

It all began in September ...

Good Morning, my name is Amanda Jones. I live in Rhode Island, born & raised. I am 35 years young. I have been happily married almost 17 wonderful years to my amazingly supportive Husband and Best Friend Jon and I'm also a Super mom to our incredibly talented and loving Son Ethan. My passion is photography. I love animals, art, food, adventure, and to travel but what I love most is to spend time with my closest family and friends.

There's one other thing I must mention. I have Myasthenia Gravis, a very rare Neuromuscular Autoimmune Disease. I am Musk Positive known as the rarer form of MG.

I didn't always have Myasthenia Gravis although my family and I are certain it was hanging around quite a few years prior to my diagnosis in 2012. It explained the chronic fatigue I had suffered during those years. The full-blown symptoms of the Myasthenia Gravis reared their ugly heads in 2011. It all began in September of that year. I began having difficulties with swallowing. In fact one afternoon my Son and I had gone to a coffee shop where I ordered an iced coffee and my Son a creamy smoothie. It was a warm Summer's day and his smoothie looked quite refreshing so I asked for a sip right there at the counter. Not only could I not suck on the straw strong enough to get anything to come up through the straw but I began drooling. Of course my Son only 10 years young at the time said "Ewwww Mom" rightfully so but the woman behind the counter looked at me a bit grossed out, again rightfully so, it was pretty gross. Thankfully my Son & I have a great sense of humor so we joked about it and laughed it off and that was that. Didn't think twice about it.

Slowly these odd occurrences began to happen more frequently. Water started shooting out through my nose whenever I'd drink anything, sometimes even food. I started to notice I was the last to finish a meal and I could chow down like the fellas. My meal portions began to shrink in size although my appetite had been the same and I began losing weight. This of course was overlooked because I could've afforded to lose a few pounds at the time. It wasn't until friends and family began voicing how very thin I was getting that I began to wonder. So I made an appointment with my Primary Care Physician and had a check-up along with some routine bloodwork. I was as healthy as a horse! This of course was great news and so we figured it was just my 30 Something year young body going through some normal aging changes.

I began to no longer sound like me. My voice changed and at times my words couldn't be understood. One evening my family and I went through a drive thru to order some dinner. When I was placing our order we all heard that the sound of my voice resembled the muffled intercom. We all laughed hysterically but later reality kicked in. My husband and I said something is very wrong here, this is not normal. I was tired all of the time. Not the typical at the end of a long day kind of tired but more like I had run a marathon sort of tired and it was only 9 am and I had only gotten the dishes done. Eventually getting off of the couch became difficult. My facial features also began to change. My eyes were droopy and my smile was missing. Despite what was happening, I had my life to live and a happy one at that. Every day was a struggle just to do even the simplest of tasks. Soon it became even difficult to breath. I felt like I was fading away. I HAD to do something.

I then made another appointment with my Primary Care Physician who agreed something was definitely not right. He suspected GERD or Acid Reflux and recommended I try antacids and gave me a script. After a month of taking it with no improvement and symptoms getting progressively worse he ordered

swallowing testing which came back normal of course. My physician suspected MG when he punched in the symptoms but didn't want to jump the gun just yet. At this time he referred me to an Ear, Nose, and Throat doctor who after examination said this was a Neurological issue and referred me to a Neurologist. We were now in November of 2011. Whatever was happening to me was happening quickly. I visited the Neurologist who ran physical exams, CT Scans, MRI's, Bloodwork, you name it. When everything came back normal he ruled my symptoms as being that of Anxiety and sent me on my merry way. As you can imagine it was at this point where my family and I not only felt confused but scared for my well-being. We clearly knew this wasn't anxiety but felt what more could we do. So life carried on.

In December of 2011 a month after my symptoms were ruled as anxiety I went to my Nephew's basketball game at the High School. About 20 minutes into the game the two teams playing on the court suddenly turned into four. Now I was feeling some real anxiety! I was seeing double and it wasn't going away. I somehow managed to drive myself home. After I calmed myself down I gave myself a pep talk and thought perhaps I had overworked my eyes with all of the editing I had been doing on the computer for some recent photo sessions I had done. I called a local photographer and asked if she had experienced any double vision from long hours editing and she said "Never" and showed concern. Later that evening my Husband, Son, and I looked up into the December night sky to watch a meteor shower that was expected to arrive when one star turned into two. The double vision never subsided from that night on.

That morning I called my Ophthalmologist. When she heard what I was experiencing she asked that I come in to see her immediately. In fact she said "Right now if you can". She spent 2 hours examining me that morning while asking what had been going on with me leading up to that point. The entire time she had a concerned look on her face. She referred me to another local Neurologist who after sitting with me for only 20 minutes clinically diagnosed me with Myasthenia Gravis and prescribed Mestinon but also referred me to a Neuromuscular Specialist because Myasthenia Gravis was so rare he felt more comfortable it be handled by a specialist.

I got in to see the specialist relatively quickly. At this point we were in a new year. February 2012. The specialist suspected Myasthenia Gravis and did a blood test. Two weeks later I got the phone call that would change my life forever. He said "Your test came up positive for Musk, you have Myasthenia Gravis"....Both my husband and I knew by this point what these results meant because we had spent most of our days and nights researching and studying Myasthenia Gravis....Now what?

I admit I was reluctant on starting treatment. I was a health nut and only wanted to put healthy things in my body so having to take these medications went against everything I stood for. After a few months of being hesitant and my symptoms getting progressively worse to the point where my doctors began to become fearful, I knew it was time that I start treatment. Being Musk Myasthenia Gravis we learned that unfortunately the commonly used treatment Mestinon wasn't going to be beneficial. I started IVIG therapy. The first couple of rounds gave me a glimpse of what it felt like to feel normal again. I hadn't realized how bad I really was until I had gotten the IVIG. I had been suffering with 24-7 double vision for 18 straight months by this time. It's crazy how one can get used to feeling sick all of the time. Unfortunately the IVIG treatment didn't help for very long and before I knew it was right back to where I started. I was in and out of ICU but thankfully never ended up on a ventilator.

In February of 2014 I started an Immunosuppressant called Cellcept and just 12 weeks later the 24-7 Double Vision went away and never came back! I have been on Cellcept only since then. It is now

December of 2015. In March of 2016 it'll be 4 years since I've been officially diagnosed with Myasthenia Gravis. I'm a lot better now than where I was then. My MG does continue to fluctuate. I'll have a few months where I'm feeling pretty great with weeks in between where I'm reminded that MG is still very much a part of my life. I am learning how to live with the Myasthenia Gravis which isn't exactly an easy thing to do when it likes to play peek-a-boo. Scheduling things has proven to be the most challenging because you just never know how you're going to feel but I schedule anyway and hope for the best. My breathing is really the only symptom that hangs around daily. I can't remember the last time I went a day without being out of breath. Currently we are looking into Rituxan with a specialist at Yale University as it is looking to be promising for those of us with Musk MG. My Team of Doctors, my Family, and I are all aiming for the same goal and that is getting me into a full remission! We are hopeful that is possible!

Despite living with Myasthenia Gravis and the daily obstacles that come along with it, I live my life to the fullest. I stay positive and focus on the things that I can do and not so much on the things that I can't. I set goals and work towards them to the best of my ability. I've got an amazing support system which consists of my Husband and Son, my closest family members and friends, my doctors, as well as a positive support group online filled with other MGers like myself who are focusing on the bright side of living with Myasthenia Gravis. I truly believe that a part of getting better is adopting a positive attitude. MG is the worst thing and the best thing that has ever happened to me. It's taken a lot from me physically but I've gained so much more back mentally. I appreciate life and all that's in it in a way I hadn't prior to getting sick. I feel more alive now than I ever have.

Thank you for letting me share my story.