

Romy's Story

Misdiagnosed

In 2000, a year after surgery for a herniated disc, I went back to my neurosurgeon to ask if he could have done something wrong. I read him my list of symptoms from a “sticky note”— chronic fatigue, muscle weakness, dropped face, slurred speech, unsteady on my feet, falling often, problems with stair climbing. He said “no” and referred me to another neurologist who saw me right away. The neurologist looked at my sticky note and said, “I’m pretty sure you have multiple sclerosis.” I walked out of his office crying and angry—and did not make a follow up appointment with him. I was pretty sure that some kind of test was required to confirm a serious diagnosis like MS.

I spent a year in shock. Then I was referred to a neurologist at the University of Pennsylvania. He did some basic strength tests and scheduled an EMG the same week. During my EMG, he gave me the diagnosis of Lambert-Eaton Myasthenia Syndrome (LEMS).

Misunderstood

Prior to diagnosis, my mom questioned me about being a drug addict because of my symptoms. My husband and girls, who are my biggest supporters, knew I was not on drugs, but they saw my struggle daily. Cops would see me staggering and ask me if I was okay, as if they thought I had been drinking.

Over the next 10 years I was put on multiple medications but none provided much improvement and eventually the effects wore off. After years of begging for an alternative treatment, the doctor wrote down the name of another medication on his prescription pad, circled it, and wished me luck finding it.

On a mission

I was on a mission. Searching the web, I was eventually able to find two clinical trials for the medication. I moved from Philly to Phoenix for three months, staying in a hotel to participate in a clinical trial. In January 2011, I started a trial with the medication. I’m hoping it receives FDA approval.

