

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

My First Name is Jackie, and I began my journey with Myasthenia Gravis (MG) in March, 2013. The diagnosis was received in March, 2013. I am a: Myasthenic / Caregiver (select one)

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

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

<input type="checkbox"/> Thymectomy <input type="checkbox"/> Plasmapheresis - will begin July 2014 <input checked="" type="checkbox"/> IVIG <input checked="" type="checkbox"/> Steroids	<input checked="" type="checkbox"/> Immunosuppressant drugs (Brand or generic) <input checked="" type="checkbox"/> Cholinesterase inhibitor (Mestinon or Pyridostigmine) <input type="checkbox"/> Other(s): _____
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My MG story:

I've got what???????

Myasthenia Gravis, I could not pronounce this autoimmune disorder let alone spell it. Now it comes naturally, but it wasn't until March of 2013 on my way home from an afternoon wedding when I was driving on the 610 loop and all of a sudden I was experiencing double vision. What's going on I thought? By myself in my vehicle I wanted to pull over but could not see well enough to even do the smallest task. Did someone put something in my drink? I knew I only had a couple glasses of wine but all sorts of things were flying through my head yet I continued driving cautiously until I arrived home safely. Upon my return, I went to bed and rested for several hours hoping and praying that when I woke the double vision would vanish. But, it didn't. That Sunday I contacted my Internist who promptly had me see a Neurologist. Monday, the Dr. performed tests, scheduled blood work and was diagnosed with MG. My Internist also had me see an Ocular Neurologist who confirmed the diagnosis. However; she requested I see a Dr. in the medical center who specializes in MG. She thought my symptoms were more than MG related. I had experienced double vision, fatigue, trouble breathing and swallowing, and the smallest task would exert all my energy. I was also experiencing numbness from my waist down and throughout my arms and hands. After seeing this specialist and having extensive testing performed she confirmed my MG diagnosis but also added that I had Peripheral Neuropathy. This refers to the condition that results when nerves that carry messages to the brain and spinal cord from the rest of the body are damaged or diseased. This only occurs with me while

I'm lying down and/or sitting or standing for periods of time. During these times I experience numbness. The summer of 2013 was the worst in fact the first year was difficult since I have been so active all my life. Suddenly, I was sleeping several hours during the day, my "to do" list dwindled down to 1 or 2 tasks and even that was an accomplishment. I was placed on medical leave for 5 months from work then returned in Sept. excited to get back to my regular routine. I learned to be cautious. My body couldn't handle the stress of some of my job requirements. It was nerve reckoning. Looking at me you could not tell anything was wrong, and that was difficult for me as well as others. I felt everyone thought I could and should do what I used to do but that was not the case. As the TX summer arrives, I begin to see my symptoms return even with my current medications. My Neurologist is working with me to begin Plasmapheresis treatments beginning next month. My suggestion is to get a great Dr., be your own advocate, treat yourself with care and don't be so hard on yourself, there's always tomorrow. These are my lessons learned thus far as I go through this chapter in my life. If you would like to reach out to me, feel free to contact me at jaclyn1225@gmail.com.



Houston...we have MG!