

DMTs and Me



Severe fatigue, brain fog, unintended weight loss and vision loss were some of the symptoms that would ultimately lead to my diagnosis of relapsing remitting multiple sclerosis (RRMS).

In May 2010 at the age of 18, I was referred by a local neurologist to a specialist at UCSF Medical Center. From the day of my diagnosis, things quickly spiraled out of control. Even with baseline disease modifying therapies (DMTs), I went completely blind in my left eye, could hardly walk, experienced numbness and burning sensations, and was unable to complete a tandem walk (heel to toe) in the doctor's office.

After 9 long months of fighting through 6 different relapses, my specialist, my parents and I decided we wanted to try something aggressive; a DMT that would stop my MS from progressing. At the time, Tysabri was my best option even though I had been tested positive for the John Cunningham virus. Going into it, I knew I had a small chance of developing progressive multifocal leukoencephalopathy, a rare brain infection, but that was a risk that I was willing to take.

Tysabri was the first treatment that would officially put me into remission. From there, I switched to Gilenya, which kept my MS under control, but it left me with a few dangerous adverse side effects. Again, my specialist suggested I switch to another treatment to avoid those adverse side effects.

On January 20, 2017, I was in the middle of yet another very bad relapse. Again, my balance was awful, my vision was blurred and my headaches were outrageously painful. My speech

also started to slur and my most frustrating new symptom was foot drop. The swelling in my brain was so severe that it started to trigger grand mal seizures. This is when my specialist and I decided to make another medication switch. Copaxone to Rituxan it was.

After I was cleared to receive my new treatment, I had a second seizure about a week after my first loading dose of Rituxan. This one left me unconscious for about 18 hours. I was poisoning my own blood because I was unable to let go of every breath I took in. I can't imagine what I put my husband and family through with having to be intubated and admitted into the Cardio Vascular ICU for 4 days.

MS is not supposed to be fatal, but I was very near death on February 28 because of MS progression.

Within a week of being discharged, I was back on my feet seeing a physical therapist and learning how walk properly again. Without the help of Rituxan (my current DMT) I don't think I'd be walking again without my walker right now.

Although I have had my fair share of negative experiences and often felt as though things were being stripped away from me, I have also lived through numerous celebrations and positive moments in living with MS. Even though there have been times when I was unable to walk or see properly, I am still thankful for every single treatment I have tried.

Why am I thankful? Because the needles (Copaxone and Rebif) helped me realize I was much stronger than I thought I was. The aggressive treatments (Tysabri, Gilenya, and Rituxan) helped me live 5 years in remission when life seemed to be "back to normal" again. They have also kept me out of a wheelchair and played a role in helping me ditch my walker.

And finally, all of these DMTs have also allowed me to see numerous MRIs with no new brain lesions, no new MS activity, and even old brain lesions that had healed! Times like these where what I called a celebration, where I cried tears of joy and was thankful that I was still alive and able to live my best life. Without being treated with DMTs, I am not completely sure where I would be.

One thing I do know is that they saved my life.