For Beth and Bradley by Nancy Warren

This is to let Beth know how much I appreciate all the times she had to take care of me when I would have a reaction to my medicine with the MG. I know how much of a burden I put on her as a young child. This is also to let Bradley know what those 13 years were like for Beth and all of us.

It all started when Beth was 2 ½ months old. It was the early 1960's. I had fed her and was going through the kitchen to put her down for her nap. I started falling to my left. There was a wall there and I had to turn so I wouldn't hit her head on the wall. I was able to get her down for her nap and went through the kitchen into the dining room where the phone was. I called my mom. I had started a load of clothes in the basement; I had a wringer washer and was afraid I would ruin the clothes if they kept agitating. When I called Mom I could barely talk, it sounded like I was drunk, my voice slurred. I did get through to her that I was worried about the clothes and we decided she would stay on the phone while I tried to go down the stairs and stop the washer. It took about 15 minutes but I made it. I could barely stand and told Mom I was going to lie down. "The next thing I knew the landlady was standing over me trying to wake me up. It had been two hours and Mom had tried to call me and I didn't answer. She called the landlady and since I never locked my doors she was able to get in. Your dad was at work and I didn't know how to get in touch with him. Mom said she and my dad would be over as soon as he got home. Meanwhile your Dad, Johnny, came home to a screwed up wife and a cranky baby. I had a roast in the oven so he fixed himself something to eat, meat only, and got ready to go to his second job. He was working at the post office sorting mail at night. It was just a Christmas job but we needed the money since I hadn't worked for way over a year. Mom and Dad showed up and your Dad took off to work. Mom took care of Beth. She fixed me something to eat but I had trouble eating. I couldn't get the food on my plate onto my fork and then when I did I couldn't chew. It was very scary. My Dad's brother had died of lateral sclerosis, Lou Gehrig's disease, and Hodgkin's disease when I was 18. All the symptoms I was showing were similar to his. ***That was the beginning.***

We had no idea what was going on. Mom and Dad moved us over to their house so Mom could take care of Beth and me. We had spent 5.5 months there when I was pregnant with Beth, only now Beth was a big responsibility for my poor mother. I had been going to an Osteopath for my back but he couldn't admit me to a hospital during the mid-1950's. We had to find a doctor who would take my case and put me in the hospital for a diagnosis. I don't remember the name of the doctor but I was admitted to old St. Vincent's on Fall Creek Parkway the day Beth had her 3 month picture taken.

I was put in a ward with 7 other women. It had originally been a sun porch so it only had one door and no restroom for the patients. The door was on the other side of the room from my bed. By the time I would walk the length of the room and passed the nurse's station, I would not be able to walk back to my bed. I had to pull the emergency cord every time. The nurse would get a wheelchair and take me back to my bed. It really got old after a while. I felt like I was going crazy. When I would try to read my eyes would bound around so much I just could not make any sense out of what I was reading. I had Johnny bring me the large Jumbo crossword puzzles. I thought if I could work them it meant I wasn't crazy. Logical thinking!

They ran all kinds of tests. Once when they had me outside the X-Ray room, I fell off the cart. They didn't have the sides up. The only person around was a janitor mopping. He helped get my back on the cart and no one knew until very much later that I had fallen. The way they found out was a nurse who I knew came up to visit and noticed I could barely move and wasn't eating my lunch. She asked why and I told her. I was paralyzed on my left side and couldn't move. She fed me and visited for a while and then left. In a very short time after, the head nurse appeared at my bedside wanting to know what had happened. I told her and believe me they kept a close watch on me after that.

One night when I couldn't sleep, and we didn't have call buttons to call for a nurse, I walked to the nurses' station to wait for a nurse. As I was standing there, nosy me was looking around. I saw a note with the letters MS in very bold letters on a pad of paper. I thought what poor person could that be and nosy me looked up to the name. It was me!! I was scared silly. In the 50's MS was a death sentence. I just had a new baby and I wanted to live!!! There wasn't anything I could do that late at night. I couldn't call Johnny because he was worried about his job, I couldn't call Mom because she would fall apart. My poor Dad was the only one left. There was no phone by the bed only a phone booth in the hall. I waited until he would be at work and called him. He gave me some very good advice. "Ask the doctor. It can't any worse than what you are thinking." I asked the doctor and he said yes that is one of the possibilities we are checking. They were going to do a spinal tap to see if that was the problem. It was called a gold test. All of their testing showed nothing. It wasn't MS, thank god.

After 2 weeks I was released with no diagnosis and all the symptoms still there. But still If I had rested for a length of time I could function, but after a short time I would be back to where I was before the rest. If you stop and think, just about everything in your body involves some kind of muscle, your breathing, your sight, your speech.

Not knowing what to do I went back to Dr. Allen, the Osteopath. He told me his wife and son had Myasthenia Gravis and he thought that that might be what I had. Willing to do anything I let him write a prescription for Mestinon. The idea was to try it, starting with a low dosage to see if it helped and then increasing it. At that time there was no way except trial and error to diagnose MG. After a short time my symptoms started to disappear and I had some strength and energy again. I stopped breaking dishes because I couldn't lift them high enough to clear the shelf they went on. I stopped ironing my hand because I couldn't get it out of the way fast enough. Those are only two of the things that I remember.

I was now able to take care of Beth and moved back home. Dr. Allen told me I had to get rid of my wringer washer; it took too much energy to use. So I went to Mom's to do my laundry, really she did it for me. The other thing he told me to do was to get a job. Hire someone to take care of my house, do the ironing and take care of Beth.

We decided we needed to move closer to my parents to have their help when I needed it. We bought a house and moved 3 blocks away from Mom and Dad.

Beth was a very good child. I always had my medicine sitting on the kitchen table. She never once tried to open the bottle. At one time I was taking 50 pills a day, just to survive. As Beth grew up she had the job of helping me with my medication. I never realized what a responsibility I put on her until she had a problem one day. I told Beth to get my medicine from the bathroom medicine cabinet. But they spilled into the sink. She came into the living room crying. I was able to tell her there were more over the stove so she got them and gave me my pill. Later she went to a neighbor, Sharon's house. She was crying and told Sharon that "I almost killed my Mommy." I still start to cry when I think of what I put her through. During the years many things would happen. So many little things exhausted me, washing my hair, putting my hands above my head.

Over the years I had many instances of weakness that caused me great distress. There was the time I was visiting family and went to rest while the others went outside. I tried to get up from the bed and fell to the floor – I laid there an hour because the others couldn't hear me calling. Another time we went to friends. I had overdone it and had to rest. Ed asked me to help his wife with the clean-up. I said I would need but needed to wait and he got mad that I didn't go to the kitchen right then. I always tried to hide my MG from friends and anyone outside of my immediate family. At work there were times when I shook up my colleagues because they didn't know what was happening. I was lucky my boss accepted my problem and kept me on.

I hope this explains some of why I am the way I am. This was very hard on all of us. My Mom and Beth especially had a great deal of responsibility taking care of me. It was no wonder that Beth eventually became a nurse.

When Bradley was born, I went into remission. I was told I would never be free of MG that it could come back with no warning. Today, I just rest if I get that extreme tiredness and that seems to take care of it. I hope it stays that way. I was lucky I had a mild version of it and for only 13 years. ***Although at times I didn't feel lucky, I was. I was lucky to have a responsible, caring daughter and a baby boy who helped me go into remission.***