

Periodic Paralysis and Traveling “A PLEASANT SURPRISE”

By Susan Q. Knittle-Hunter

It is 6:15 in the morning and I am sitting on the sofa of our thirty-foot trailer in the Mazama Campground at Crater Lake National Park. Just a few weeks ago, I would not have thought this possible.

You see, I have Periodic Paralysis a very rare hereditary disease that affects the muscles. It is an ion channelopathy. When potassium shifts in my body it enters the cells in my muscles and paralyzes them. For many years it only partially paralyzed me making it look like MS or other neuromuscular diseases so I was misdiagnosed and mistreated.

Two years ago, I had my first total body paralysis attack. I physically went downhill from there. At this time, I am hooked to an oxygen system 24 hours a day. Physically, I can do not much more than walk a few steps at a time. I need to be pushed in a wheelchair or use a powered chair for any longer distances. The electrical parts of my heart have been damaged and my breathing muscles have been compromised. Basically, I can do very little to take care of myself.

The idea of traveling, my favorite thing to do, was no longer a viable option for me. This was difficult for me to accept. I still wanted to see Alaska and all of the National Parks. I wanted to visit family and friends spread across the United States.

Most of my time is spent sitting in my recliner working on my computer, watching television, reading or knitting. I can no longer cook, clean or shop. My husband has had to adopt these chores. He has become my caregiver.

Knowing that I still wanted to travel and wanting to travel himself, he set out to make it a possibility for us. He bought a large travel trailer and traded our minivan in for a truck, both easily accessible by me. He searched and found an oxygen system that is portable and does not require tanks to carry around. It can run off of a car battery as we travel and runs on batteries when outside of the car or trailer.

He has organized a bag with all of my medical devices to carry around with us and we have put together a folder with all of my medical records and information on my disease, so in an emergency, medical professionals will know how to take care of my needs.

I am on a very restricted diet, so he prepared all of my food ahead of time to make it easy to eat our meals on the road.

He has hooked up a satellite system for television and purchased a smart phone with tethering capabilities to be able to have computer access.

I have a heart monitor implanted in my chest and we have a portable monitor for it and a portable transmission system in case we need to send one to a hospital if I have a problem with my heart.

So, here I sit looking out the trailer window, into the lovely alpine forest of Crater Lake National Park as I write this. Today we will drive around the rim of the magnificent lake, taking pictures and enjoying the day. I am sure we will have a picnic lunch in a peaceful forest setting with perhaps a cool, clear stream nearby to add to the ambiance.

Today Crater Lake National Park, next month Yosemite National Park and next year Denali National Park in Alaska!!!!

