

## Plan Ahead for a Great Travel Experience

Carol Meyer, Ankeny, Iowa

*Traveling to the Post-Polio International Conference in St. Louis this spring was amazing and a joy! I met so many other polio survivors, listened to very interesting presentations and learned a lot! It was no small feat for any of us polio survivors to attend, but I was really surprised to learn that my presence there was especially unique because I am trached and hooked up to a vent 24/7. But before I get into that, here is a little bit of my polio story.*

**M**y brother, sister and I had seen a movie about the Little Rascals going camping the night before, and that Sunday afternoon in September 1952, we were reenacting the movie in our yard. One minute I was playing and having fun, and the next minute I felt cold and tired. I wrapped up in one of the blankets we were playing with and fell asleep in the grass. This was an immediate red flag for my mother because I was the kind of kid who couldn't be bothered with naps. She was so alarmed and frightened that I might have polio that she took me to the doctor the next day, but he didn't think that I had it.

The following day I couldn't swallow the orange juice that Mom gave me to drink and when I tried to walk across the room, my legs collapsed and I fell to the floor. At that point, Mom picked me up and drove me to the hospital in Mason City, Iowa, where a spinal tap confirmed her worst fears. Because all of the major hospitals in Iowa were filled with polio patients, I was admitted to Mercy Hospital in Mason City with spinal and bulbar polio. Both of my legs were paralyzed and I had trouble swallowing food.

The paralysis left my legs and I was discharged. I worked hard at all of the exercises that I was given, and I was able to join my classmates in second grade yet that fall. By the time I was in fourth grade, my scoliosis was beginning to be visible and my doctors at Children's Hospital in Iowa City thought that I should start wearing a body brace. It wasn't the most comfortable thing in the world as it was made from leather and steel, but it helped support my body.



Carol Meyer at Emigrant Gap, a gap in a ridge on the California Trail as it crosses the Sierra Nevada, to the west of what is now known as Donner Pass.

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## POST-POLIO HEALTH

Summer 2014

Vol. 30, No. 3

ISSN 1066-5331

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*PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.*

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I went on to the University of Missouri—Columbia and became a high school English and speech teacher, but I kept being plagued by bronchitis and pneumonia. I had a spinal fusion in 1978 and wore a halo body cast for nine months, and when I emerged from my cocoon, I got to throw away that heavy old body brace for good!

I returned to my teaching job and met the man of my dreams at a ballroom

dance class in Edina, Minnesota! We got married in June 1981, and soon I was pregnant. Little did I realize what a nightmare that pregnancy would be. At six months, I started to have lots of problems with my breathing, and my efforts to breathe spiraled downward because I was unable to blow off the CO<sub>2</sub>. Finally I had an emergency C-section. My baby girl was fine, but I was not.

I fought valiantly to live, but I still couldn't breathe well and sleeping was out of the question. Since I was in a hospital in Minneapolis, Minnesota, my

pulmonary specialist decided to get an iron lung out of storage to save my life ... and it did! I was finally discharged from the hospital, but for a year afterwards I had to go into the hospital every once in a while to sleep in the lung for a few days.

When our daughter was in first grade, I caught a cold, which turned into pneumonia. I ended up in the hospital on New Year's Day, 1989. I finally consented to being intubated, but I was faced with another life and death situation a few weeks later: to have a tracheotomy or not. I chose to live and consented to the tracheotomy. Immediately I started to

get better, I could talk and eat real food, I could go down to physical therapy, and I could sleep hooked up to a vent. I had a great nurse who taught me how to clean my stoma, suction myself and hook up to my portable vent. Later after being home for a while, my husband learned how to change my trach tube, something that has to be done every two or three months.

***“They have not been ‘polio doctors,’ but they have been extremely insightful and careful in their medicine, yet aggressive when needed in emergencies.”***

I have been lucky to have several wonderful pulmonary specialists throughout the years. They have not been “polio doctors,” but they have been extremely insightful and careful in their medicine, yet aggressive when needed in emergencies. I refuse to work with any doctor who has an ego problem and doesn't treat me like an intelligent human being who is very much in touch with her body.

Whenever we've moved to a new area, I have interviewed my doctors to make sure that they are willing to work with



Carol and Chuck Meyer in Napa Valley, California.



Carol shopping in St. Helena, California.





Carol in St. Helena, California.

me as a team in my health care. I learned early on how necessary it is to be my own advocate. All of my pulmonary specialists have cared so much about my health that they've generously given me their home/cell phone numbers (unsolicited) and have encouraged me to call if I am ever in trouble. I never abuse that privilege.

***“Having the trach was one of the best decisions I’ve ever made for myself.”***

Since I’ve been trached, I have not been hospitalized, and I haven’t had either bronchitis or pneumonia because I can suction myself. Having the trach was one of the best decisions I’ve ever made for myself. I’ve been trached now for over 25 years and have never had an infection in my stoma. I continue to live a full life, I’ve gotten to watch our daughter grow up and begin her career, and my husband and I have been able to travel from coast to coast almost every year. We drive to California every summer to visit my husband’s siblings and mother, and later in the summer, we drive to

Massachusetts to visit our daughter. In between these major road trips, we often do several smaller ones.

I no longer fly because I have to carry along a small medical clinic wherever I go, but we do road trips. To do a road trip safely means lots of planning in advance. At least a month before we leave, I get our route all mapped out and make our hotel reservations. We travel with our cell phones, GPS and laptops. I carefully pack all of the trach and vent supplies that I will need on the trip.

I have learned the hard way to make sure that I have spares of everything with me whenever we travel, e.g., extra vent hoses, trach care kits, external batteries and charger, viral filters for my vent hose, humidifiers that fit onto my vent hose, swivel elbows that connect my vent hose to my trach tube. I also always take along an extra trach tube (Portex Blue Line Cuffed, 6mm) with all of the materials needed to do an emergency trach change, clean ribbons that hold my trach tube in place, lots of Q-tips and saline solution for trach care, approximately 10 suction kits for each day that I will be gone, my two DeVilbiss suction machines, my pillow wedge and extra pillows for sleeping. (We sleep in an adjustable bed at home.)

I travel with two LTV®950 vents, each the size of a laptop computer. Finally, I use 1½ liters of liquid oxygen per minute; it is fed to me from a small portable canister into my vent. On road trips, we carry a four-foot tank of liquid oxygen with us in the car; it holds 45 liters of liquid O<sub>2</sub> when it’s full. My husband Chuck keeps it well-anchored in our Toyota Sienna, and he fills my little portable canister from that about three times per day. I would not be able to travel in high elevations without my vent and O<sub>2</sub>. I get my liquid O<sub>2</sub>, trach and vent supplies from Apria Healthcare, which is



Chuck filling Carol's portable oxygen canister.

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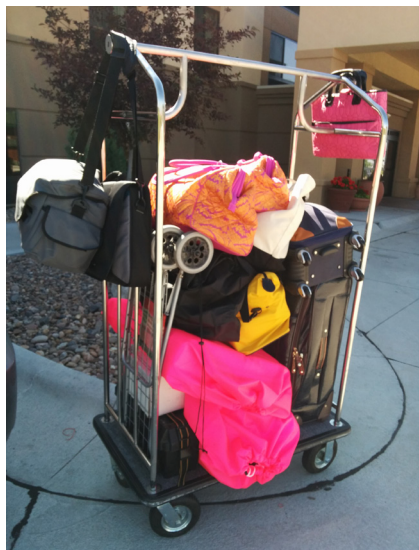
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a nationwide company. Before we travel, I always make an appointment to stop at an Apria location to have my liquid O<sub>2</sub> tank filled if I need to.

Even though I am trached and vented, I am able to walk. At home I have a miniature grocery cart that I push; it carries my external battery, vent and liquid O<sub>2</sub> canister. I am able to cook, do our laundry, entertain guests, etc., with this system. When I go out to eat or to the grocery store or anywhere out of our apartment, I pull my external battery, vent and canister in a black bag on wheels (made by Reisenethel). It is made out of a heavy mesh material so that my vent can breathe. (A vent puts out a lot of heat and requires good air flow.) My husband lifts this bag in and out of the car when we go places.

Unfortunately there are so few vent users who are mobile like I am that we had to figure out all of these travel and living methods ourselves. I purchased both the push cart and the pull bag at The Container Store.

Since Chuck and I are old hands at traveling like this, it was with great confidence that we made



Carol's equipment ready for hotel check-in.



The Meyer van ready for a road trip.

plans to attend the wonderful conference in St. Louis. I got along just fine at the conference. If you attended, you might have noticed me walking around with a hose connecting me to my vent in my black pull bag.

***“The key for a great travel experience is to plan ahead ...”***

The key for a great travel experience is to plan ahead and make sure that my small medical clinic is intact! Then we can enjoy all of the splendor that our beautiful country has to offer. ■

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