

## Living with **Myasthenia Gravis** and Graves Disease

This story is about Graves Disease (thyroid)) and **Myasthenia Gravis (MG means grave muscle)**. Both are very difficult to live with.

My life changed approximately 2004 with the diagnosis of Graves Disease. I knew nothing about the thyroid nor did I know what it actually does. I was losing weight, very jittery, anxious, fast heart rate, foggy brain and unable to sleep. I went to my primary doctor who happened to be an Endocrinologist (didn't know what that was) who recognized the symptoms. She did a thorough exam and I had labs drawn. The next day I was called to come to her office. She explained to me that I have Graves Disease. I started the anti-thyroid medication but was allergic to it. She thought it would be better to have the RAI instead of the surgery as I just had surgery for the removal of my gallbladder and appendix. What a journey that was and still is. Many times my thyroid hormone levels fluctuate between hypothyroid and hyperthyroid so an adjustment is made with the medication. I currently get my thyroid hormone levels checked approximately every 3 to 4 months.

Soon after learning how to live with Graves Disease I started having muscle problems. I kind of ignored them as I thought it was related to Graves. The symptoms were a very droopy left eye, extreme fatigue in the thighs and upper arms and my jaw would fatigue while chewing. I would have to rest my jaw with food in my mouth before I could continue to chew. The fatigue in the arms were so bad that lifting laundry from the washer to the dryer was difficult. If I walked any great length my muscles in the legs would fatigue and sometimes I would trip and fall. My neck muscles were and still are the worse. I was and still do look for a place to sit to rest my head to lean back onto a chair. Sometimes the muscles spasm trying to hold my head up and it becomes very painful. Tired necks cause immense and intense pain. I went back to my primary doctor and she once again did a complete assessment of my physical condition. After spending quite some time with me she blurted out it might be Myasthenia Gravis. That sounded so foreign to me. She said I would need to see a neurologist and a neuro ophthalmologist for further testing. With all this taking weeks to months I was getting worse. During this extremely difficult time I always leaned on my primary care doctor. She was always available to answer questions and hear my frustrations with both the disease and navigating the issues I had with neurologists and insurance for authorizations for procedures. Finally the diagnosis of MG came and the list of medications came along with it. I was put on Prednisone which has many serious side effects, but also is a wonder drug and helps MG. I was also put on Mestinon which has gastro side effects. I was and still am seeing a nutritionist. She has guided me through the journey of keeping the weight off that comes along with continued Prednisone use. It's truly amazing the right foods to eat that will help keep the dreaded pounds off. Yes I did get the "moon" face from the Prednisone, but with continuous monitoring and following directions the weight has been under control. It's a constant battle as Prednisone makes me hungry all the time. If not for her knowledge and me following it, I can't imagine where I would be today. The Prednisone causes one to be very hyper, unable to sleep, osteoporosis, weight gain and constant hunger. With lack of sleep comes fatigue and weakness. I fractured both feet a few times due to the Prednisone. Unfortunately these two medications did not do put the MG into remission. I then

started **IVIG** for a few years as outpatient. A few times I would get severe side effects and a few occasions I had Aseptic Meningitis. **IVIG** is a wonder drug, but for me it has to be done at an extremely slow drip and lots of pre medications. Being outpatient it's impossible to slow the drip down enough as the clinics have limited hours. My current neurologist did some research on Rituximab and thought I should try that. Unfortunately I had an extremely dangerous side effect of Serum Sickness. I woke up one day (approx. 10 days after the Rituximab treatment) with excruciating bone pain in the hips, elbows and then the jaw. For the most part I was unable to move or open my jaw. My blood pressure was low, I passed out. I was hospitalized for a few days until my Primary Doctor told me what I had. I was treated with steroids for several days. I then tried Cellcept for a few months. Cellcept lowers the immune system even further than Prednisone so I became susceptible to all kinds of infections. Within a few months I had Bacteremia/Ecoli/extended spectrum beta lactamase, Cryptosporidium, and C-Diff. These three infections came within a few months of each other. I was extremely ill with each of these infections. My primary doctor saved my life. Due to her quick action and care I am very fortunate to be alive after these infections. Many times she will see me without a scheduled appointment and then follow up the next few days to assure I was feeling better. Because I can no longer take Cellcept I am back to **IVIG**. For several months I was doing the **IVIG** inpatient at a hospital. The **IVIG** drip was extremely slow for 5 days, 24/7. My primary doctor did the admission and monitored me daily. It is very difficult being in a hospital due to the medications I take. Some of the medications must be taken before I can eat because it allows me to chew and swallow without choking. In the hospital they administer medications at certain times so my primary doctor made sure that I received my medication at the time I needed it. And even with her notes, I still had to remind the medical staff that I need my medication. I realize they have many patients, however I must advocate for myself. I am also still on Prednisone and Mestinon along with a list of other medications due to the side effect of both of these medications. I did the inpatient for several months.

My Neurologist and Primary Care doctor worked closely together and came up with a plan for me to try **IVIG** as outpatient with lowering the dosage and a very slow drip at an oncology center. I am doing that now and we are closely monitoring the side effects. It's all about keeping me out of the hospital, getting the benefits of the **IVIG** and attempting to have somewhat of a quality of life and not suffering the severity of the side effects. There are a few different brands of **IVIG** and one of them I appear to have a reaction to. Unfortunately that is the brand most places have. My neurologist and primary doctor have to advocate for me to get another brand of **IVIG**. The **IVIG** does help along with my other medications. Usually after an **IVIG** treatment I have relief of some of the symptoms of MG for a few weeks.

With MG it's difficult for the patient to understand let alone family and friends. Because one can look "healthy" on the outside people take for granted that everything is fine. Due to the many medications I am on, I am constantly watching my diet under the guidance of my nutritionist. I follow her directions very closely as I don't want other illnesses (diabetes, high glucose, over weight) that can come from taking Prednisone. Because I look healthy people think I can eat whatever I want, but they don't understand that if I did my medical problems would be worse than they are today. On many occasions I am home I am on the couch or recliner resting my muscles as they are just fatigued and worn out. There

are times when swallowing can be difficult, or my neck muscles are unable to support my head. The pain I get from the neck muscles trying to hold my head up is severe.

I am very fortunate that I have three medical professionals, a primary doctor, nutritionist and neurologist who all allow me to contact them after hours, weekends, and holidays if I have any medical crisis. All three doctors are the most important people I can have in my life while living with this disease.

It has taken a lot of education and preaching the same thing over for some people to understand the seriousness of this disease. Others have picked up on it and have a better understanding. My family and friends have learned a lot and for the most part have come a long way about learning of this awful disease. I try not to let Myasthenia Gravis define who I am. I know I am not the same person I used to be, nor do I take for granted the things I used to. Every day is a new day and I always hope for a good one. Sometimes it's difficult and other times I am able to enjoy my day.

The most important part of my journey through Graves' disease and Myasthenia Gravis is my relationship with my three doctors (primary, nutritionist and neurologist). I must be able to communicate with them. My team I now have allows me to do that. I always keep my primary doctor informed of what is happening if another doctor has changed anything. My primary doctor has seen me through the roughest of times and knows me the best. With the communication she has with the neurologist I feel more at ease than I would if they worked independent of each other. I do not have an advocate, so I must do it myself that is why I place my team of doctors at a high priority. As important as my doctors are so are the staff that work for them. I have left a neurologist due to the staff that worked for her as it was impossible to get an appointment or a return phone call within a reasonable amount of time. For me to have somewhat of a quality of life all this must come together. I don't know why I have this disease and I never will. I must not question that, as it won't bring me to a better place.