

Rancho Los Amigos

Post-Polio Support Group

Newsletter - February 2014

Living with Polio (continued)

In our August 2013 newsletter we asked readers to submit their early recollections of polio. The story on the next page is the second half of Astrid Gallagher's polio recollections. In Part One, the author began her "Living with Polio" story in this way:

"At this late date it is impossible to separate the polio experience from the rest of my life. I suspect that the disease hasn't influenced who I am, my personality, how I think, feel and react. It changed who I married, where I lived, my work, and what physical activities I can do. And it taught me at an early age to cope with adversity and not take too much for granted."

She continued to describe her life through the acute stage of polio and rehabilitation at Rancho Los Amigos hospital.

"Rancho was a great place, a happy place. We were too busy to ponder our futures. I improved dramatically. I regained muscle power in my back, shoulders, arms, hands, and feet. Without quads I learned to walk lock-kneed and use gravity to throw my legs forward. I had a sense of balance that allowed me to move despite lacking some crucial muscles. Eventually, I walked with only one forearm crutch. Steps, curbs, getting up from the floor, a toilet or from chairs would always be a problem."

In Part Two, Astrid describes how she faced the challenges of an adult polio survivor. The October 2013 newsletter featured Part One of this personal story "Living with Polio," and is posted on our website: http://www.ranchoppsg.com/Newsletters.html You can read and print a personal copy directly from the website.

(Continued on page 2)

<u>No</u> article in this newsletter may be reprinted without written approval. <u>No</u> article may be edited. The full text of an article, including most graphics, can be obtained by request. Please send requests to: RanchoPPSG, 12720 La Reina Avenue, Downey, CA 90242 or **RanchoPPSG@hotmail.com**

The information presented at our meetings and/or contained in this newsletter is solely for information. It is not an endorsement of any product, medication, or individual.

(Continued from page 1)

Living with Polio - Part Two

By Astrid Gallagher

I returned to college in time for my senior year, but one year late. I was limited to 12 credits the first semester, and 15 the second. In order to graduate in 1957 I had to take a summer session.

And I could drive again. My mother bought a 1956 two door Chevy that had the gas and brake pedal at the same level so I didn't need to lift my leg to use them. She rented a house in Claremont, California and the college allowed me to live off campus with her. This proved less expensive and more convenient.

The second semester I met Lee Gallagher who was doing research in nuclear physics at Cal-Tech. He was quirky, and fun to hang around with. He didn't notice that I wasn't normal. He danced with me, a kind of two step shuffle with me hanging on tightly. He, of course, was delighted with the 'tightly.' I realized that living in Colombia would be hard for me. The physical barriers would be so great I couldn't live a normal life there. I knew I wanted to work, and in Colombia that wouldn't be easy. It was a difficult choice.

After I'd completed the summer session and all graduation requirements, I flew home to see if my boyfriend was actually the man I wanted. As it turned out, he didn't want me either. So I returned to the U.S., to Lee, and to the American Graduate School for International Management in Phoenix, AZ to pursue a master's degree. My goal was a job in the import-export business.

Thunderbird, as it was called, was ideal for me; a flat campus with no steps. The institute trained executives for overseas assignments. Their wives were included, and received a specialized course of studies. I was one of the first four women enrolled in the same program as the men. I loved the courses and my fellow students. As the semester progressed I realized that getting a job wouldn't be easy with my need for an accessible work environment. Lee wanted to marry me and have children. I knew I wasn't ready for such a decision. My dilemma was solved when I got pregnant (despite using birth control methods), and we got married in November. I finished out the semester.

We rented a little house in Pasadena, California and I tried to find work. Everywhere I went there were barriers; stairs with no railings, heavy doors, and high curbs. And of course a

(Continued from page 2)

woman with a liberal arts degree and no typing skills was unemployable. I soon gave up, and concentrated on housework, the job I really disliked. I'd never learned to cook, clean, iron, or make beds. (I still don't do it willingly or well.)

Without stomach muscles, I fell frequently. I never injured myself, though some of the falls were quite spectacular. Dr. Perry corrected this with an abdominal fascia transplant, a kind of crisscross from hip to rib that is similar to the leather braces under a 19th century freighter's wagon. This corrected the problem, but gave a funny appearance to my stomach on the next pregnancy. These 'struts' were pushed up and my belly protruded out from under the struts like a rounded tube.

The next few years passed in a blur. We had three children in 3 1/2 years. I couldn't carry the babies and would pick up the baby and push him around in a foldable baby buggy. This worked very well for me. The kids learned to do household chores from an early age. They didn't like to do them any more than I did.

Twice a week I attended Cal State Los Angeles for a Masters Degree in geography. Cartography, a course that required me to carry an easel to class, to work on the maps, and draw with a steady hand, proved my undoing. I simply couldn't do it. To top it off, on the night of the final exam, I drove around the immense parking lot trying to find a parking space. I found one that barely fit my car. I opened the door to step out, but I couldn't extricate my 8-month pregnant stomach. Again, sense told me this was not going to work for me.

In 1964 my parents immigrated into the U.S. My mother knew she had to work and, as she already had teaching experience, decided to study for her credentials. I took the courses with her, and when I got the certificates, a part time job dropped in my lap, teaching junior high Spanish and French. I had found a profession I enjoyed, and a job I could physically do.

In 1968 Lee accepted a job in New Jersey. He found a hillside California style house, with all the main rooms on one level. I needed a few more courses to get a New Jersey high school credential. The local college provided me with a key to the elevator, and a special parking spot. I taught high school Spanish for twenty-two years.

During these years, every school vacation I took the kids on camping trips in our old station wagon. We visited historic monuments and national parks all over the U.S. and Canada. The kids were great travelers. Whenever Lee could go with us, our trips were to Europe, Mexico, Egypt, South Africa, and Kenya.

(Continued on page 4)

(Continued from page 3)

Teaching took its toll. The classrooms were upstairs. All the stairs had railings, but I needed an enormous effort to use them. When my department head found out I was studying for an administrative credential, she said I was too handicapped. In hindsight, she may have been right.

I had nightly muscle cramps, and my knees hurt. I went from one crutch to two. The knees deteriorated until I was in constant pain while walking. While I have a very high tolerance for pain, I was losing my sense of balance. Without that, I knew I'd be in deep trouble.

In 1984 I called Dr. Perry. She said, "Of course you're having problems. You've been abusing your knees for 25 years. You have to learn to teach sitting down." This I couldn't do. So she suggested I come to Rancho and talk to the surgeons.

When I met Dr. Chris Jordan I knew he'd help. In 1985 he installed a braided dacron rope screwed to the bones in back of the knee both above and below. After the surgery, a cast kept the knee in 5-degree flexion for several months, allowing scar tissue to grow around the braid and strengthen it. The cast came off and Dr. Jordan pushed back the knee into 5-degree extension (man that's painful). This would allow me to walk lock-kneed. Without quads I can never have a normal gait. I wore a brace for a year. The surgery was successful for two years.

Because of the enormous stress on my knees, by 1988 I was again developing a 30-degree back kneeing. Dr. Jordan suggested another surgery but with a freeze-dried patellar tendon. The surgery was the same as before. While I was recuperating in California, I received a letter from the superintendent of schools that my increment would be withheld due to my lengthy absences for 'frivolous' surgery. The head of our teachers' union went to bat for me, as the situation would set a dangerous precedent. As it turned out, the superintendent held the absence record. I was 'punished' by being assigned to the middle school. If you don't take kids too seriously middle school students are fun to teach, and much less work than 3rd and 4th year foreign language students. At this point I finally sat down to teach – in an electric Pace Saver scooter. What a relief, and why hadn't I done that years before?

In 1989 the left knee needed the same surgery. And I knew then that eventually both of these surgeries would also fail. But this time I had a scooter, so all was well. I retired in January, 1992, and received disability social security.

In 1983 Lee suffered a severe heart attack at age 50. He recuperated somewhat, went back to work, but his heart slowly weakened. My mother died in 1991, and Lee died in 1994. My

(Continued from page 4)

lifelong supporters had vanished, though I didn't realize until then that I needed them. At 59, I was living alone for the first time in my life. I was scared. Who would lift me when I fell, cough me when I was choking, carry me up stairs? Who could I call to complain and chat with, to go on road trips with? I learned to recognize that I was disabled and that it was okay to ask for help. I made the physical changes that make my life easier.

Lee and I had planned to move to San Luis Obispo, California, so I finished the job. I bought a lift for my car so I could haul my scooter. My son built the totally accessible house we'd planned. I was busier retired than working. Yet walking gradually got more difficult and more painful. I lost my back muscles, so could no longer stand. I learned to do housework from the scooter. But I needed the scooter to grocery shop and run errands. The perfect solution was a camper van with an under vehicle lift. I've driven to Mexico, Canada, and all over the U.S. by myself.

Quite suddenly I had sharp pains in my shoulder, then in my back, neck, arms, and hands. I knew I had arthritis. The rheumatologist said no, but told me I had osteoporosis. I was incredibly tired every afternoon. I'd wake up nights gasping for breath. I needed electric blankets and heating pads to warm me enough to fall asleep. And I couldn't stop gaining weight. I was certain I was aging at an unusually rapid pace.

Incredibly, through all these years I came across only one other polio survivor. A chance polio newsletter convinced me it was time to return to Rancho. A full evaluation revealed a lack of oxygen as the cause for tiredness. My vital capacity has dropped to below 40%. A BiPAP machine and humidifier solved that problem. A cortisone shot, and naproxen sodium keep the pain under control. An electric bed eases the pressure on my back. I've been on the Atkins diet for two years, sort of. I've no self-control against food. Losing weight is the most challenging job I have, and also the most important. So I'm trying.

The scooter is no longer adequate for daily use. I have a Permobil electric chair that's difficult to travel with overseas. I recently acquired an E-Z Power collapsible electric wheelchair that folds flat and fits into an airplane's coat closet, and into the trunk of a rental car, allowing me to travel anywhere I want to go. The camper van no longer works for me, instead, I sit in my wheelchair locked down in the driver's side of a minivan, and go to motels.

I haven't walked in several years, and even transfers are difficult. As time goes on, there will be new medical issues and continued deterioration that I will confront. I'm happy to be alive. I feel that I've got everything going my way, and that it will continue to do so. I'm fortunate to

(Continued from page 5)

have support from my adult kids and now my growing grandchildren. All my polio life, my parents, husband, and children treated me like a normal human being. No one did for me something I could do myself. No one hovered over me. Frankly, for the most part I myself didn't notice I was handicapped. Every time a door closed a new one opened. And I'm still in the race of life, with as much gusto as ever.

Our thanks to Astrid Gallagher for sharing her polio story. Perhaps Astrid's recollections have reminded you of your own polio story. Please jot down your thoughts and send them to us. We'll work with you and obtain your approval before publication. We can share it in a future newsletter.

Meeting Notices

Rancho Los Amigos Post-Polio Support Group

Saturday, February 22, 2014 - 2:00p.m. to 4:00 p.m. - Annual Pot Luck

It's our Birthday! Come and have a great time with some great people. It's a party and a potluck, so, if you can, brink some easy to eat food to share.

Saturday, March 22, 2013 - 2:00p.m. to 4:00 p.m. - Pulmonary and other Bulbar Issues

Many polio survivors had bulbar polio but may not have realized it. Just because you never used an iron lung, or thought that breathing problems were the only sign of bulbar polio, you might still be experiencing bulbar related issues as you age. Richard Daggett will present facts on the many manifestations of bulbar polio, and suggest some relevant questions to ask your healthcare team. Richard is president of the Polio Survivors Association and a member of the American Academy of Home Care Medicine.

Post-Polio Support Group of Orange County

No meeting in February

Saturday, March 8, 2014 - 2:00p.m. to 4:00 p.m. - Financial Elder Abuse

Knowledge and Protection to Avoid Financial Predators: Learn how to protect yourself and your loved ones from the fastest growing form of elder abuse.

No meeting in April

May - Date and time to be announced - Dr. Susan Perlman

Why We Need To Continue Polio Vaccination

In the last few years, I have heard some people say that the polio vaccine is no longer needed, or that all vaccines are bad and cause more harm than good. With religious zeal they condemn drug companies, our government, and the medical establishment. Facts don't seem to faze them. They continue to preach bad medicine and are sometimes successful in clouding the minds of parents.

Vaccines have nearly eliminated polio and have actually eliminated smallpox. What a gift to mankind! This gift is not recognized by the anti-vaccination lobby. They have benefited from this gift because other, more enlightened, people have accepted the gift. The vaccine opponents have been given a free ride. They are smallpox and polio free because other people have done the responsible thing and gotten vaccinated. In 1953, the year I contracted polio, there were approximately 32,000 documented cases of polio in the United States and more American children died of polio than any other communicable disease. The year before there were more than 58,000 documented cases of polio in the United States. Just imagine how many hospital wards we would need now, more than fifty years later, if there had been no vaccine.

Polio is still endemic in parts of the world. We are all, infants and adults, just one airplane flight away from this scourge. Some people might think they are safe because it is, "over there." But one person traveling "over there" can quickly bring it, "over here."

New cases of polio have been reported in countries that had previously been declared "polio free." The polio virus is highly contagious, and the incubation period can be days or weeks. A traveler can contract the polio virus and be unaware that he or she is infected. The infected person can get on an airplane and return to their home, or continue their travels to other "polio free" countries. This highly contagious disease can quickly spread to unvaccinated children and adults.

Imagine how you would feel if you knew you were responsible for the paralysis or death of your family members, friends, or neighbors? Is it worth the risk? I don't believe it is, because I have seen and experienced the devastation caused by polio.

What are your thoughts?

Richard Lloyd Daggett President, Polio Survivors Association Member, American Academy of Home Care Medicine Richard@polioassociation.org Rancho Los Amigos PPSG 12720 La Reina Avenue Downey, California 90242 USA

FREE MATTER FOR THE BLIND OR DISABLED

The Rancho Los Amigos Post-Polio Support Group and the Post-Polio Support Group of Orange County share a mailing list and publish newsletters on alternate months. All of our meetings are open to polio survivors, family, and friends.

Our meetings are relaxed, informal, and provide a supportive atmosphere for the exchange of ideas and concerns.

Visit your local support group. You will be glad you did.