

Rituximab and MuSK MG
A Personal Narrative
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Before Rituximab Treatment



After Rituximab Treatment

My daughter got married in October last year, and I could see, smile, walk her down the aisle with my husband, dance the hora, enjoy the good food, smile and laugh with our family and friends...I felt absolutely fantastic! Anti-MuSK Myasthenia Gravis (MuSK MG) was a distant memory that day and it has become a distant memory since my last rituximab treatment. Rituximab infusions have given back my health/life!

It is however a treatment my insurance company has refused to endorse and pay. We fought long and hard, along with my neurologists who sent in appeals accompanied by clinical trial reports but to no avail.

I experienced my first symptoms of MG in late 2010, and was properly diagnosed in April 2011 with MuSK MG. From the start, my kind and brilliant neurologist, Dr. Jeffrey Allen at Northwestern Memorial, knew that the protocol treatment like aziathioprine or cellcept with corticosteroids would not be effective in managing MuSK MG. He appealed relentlessly for the rituximab treatment. But the appeals fell on deaf ears and hard hearts. When Dr. Allen moved to take up another position out of state, I looked for another neurologist closer to my permanent home in Dallas. I was fortunate to find an equally caring and brilliant doctor, Dr. Sharon Nations at UT Southwestern. She, like Dr. Allen, knew that rituximab was my best treatment option. She too appealed to the insurance company on my behalf, but was similarly turned down. That was especially disheartening, considering Dr. Nations's history of successes in using rituximab to treat MG. To help me function, I was put on prednisone and azathioprine, the dosage going up and down depending on the severity of my symptoms, but they were never effective in eradicating the symptoms. In the interim, I sadly suffered the many ugly side effects of taking prednisone, developing severe osteoporosis, cataracts, glaucoma, a swollen moon face, and becoming pre-diabetic.

Things came to a head in the summer of 2015 when my liver showed stress from prolonged use of azathioprine, and despite the substantial increase of prednisone, my symptoms were still not being managed. I was desperate--with the high dosage, I still couldn't

hold my head up, bend, go up the stairs, experienced double vision, droopy eyelids, slurred speech, difficulty in swallowing and breathing. We appealed once again to the insurance company with medical studies from my neurologist, and supporting letters this time from my endocrinologist, ophthalmologist, primary care physician testifying to the damage that prednisone had done to my body. We were confronted with rejections all over again from the insurance company.

Because my husband's company at that time was privately insured, we appealed to the company to make an exception for the treatment. They agreed and I had my first round of rituximab in September of 2015. After two weeks, I was already experiencing remarkable improvements. By my second infusion, I was symptom free.

Rituximab is resoundingly effective in battling MuSK MG, not just for me but for many (evidenced from the many studies). I am happily in remission, taking absolutely no medication for MG. I urge the insurance companies to finally recognize the value of it, not only for the good of MG sufferers, but also for themselves, considering their cost savings if they did not have to pay for treatments of illnesses that inevitably follow chronic use of steroids.

MG is a debilitating condition and the suffering it produces could be easily curtailed if rituximab treatment were made readily available at no overall additional cost to the insurers in the long run.