

## Amanda & Jessica & the MG War



My name is Jessica. I have a 19 year old daughter who was diagnosed with Myasthenia Gravis in December of 2013. Her name is Amanda. She has one of the most aggressive forms of MG.

Amanda used to be a very active teenager. She was involved in almost every physical activity or sport her high school offered. She was agile and full of both life and energy. The year prior to diagnosis we had a car accident and since the trauma she began developing the MG symptoms. Unfortunately all of them at

different times, each month a new symptom and another trip to the Emergency Room Plus numerous doctor and specialist visits with irrelevant dead end answers.

Amanda's first major crisis was December 23rd, 2013 two days before Christmas. Her left lung collapsed and she was admitted to the Pediatric ICU for several weeks. Needless to say we brought in the New Year there too. Since then she has been hospitalized 54 times; had numerous surgeries including placements of catheters, removal of such, port placements and the thymectomy. She has unfortunately been intubated 13 times, having had 10 intubations alone within the last 10 months; without counting re-intubation.

I am writing currently from her room bedside in the adult Medical ICU 6/17/17 in N.Y., where we have already spent 3 days. I never leave her side. This is my battle as well. We were drafted against our will, but are fighting nevertheless until we end this war. I have lost everything to this disease BUT I WILL NOT LOOSE HER! I will continue to fight and research and stay by her side until we beat this or it beats me. As God is my witness she will get her life back! Thank you for taking the time to read our story.

*Jessica*