

Donna Whittaker-- A Long Fulfilling Life



My MG journey started at age 10. Hot summer days, I lagged my mother walking to her vegetable garden. When school started, the principal encouraged my mother to take me to a doctor because I had changed so much over the summer. I was falling up steps at school. My smile was a snarl. My speech was soft. I couldn't enunciate m's.

The first doctor's visit my dad was upset because the doctor thought I was malnourished. As a farmer, he provided plenty of fresh food – milk, eggs, pork, beef, vegetables – and I ate well. That had been a morning visit.

The second visit was late afternoon after school. The doctor asked me to lie back on the exam table. My muscles let go.... I plopped. "Oh, my goodness girl, I didn't expect that." I was admitted to the hospital to test for a brain tumor. After a spinal tap and a trip to Chicago to consult experts, my St. Joseph, Missouri, pediatrician diagnosed myasthenia gravis and started prostigmin.

For that school year, I could barely do the two high steps onto the school bus. I took my prostigmin as prescribed. Using my Optican wristwatch, I quietly left the classroom to go to the water fountain to take my pill at the correct time.

My grandparents thought my parents should keep me home because as farmers they didn't value 'book learning' and I had a strange condition no one knew. My mother knew I loved school and sent me.

After a year of struggling with weak muscles, my pediatrician added a pink capsule to my medication regime. My droopy eyes improved, my sardonic smile disappeared, my enunciation improved, I bounced onto the school bus. By the following year the pediatrician began to slowly decrease my medications.

Three years after diagnosis I was in drug-free symptom-free remission. Remission lasted through high school, college, and two years of teaching middle schoolers.

Shortly after marriage in 1972, my world changed. Symptoms returned. My legs gave way, my eyes drooped, the sardonic smile returned, and I couldn't raise my arms to do my hair. My symptoms were worse on hot summer days. Spring and fall were better. I adapted to my limitations and trudged on. I went from doctor to doctor for four years trying to get re-diagnosed. The first doctor was the Kansas City myasthenia expert. He didn't think I had it as a child.

In college, I had one roommate who had heard of myasthenia gravis. Other than her, no one in our world had heard of myasthenia. My family and I were alone.

In 1978, I met a person who had myasthenia gravis. I was not alone. Through a myasthenia gravis clinic in Kansas City I met others who understood. At support group meetings, my family met other families who faced the challenges we had faced for over 20 years alone.

In the 1990's I became active in the myasthenia gravis internet community. Now I have friends who understand MG all over the world. My family's goal has been that through awareness no other family would have to face MG alone.

At age 70 I do well on four Mestinon, 60 mg, a day and continue working part-time teaching adult literacy. It's been a roller coaster ride with far more good years than bad years. I have a huge myasthenia gravis family I would not have had without this diagnosis.

My advice to others with MG is to get involved in learning as much as you can about MG, in meeting others in person and online, in continuing your personal education, in finding activities you can do and enjoy. If there are no myasthenia gravis groups in your area, join multi-disability groups, such as those available through independent living centers.

You can have a long fulfilling life with myasthenia gravis. By connecting with others, I now know that I am not the only one who has lived with MG for 60 years.

Donna