



Rachel Higgins, *“When we find a cure, we’ll dance!”*

Hey, I’m Rachel. I live in Austin, TX and my symptoms began in late 2008. One morning I woke up and was unable to spit my toothpaste out. By the end of the day, my speech was nasal. Over the coming months, my vision doubled, my neck muscles quit supporting my noggin, and eventually I couldn’t chew and swallow food. Like many MG families, my husband Lee and I went through the barrage of tests and saw many doctors. “We think you have Myasthenia.” “We think you have Multiple Sclerosis.” “This could be Bells Palsy.” “We don’t believe you had a stroke.” “We need to rule out ALS.” “You don’t have ALS, but you DO have Maysthenia, only a rare variety.”

What? How do you pronounce My-uhh-sten-knee-uhhh? What the heck is it? How did I catch this? What did I do? How do we cure this? Why didn’t we catch this sooner? Could I have prevented this?

Then the reality: Your body is fighting itself. You can manage MG, but right now, there is no cure. You did not catch MG, and didn’t really do anything to cause MG. You must learn to live with Myasthenia Gravis.

After trying many immunosuppressant drugs, steroids, IVIG therapy, and plasmapheresis, it turned out my variety of MG (MuSK+) was going to best respond to plasmapheresis. My poor body needed to have the blood plasma cleaned very regularly, so a permacath was installed in my chest wall. I lovingly called it my ‘tentacles.’ Over the next 3-year period, we would do plasmapheresis every 3-4 days or every other day, depending on symptoms. We would also experience 5 catheter installations, a nasal feeding tube install (ouch!!!), learn to battle pulmonary embolism, sepsis blood infection, iron deficiency, dramatic blood pressure swings, and the medical bills.

What do you do? You pace yourself. You surround yourself with those who know MG and those who can support your ‘new normal’. You find the right medical professionals for YOUR journey. You connect with a support group, and learn from others. Most important, you learn to share your story. Your journey is your journey, and not without purpose. Your experience is special, and it has been/will be difficult, but you are strong! You will be helping others along the way. You will share what you’ve learned. You will open the eyes of many by sharing your story and spreading awareness. Through awareness, we raise funds. Through funds, we support research and families. Through research, we find a cure. When we find a cure, we’ll dance! Until that day arrives, we support each other, we share awareness; we fight. Why? Because We Are MG!

Rachel