

June is Myasthenia Gravis (MG) Awareness Month, and I have MG!

My First Name is **CYNTHIA**, and I began my journey with Myasthenia Gravis (MG) in **1997**. The diagnosis was received in **6 MONTHS LATER (1997)**. I am a: **Myasthenic** / Caregiver (select one)

The MG symptoms that I/we have learned to live with include: (select all that apply)

- Shaky or Double Vision
- Weakness in my Shoulders and Arms
- Difficulty Chewing
- Difficulty Breathing
- Difficulty Swallowing
- Generally, I'm tired!
- My Voice can sound nasally
- Other(s): **Extreme leg weakness**

Treatments I/we have tried: (select all that apply)

- Thymectomy (1997)
- Immunosuppressant drugs (Brand or generic)
- Plasmapheresis (1st time in 2014)
- Cholinesterase inhibitor (Mestinon or Pyridostigmine)
- IVIG (As needed between 2006-2013)
- Other(s): _____
- Steroids

My MG story:

In 1997, I began experiencing extreme fatigue. I attributed my fatigue to the stress of working a full-time job and attending school part-time. I took energy boosters, vitamins, etc but my fatigue increased. I went to my general doctor who informed me that I was just experiencing stress and needed to manage my time better. Shortly after, I began having difficulty raising my arms to comb my hair and brush my teeth, chewing difficulty, and double vision.

One afternoon, I arrived home to my upstairs apartment. As I walked up the stairs I felt some weakness in my legs and immediately fell down. My neighbor came outside to help me into my apartment. I was bruised and in pain. I was taken to the doctor's office where I was given muscle relaxers to control the pain. The next morning, I was unable to move at all and my breathing was shallow. I was able to see and hear around me, but I could not move one muscle in my body. The muscle relaxers had an adverse effect on my body. I went back to my general doctor where I demanded to have test ran. I knew there was something much more than just stress and fatigue that was causing my issues. I was referred to a neurologist where over the next several months I had blood test, physical test, breathing test, x-rays and scans and then I was given a Tensilon test.

After receiving the results of the Tensilon test, I was told I had Myasthenia Gravis. My reaction: "Mya WHAT"? I had never heard of Myasthenia Gravis (MG) so I was terrified. I was also informed that I had an enlarged Thymus and needed to have it removed (Thymectomy). Major surgery?! Oh no, I don't think I can handle this MG or Thymectomy thing! Lord why me?!

Over the next 10 years I was able to remain stable with just medications and rest. A few years ago, I experienced my first MG crisis. I was unable to walk or use my legs at all. My lungs were weak and breathing was difficult. I was transported by ambulance to the hospital where I was given IVIG and steroids intravenously. During my 9 day hospital stay, I had to learn to walk again. My leg muscles were stationary and had to be "trained" to work properly. I proceeded to have IVIG every month to get that boost that I needed.

I took a long time, but I learned to listen to my body when it said "Cynthia, its time to rest. I'm getting weak". I made changes in how I managed my everyday normal activity so I wouldn't tire myself out. It was very difficult for someone who loves to travel, dance, be active, and enjoy exciting adventures.

Living with MG has been a challenge that I never knew I would have to accept. My Faith has kept me and my outstanding support system has been my saving grace. Every day is challenge, but with prayer and the will to fight, I make it thru. I fight MG because I have to. I WIN because God says so!