

and unfortunately I can't see him because he is not on my insurance plan. But despite the fact that not that many people know about PPS, it is real and many people who thought they had beaten the polio virus are now having to deal with health issues they never expected to, brought about because of the polio. It brings much frustration and uncertainty in its wake. This is my story about how post-polio syndrome has affected my life. I was born in August of 1953. I was a healthy baby and began the normal cycle of growing and developing. In fact, I would reach stages before the baby books said I should. I even started walking at seven months of age. Mother said I looked like a tiny porcelain doll toddling around. Then about the middle of 1954, I stopped walking; I cried constantly and wouldn't eat. I ran a high fever. Mother took me to the navy hospital where I was diagnosed with paralytic polio. With the proper treatment and physical therapy, I began walking again. The funny thing was that at therapy, they taught me how to fall, which was a good thing because I have done a lot of falling through the course of my life. Because of the training I received in therapy, most of the time I did not get hurt. In looking back, I was one of the luckier polio victims. My right leg was shorter than my left leg by one inch and weaker but I was able to walk again and it seemed like all was back to normal. In looking at pictures of me as a child, you could tell the right leg was shorter. I would stand on the right leg and throw the left one out or lay it on its side to even out my stance. I had drop foot real bad and still do. I began to run and jump, just like all the other children. Mom raised me to believe there wasn't anything I couldn't do. I developed a type A personality and the word can't was not in my vocabulary. Let me clarify that my run was more like a hop step, hop step, but hey, I had that down to a tee and got quite fast at it. I wasn't even aware of it until I saw myself on a home video my aunt had made of all of us cousins playing ball. It was a funny sight but I held my own. At about 10 years of age, the doctors recommended that I start wearing shoes with a lift on my right foot. I did and kept right on going, although the falls became frequent because of the weight of the shoe and with the drop foot, I was constantly stumbling over the toe of the shoe. Also at that time I had become the brunt of many children's jokes. It broke my confidence in many areas and made me very self-conscious, but there still wasn't anything I couldn't do. My mother said so and she was always right. I had always wanted to play the piano, but the idea of getting up in front of people scared me to death (I just knew they would be staring at my shoe with a lift) so mom got the beginner piano books and got me started. Mostly I would read the books and do what they said. Mom would come in from time to time to check on me. I spent a lot of time at the piano. Music became very important to me. Later in my teen years, my mother took me back to the doctors for a re-evaluation of my right side, the side most affected by polio. It was still one inch short and at 60% strength of the left side which was not as strong as it should be. They also told my mother that I might not be able to have children. That went in one ear and out the other of both my mother and me. I believe I lived in denial because my parents were in denial. I was so determined to succeed at anything I did, I became a top student with plans to go to college. I graduated in the top 10% of my high school class and graduated from college just short of graduating with honors. I received a bachelors in music. By now I was convinced that I could do anything I set my mind to. Now it was time to think about starting my career as well as marriage and a family. I met the most wonderful man and we married six months later. I

was determined to be the perfect wife and take care of everything as well as start my career. I told him that there might be a possibility that I might not be able to have children. The words came out of my mouth but the belief was not there; that type A personality again. It took a little while but two years later, I had a beautiful healthy baby girl. The delivery was long and painful but I did it. I told my husband I never wanted to do it again and at that time I didn't want to push my luck. Then I set out to be the perfect mom. I felt I was so good at this wife and mommy thing that several years later I told my husband I wanted to have another child. He was hesitant because of the difficulty in labor and delivery, but I convinced him I could do it. About a year later we had a beautiful healthy baby boy. There really wasn't anything I couldn't do. I was in the height of my life. I had the title of Super Mom a husband who loved me and two wonderful children that I did everything for. I climbed, ran, jumped, rolled in the floor with the children; everything just like a normal person. As my children grew, I took an active part in their school lives. I was an A number one volunteer. I liked being thought of as someone who could do anything. I had no idea what was going on inside my body. The nerve sprouts that were working the muscles were being overworked because of the damage that the polio virus had done. They would eventually begin to fail but I didn't know that. No one did. In the spring of 1988, I woke up one morning and my right leg was considerably weak. I had to drive with both feet over to my mother's house. I showed her that I couldn't lift my leg. Her response was just hmm. She didn't seem concerned, so why should I be. I didn't start getting concerned about it until I started to fall. Yes, I fell a lot as a child but this was different. I could be walking along and all of a sudden it was like my right leg was not even there. Yet, I didn't do anything about until one of the falls was in front of a mass of people. I was to sing a special song with an ensemble of people in church one Sunday morning. I made it up off the piano bench (yes, I was the pianist. I told you there wasn't anything I couldn't do if I set my mind to it, even play in front of people) and was headed up the steps to the stage area when step with the left, ok; step with the right, nope. Down I went in front of everyone. I almost knocked the preacher off of his feet. The men in the group had to help me to my feet and get me seated. Now I was supposed to sing in front of these very people I had taken a tumble in front of. Should I run? No, can't do that; I would probably fall again. I can't cry I have to sing. O.K., suck it up and stand up and do what you are supposed to. So I did. I stood up and sang my part, but there was no making eye contact with anyone. I was too embarrassed. After church I was inundated with people who were nosey or concerned, mostly concerned about the fall. I must admit, that was enough to scare me into doing something about it. I went to one doctor who sent me to another doctor. After a year of tests and constant doctors visits, I still was in the dark as to what had happened. I kept asking if this could have anything to do with the polio. He said no and told me it was just a virus that would eventually go away. Wasn't polio an attack of a virus? Well, the falls became less frequent and the strength came back a little, so here we go again. The cane I was using was put away. I'm a little weaker but hey, theres nothing I can't do and I set out to prove just that; at least to myself. A year later a worn out hip had to be replaced and that set me back a bit. This was the first time I heard about Post-Polio Syndrome-PPS. I began to research this new condition and did not find much about it at first. I read what I could find. Yes, all the symptoms seemed to

describe me but that was ok because I was still on my feet (although it took me a long recovery period of time to do so), taking care of my family, taking care of my house. Hey, this PPS isn't so bad. I'm still going full steam ahead. Denial is something I became a professional at. I read more and more articles about this PPS and yet it still didn't sink in. The articles said to pace yourself, so I did; four hours of work, ten minutes of rest. To say that the falls were less frequent is not to be taken as hardly every fell. Far from the truth, I still fell quite a lot. The thing is that they actually became rather funny. When I fell, I would do a mental check up to make sure nothing was damaged and then just laugh. The family got to where they would laugh too. When it came time for my son to attend college, we didn't have enough money to send him to the college of his choice. He had good scholarships but a private college is very expensive. OK, he wants to go to this college (I graduated from here and so did his sister), he was going to this college. I had enough confidence in myself that I took on a full time job to put my son through college. I believed I had the stamina to work full time, take care of the house, the yard, and continue to play the piano at church. I worked for the four years he was in school and it was so well worth it because he graduated with honors. Both of my children did. I knew that my strength was waning some but somehow I was still doing everything I wanted and needed to do. It just took longer and caused me some pain. I was still Super-Mom. About the time I quit work, everything started to spiral down. I had to have my left knee replaced. It too was worn out. I was determined to recover from this surgery as I had done before. Super-Mom would rise again. With a lot of work, tears, pain, and determination, I was back on my feet. But this time I wasn't as strong as I hoped to be. Now my back was causing me a great deal of pain and my right knee was also causing me pain. Back to the doctors I go. After a year and a half, my back is still causing me a great deal of pain and my right knee has completely failed me. I have to walk with a cane, even in the house just to keep from falling. Falls are more dangerous for me and don't carry the humor they once did. It's amazing what a few months can do to change things. Now I fear a fall and my family and I don't laugh anymore. A hard fall could hurt me in such a way that I would be off my feet permanently. If I sit for any length of time, I can hardly get up. I stay cold all the time now, even more so than before. My joints ache, I tire more easily than ever before, I can get choked on the least little thing, and I long for one night of uninterrupted sleep. I have pains that shoot up my legs that can bring me to tears. The doctors diagnosed it as poly-neuropathy. Somewhere along the course of time can't has slipped into my vocabulary. I try working on a project that takes physical exertion and I find I have to stop and rest frequently. The ratio is now ten minutes of work, thirty to forty minutes of rest; sometimes I have to lie down and take a nap to get rested. I've had to find alternative methods to do some of the cleaning. I can't get down in the floor and clean anymore; I have to use a mop. I can't climb and clean high places. I have to use a broom or mop to get to it or get one of my family members to do it. I've always taken care of everything. This is very frustrating. I look in the mirror and the person staring back at me is not the same person I used to see only a few years ago. Where did Super-Mom go? Now I see struggling mom. I can see Super-Mom trying to get out, but as time passes, she fades more and more. I have now had my right knee replaced and had to wear a leg brace on that leg during recovery just to keep it stable and keep it from buckling. I still have to use my cane to keep from

falling and I know that one day I might even have to use crutches or a wheelchair. At least I can still play the piano from a wheel chair. That is very important to me. In retrospect, I look back and realize that I was a lucky polio survivor. I had many years of a basically normal life. I raised two children. I was there for my family when I was needed. I was there for my friends when I was needed. Hey, I was Super-Mom. I don't look forward to possibly being wheel-chair ridden but as long as I feel like I can still be useful to those around me, it will be ok. Can't is not such a nasty word anymore. Asking for help is not a crime. Realizing that the body is failing doesn't mean that the mind is failing also. There are still things that can be accomplished from a sitting position and I am still a type A personality. Anything I attempt, I am determined to see it through to the finish, even if it takes me longer and maybe even have to ask for help. I am not bitter about this because no one knew that leading a normal life would put such a strain on the already weak parts; that they would reach a point where they would begin to fail. Because PPS is relatively new, the future is uncertain for us. The knowledge of it's affects on its victims is being gained on a day by day basis. I don't think anyone can say for certain what we can expect. I encourage my family and friends to read up on PPS so they can understand a little of what we are going through. Support groups are a wonderful resource to help PPS victims gain knowledge, support and understanding. One thing I know, no matter what the future holds for me, I will try to face it with optimism and with gratefulness for what I still have and not for what I have lost. As the song says, I will take it One Day at a Time. One of the biggest things that will help me face the future is the three Faith, Family and Friends.

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