

Polio and I, Hidden From the World

By Roger Reed, Member of Central Virginia Post-Polio Support Group

The events that I'm about to relay are things I didn't find out until I was in my late thirties, so keep this in mind when you are reading this article. I am writing this article to help myself and hopefully someone else in the PPS community.

I was born in 1959 in a mountain community in Virginia to a poor working-class family who weren't highly educated and who held onto the old ways of life. My parents and many members of my immediate family grew up during the Great Depression and although poor, they had a great deal of pride. They saw things differently and had to rely on what they thought would work for that situation, including the practice of medicine.

All through the years, my dad said nothing to me about having polio, but my mother would say things like, "The doctor said you had polio." "You didn't walk until you were over two years old because you were fat." One day, out of the blue she said, "When you were little you were very sick. You couldn't move your body and ran a high fever. The only thing you could move were your eyes."

This was about all the information I ever heard, but I still didn't know what she meant because I was young and really didn't understand.

What seems to have happened was: my parents were not giving me any of my vaccinations and when I got sick, the doctor admitted me to the local hospital. Whether that was my onset of polio or not, I don't know.

When I started having medical problems in my thirties, I thought something was wrong with me. I started researching through the internet and looking up polio websites because of what my mother had told me years earlier. Sure enough, my symptoms were just like the ones for post-polio syndrome. I started asking questions and wrote a letter to my original doctor. He wrote me back and denied the "polio ordeal". My father told me to stop looking for my records; that they were all destroyed years ago and to stop asking questions.

I started looking for my hospital/doctors records anyway and eventually got copies of everything they still had. Most of them were fairly new, but in the copies were three pages of handwritten records from my doctor, every time I had been to see him. Although the word "polio" never appeared, it did give me some useful information about their treatment. After I was admitted, I got sick again and they started giving me a lot of antibiotics, plus gave me all my vaccinations. I guess that is all they knew to do at that point, but for the polio vaccine, it was too late.

My dad told me not to ask anymore questions because it would "only hurt me", but I disagreed. I was 99% sure I had figured it out, but I still wanted someone to tell me.

I wanted to hear the words. There was something about hearing it that would make me feel better, but it will most likely never happen and for this I am sad.

From a young age, I have always had a lot of health problems and wondered how I could be sick so much. In my twenties, there was a period of time when I felt so good I almost worked myself to death. I didn't even catch a cold. But soon afterward, things started downhill again. I worked very hard, with long hours in a factory for 25 years. I have a wonderful wife, raised three children and helped each of them through college.

One day near my 40's, I just couldn't "go" anymore. I could hardly climb the steps to go to the restroom and when I came down, I would become disoriented and didn't know my way back to my work area. Every time I picked up a piece of equipment, I would pull something in my arms or shoulders. I eventually stopped working.

I was diagnosed with post-polio syndrome, fibromyalgia, osteoarthritis, sleep apnea, high blood pressure, high cholesterol, degenerative disc, scoliosis in my neck and lumbar area and nerve damage in my left arm and leg. I have severe pain in my "good leg" and carpal tunnel in both hands. I've had several surgeries, a broken ankle and a bout with viral meningitis that kept me in the hospital for a week. I was released back to work and was so weak that I had to lean on my work bench to stand and do my job.

There have been many unfortunate events in my life; be it family-oriented or circumstance. Though I may never have answers to many of my questions, I still feel blessed to be alive. I have a caring wife, but she can't understand all that I feel physically or mentally. And I don't expect her to. Sometimes I feel alone and I suppose that is why I'm writing of my experiences. I read the newsletters to gain information about my problems and it helps to hear of other's experiences.

My biggest problem now is the weakness. It's a bad feeling when you don't have the energy to shave your face. I take rest breaks, but I have to try to help my wife since she is carrying the financial load. It's a delicate act to balance.

***Editor's note:** Roger Reed sent me his moving story in November. I hope my editing meets with his approval. Many PPSers have taken the time to "tell their story" in hopes that it will help others. I believe it is a cathartic process that does the "teller" as much good as the reader. Many thanks to you Roger.*

CTR