

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

My First Name is Rachel, and I began my journey with Myasthenia Gravis (MG) in 2008. The diagnosis was received in 2009. I am a: Myasthenic / Caregiver (select one)

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

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| <input checked="" type="checkbox"/> Shaky or Double Vision | <input checked="" type="checkbox"/> Weakness in my Shoulders and Arms |
| <input checked="" type="checkbox"/> Difficulty Chewing | <input checked="" type="checkbox"/> Difficulty Breathing |
| <input checked="" type="checkbox"/> Difficulty Swallowing | <input checked="" type="checkbox"/> Generally, I'm tired! |
| <input checked="" type="checkbox"/> My Voice can sound nasally | <input type="checkbox"/> Other(s): _____ |

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

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|--|---|
| <input type="checkbox"/> Thymectomy | <input checked="" type="checkbox"/> Immunosuppressant drugs (Brand or generic) |
| <input checked="" type="checkbox"/> Plasmapheresis | <input checked="" type="checkbox"/> Cholinesterase inhibitor (Mestinon or Pyridostigmine) |
| <input checked="" type="checkbox"/> IVIG | <input checked="" type="checkbox"/> Other(s): <u>Rituxan (brand)</u> |
| <input checked="" type="checkbox"/> Steroids | |

My MG story:

I moved to Texas early 2008. Maybe it was the stress of a new city, new job, new life, that triggered my MG. Who knows? In November of 2008, I experienced my first notable symptom, when one morning, after brushing my teeth, I was unable to spit my toothpaste out. My tongue had stopped working.

After scraping the toothpaste off my tongue and rinsing my mouth with water, the day carried on. By the end of the same day, my voice altered to something new. It began to sound as if I had a retainer in my mouth. My thought was that I had slept wrong and pinched a nerve.

Over the next weeks, my vision doubled and my strength weakened. After seeing a general doctor, a chiropractor, and a neurologist, we began by ruling things out. My first neuro was great to work with us on this. We began by testing/scanning for strokes, Bell's Palsy, Multiple Sclerosis, Fibromyalgia, Myasthenia, cancers, and ALS. We (my boyfriend then/husband now) traveled from Austin, TX, to Houston and to Dallas, and met with four various neurologists.

I was poked with needles, shocked, tried different medications, IVIG, and so on, but nothing worked. My symptoms became worse. Chewing food was difficult. Choking became part of having a meal. I had double vision for weeks at a time. My voice was gone, or I sounded severely impaired. Breathing became a chore and the Texas summer heat caught me off guard. Because I couldn't eat or drink without problems, my weight dropped quickly. It really became tiresome hearing the very nice people who simply didn't know what to say, actually say they 'wish they could lose weight like that'. No. No you don't. My mind and body were tired. So I slept a lot.

It didn't take long and I was admitted to the hospital due to a number of crisis. The only thing we hadn't tried was plasmapheresis. Thank God for the brilliant minds who created this treatment, as plasmapheresis became my lifeline. For three (3) years, my primary treatment was plasmapheresis. During this time, we tried many immunosuppressant drugs, but none would work well enough to wean me from the centrifuge machine. My body required my blood be cleaned every other day or no less than twice a week. Due to infections, over the 3-year period, I had 5 different permacath units installed in my chest, was admitted to the hospital 3 times, and became a HUGE fan of many nurses, technicians, and doctors. Several even came to our wedding!

Thanks to prayer warriors, an amazing support system, and doctors who were willing to collaborate, I like to say that WE ARE IN MEDICAL REMISSION, and have been since December 2011. We were able to experiment with a drug/infusion therapy called Rituxan (brand), and it has been my treatment plan for 2.5 years now.