recalling many scenes and events from my childhood. Later when I was moved to another respiratory center many miles from my home, and then to another hospital just as far, going over and over these memories became an important bridge to those people that I loved and just as importantly, to the child I had been. That child had the name of Margy (with a hard g), while all these

new people in my life called me Maggie, Peggy, Margie, Margaret, Madge, *ad infinitum*. It was only relatively late in adulthood that I realized that I could insist that people call me that name from the past, and that became important to me as a symbol of the continuity I sought.

I had a very frightening dream in those early months about going across a very high bridge that suddenly broke off in the middle. In later life I thought the dream had been about fear of death, but I think now, at another level, it was also about being cut off from my former life and my former identity. My family was fortunately very good about keeping in touch with me with wonderful letters, and visits, but the memories served a central function in keeping me connected. I wonder if others of you found that your memories of life before polio became highlighted and valued for that sense of continuity. For some, of course, they were too young to have such memories, and for others perhaps it was too painful to think about.

The next stage occurred when I was finally discharged from the hospital and returned to a new home in a new city. I found myself compulsively remembering many details of my experiences in the hospital, sharing them with my family and my friends who came to visit. I wonder now if it was *ad nauseam*, but I don't recall anyone complaining. Some of the stories were memories of suffering, but many of them were about funny things that happened with friends on the wards, interchanges with therapists, times that I was clever or brave. I think in this period, my memories served the purpose of helping me to integrate the entire experience in my mind, to build a solid base from which to move on with my life. Freud talked about repetitive dreams of trauma experiences that seemed to go against his theory about dreams representing the pleasure principle. He used the term *retroactive mastery of stress* as an explanation of why we both dream about and mull over negative or painful life events. Going over and over those events helped me to feel less a victim, and more as someone who had surmounted difficulties and thrived. Did others of you also find yourselves dwelling on those early experiences of acute polio?

Have others of you polio survivors found yourselves thinking about the kind of person you might have become and how different, if at all, you would have been without the polio experience?

Later in my life, in fact more frequently now in retirement when I again have more time to think, I find a new stage of memory occurring. I find myself noticing things about myself now or at other times in my adult life, and wondering if that quality was part of the Essential Margy (as I now say, "with a hard g, because I'm tough"), or if it was something that developed as a consequence of coping with disability. This process involves searching for times in that early life when I was stubborn, or persistent as I prefer to call it, when I was obsessed with learning new things (the dinosaurs and the caveman), when I was daring (climbing trees), when I was focused on the practical (watching with envy when my mother slipped on a pillowcase with such ease). When I was in graduate school, I was criticized by one of my first professors for being too caught up in the details of the life of the person I was interviewing instead of going for the underlying feelings, attitudes and so forth. I learned to respect the latter, but I never lost my interest in the circumstances in which my clients lived, believing that the risk of homelessness, for example, took priority over low self-esteem as something to be addressed first. When it was my turn to be the supervisor, I made sure that my students paid attention to the gritty details of daily life problems. Would I have been that way if I hadn't had polio and learned to become obsessed with adaptation,

or would the little girl Margy have been that way too if she grew up as a therapist without having had polio? This line of thinking has been encouraged by the fascinating studies of identical twins raised apart, who often end up having amazing similarities such as loving to collect fine china, which one would never

have thought as being genetically rather than environmentally determined.

Of course, there are no answers to these questions, and if I overdid it, it would be perhaps a bit unhealthy. There is the danger of slipping into a version of Marlon Brando *On the Waterfront* saying "I couda been somebody, I couda been a contender". But I seem to find myself enjoying such memories, and finding them meaningful. Have others of you polio survivors found yourselves thinking about the kind of person you might have become and how different, if at all, you would have been without the polio ex-

perience? If so, do you see it as healthy or not so much? If such uses of memory seem to conflict with my earlier emphasis on being in the here and now, considering that forays into the past are also *experience* in the moment and as such we can choose to bring to them the same nonjudgmental open-mindedness, trust in self, and all the other qualities of mindfulness.

In each of these three stages of using memory in slightly different ways, there was the common thread of seeking a coherent, positive sense of identity for my life. Next time we will consider more about how memory is important in creating identity. □

Margy Hull Ph.D. is a Psychologist who formerly worked in a community mental health center in Atlantic County, New Jersey.

Reprinted from PPASS Times, Newsletter of the Post Polio Awareness & Support Society of MN, 7720 York Ave. So. #520, Edina, MN 55435-4461

POST-POLIO PATIENTS HAVE SWALLOWING ABNORMALITIES THAT INCREASE THE RISK OF CHOKING: NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE (NINDS)

Many post-polio patients have swallowing abnormalities that increase the risk of choking but are unaware of their condition, according to a study directed by a scientist at the National Institute of Neurological Disorders and Stroke (NINDS) and published in the April 25 issue of the *New England Journal of Medicine*. *

Of the 500,000 Americans who survived acute polio, more than 125,000 now have post-polio syndrome, in which progressive muscle weakness develops 25 to 30 years after the initial disease.

Previous reports have demonstrated that post-polio syndrome weakens the muscles of the arms and legs — causing patients difficulty when walking, lifting, or reaching. The recent study shows that this progressive weakness also affects the bulbar muscles of the tongue, mouth and throat and triggers swallowing problems — called dysphagia — in most patients.

"These findings should prompt physicians to check their post-polio patients closely for

abnormal swallowing," said Marinos C. Dalakas, M.D., the NINDS scientist who directed the study. "Unlike new weakness in the arm or legs, which causes obvious problems with movement, deterioration in swallowing is easily overlooked — even with standard neurological exams," Dr. Dalakas stressed. "If dysphagia is not specifically tested, problems may remain hidden until the patient suddenly becomes aware of choking."

During the study, scientists examined swallowing among 32 patients randomly chosen from a larger group of post-polio patients. Using specialized imaging techniques, including videofluoroscopy and ultrasonography, they detected dysphagia in 31 patients — but only 14 were aware of this problem.

Typical signs of dysphagia included excessive tongue movements, a delay in the swallowing reflex and constriction of throat muscles, and uncontrolled flow of food from the mouth into the throat. These problems were often more severe on one side of the mouth and throat.

Dr. Dalakas and his colleague Barbara Sonies, Ph.D., of the National Institutes of Health also detected dysphagia using an index that assesses oral motor function based on 10 tests of muscle strength and motion, such as strength of tongue and lips, voice quality, and swallowing ability. "As the index score rises, the patient's risk of choking also goes up," Dr. Dalakas said. "Using this index, physicians can predict which patients are likely to choke."

Dr. Dalakas suggested that patients with post-polio syndrome visit their physician for a check of dysphagia and, in some cases, change eating routines to reduce choking risk. For example, patients with significant dysphagia should chew food on the less affected side, consume softer foods, use smaller bites when eating, and eat more slowly. He also recommended that family members or companions of such patients learn the Heimlich maneuver.

The exact cause of post-polio syndrome is unknown. During the first, acute polio infection, the virus destroys nerve cells that control limb and bulbar muscles. This causes symptoms that range from weakness to paralysis, depending on the number of nerve cells destroyed and how well the remaining, healthy neurons can compensate.

In post-polio syndrome, however, the compensating neurons become overworked and are no longer able to control muscles as effectively, Dr. Dalakas said. Post-polio syndrome may also be aggravated by the aging process, in which all individuals lose some neurons. In most individuals, half of the nerve cells controlling a muscle must die for weakness to result. Since the number of neurons is already abnormally low in post-polio patients, small additional losses can easily trigger muscle weakness.

"Studies of post-polio syndrome are rapidly advancing our knowledge of how motor neurons survive and endure and what causes them to dysfunction," said Murray Goldstein, D.O., M.P.H., NINDS director. "Thus, this research could have implications for other diseases that affect motor neurons — such as amyotrophic lateral sclerosis, or Lou Gehrig's disease, and the neuropathies. It may also help scientists to understand how aging affects the nervous system." □

Reprinted from Web page of NINDS. The National Institute of Neurological Disorders and Stroke, one of the 13 National Institutes of Health in Bethesda, MD, is the primary supporter of brain and nervous system research in the United States.

Date Last Modified: April 24, 2006

* "Dysphagia in Patients with the Post-Polio Syndrome." Barbara C. Sonies, Ph.D., and Marions C. Dalakas, M.D. *New England Journal of Medicine*; April 25, 1991; pp. 82-91.

"DID YOU GET HERE BY YOURSELF?"

A BRIEF EDITORIAL

by *Linda Wheeler Donahue*

Did you get here yourself? These were the unexpected words I heard from a store clerk in a gift shop last week.

Hmmm. How should I have answered? I might have said, "Yes, I have retractable wings that I use to fly." or "No, 'my people' brought me; the entourage is waiting out there in the parking lot." Or how about ... "By myself? Why, no, of course not. Don't you see all these people here next to me?"

Well, I did not deliver any of those wise cracks, I just said, "Yes" and left the store. I started down

the sidewalk and then, before reaching my van, I decided that I should take this opportunity to educate the young woman in the store. So I turned back. When I re-entered the shop, another customer was checking out, so I waited my turn. When the shopper left, I rolled up to the counter. "Is there a problem?" the clerk asked. "Oh, no, everything is fine. A few minutes ago you asked me if I came here by myself and I wanted to explain."

She seemed embarrassed, blushed, and looked away momentarily. I smiled and explained that I am able to drive my own vehicle using hand controls. I added that my van is modified with a lift so I can drive my wheelchair aboard to reach the driver's seat. She seemed visibly surprised, almost astonished. So I continued, saying that modern technology is very helpful enabling people with disabilities to work, raise families, garden, pursue sports, outdoor activities and, yes, to drive!

She replied with a simple "Oh Wow." I turned to leave and she rushed to reach the door ahead of me to politely open it. "Bye. Have a nice day," I said. As I boarded my van in the parking lot, I smiled to myself wondering if she was straining to observe me. I drove away feeling that I had done a small bit of good to inform someone who was ignorant about the world of people with disabilities.

That interaction brought to mind my emotional response when someone says, "she is wheelchair-bound" or "confined to a wheelchair." I always want to shout: "NO, I am wheelchair-independent. I am wheelchair-liberated!"

So back to that unexpected question from the store clerk: "Did you get here yourself?" The query revealed the unawareness of the clerk and indicates that she needs to read more, observe more, and study life around her more. I am glad I did not just quietly leave, but returned to edify and inform the clerk.

I hope our interaction enlightened a young woman to the facts that people with disabilities DO get out of their homes, they DO go shopping, and many even drive their own vehicles! □

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