The Rollercoaster of Trying New Meds for MS

by LIBBY SELINSKY

Trial and Error: Trying New Meds for MS

Today is the day I start Gilenya. I am sure all of you know how it feels — another day, another medication, that is what life with multiple sclerosis (MS) is like.

In 2008 I took part in the phase three clinical trial for Gilenya, which still went by the name fingolimod at that time. I only was in the trial for a couple of weeks because my liver reacted. To be fair, I had taken a lot of Tylenol the day before the blood test and I later found out I had been assigned the higher dose of the med during the trial.

Still, my doctors have been standoffish with placing me back onto this med since it hit the market. But recently, like many with MS, I have been funneled through a few other meds and was tired of their side effects, so I finally decided it was worth the risk.

Trial and Error

Shopping for the right med is one of those things I really never expected to do when I was diagnosed with this disease. I had always figured my doctors would have a set protocol of drugs and treatments, but MS has taught me that reality is a bit different than that.

The truth is that everyone is different. We all respond to the different medications in our own way. It isn’t as easy of a decision as only figuring out which medication has proven to be the most effective. We must also consider which has the most tolerable amount or types of side effects for our bodies.

The first medicine I tried was Rebif. It, for me, was fairly tolerable. I was able to take my medicine on time, every time, and I would take some ibuprofen and go to sleep early on the dosage evenings.

Five years passed and I became tired of sleeping through three evenings a week. I became tired of having the flu every Monday, Wednesday and Friday night. Mostly I became tired of being tired and began realizing most of the years of my son’s life were filled with this tired version of me.

Countless bedtime stories and goodnight kisses went missed. I was sad and it was time for a change.

Almost two years ago I began Tecfidera. Again, the drug did what it was supposed to do. I took my medication religiously and it rewarded me with preventing any new lesions to my brain and spine.

This medicine was different; I no longer had injections or the fatigue and flu three nights a week. In that way, Tecfidera felt like a cold glass of water.

On the other hand, there were the side effects. My experience with this med was severe stomach pains and turning red multiple times a day.

Dealing With Side Effects

I was told the side effects would lessen over time, but they didn’t. I was told eating proteins and fats when I took the pills would help, and it did.

The problem, for me, was that my life became a balancing act of eating the right foods in order to get past the side effects. Two years of my life yielded about 20 pounds of weight gain without a valid way to lose the pounds.

I became depressed and felt overrun and worn down. I needed to be free of these terrible side effects.

It is amazing what daily stomach aches and burning skin sensations can do to your mind after the days pile up.

Next page: more of Libby's experience with trying new meds.

Dealing With Side Effects

Eating past the meds was not working as well as it used to, so I began to feel a tunnel vision view of my life and happiness encroaching. For the first time in many years, I felt terrified.

My big decision to quit came about a month ago when I had been doing some shopping at the mall with my husband and son. I had done everything right; I had eaten a hearty breakfast that was low in carbs, but it was one of those days when eating right wasn’t enough.

My husband looked at me — I knew that look so well — and said, “Honey, we need to get you something to eat. You’re turning red.”

“Not again, not again,” I thought, but I knew it was true. The burning began to drip its way down my scalp and people had already begun to stare.

We rushed to the healthiest thing we could find and picked up some crêpes. I had accidentally chosen the wrong kind; I wanted a Caprese crêpe, but the one I actually chose was covered in canned mushrooms, which are the absolute worst.

In the meantime, I looked like an Oompa Loompa. I was so flushed I was almost purple. I was faced with continuing with this reaction or shoving more terrible food down my throat.

I sat at the table frozen, on the verge of tears. My husband was getting worried and tried to get me to talk. My head was reeling. I had told every doctor I had seen in the past two years about these side effects.

Oftentimes, I would turn red in their offices, right before their eyes. I had been searching for help and none of them seemed at all concerned. They had all fluffed it off like it was just a small tradeoff for not losing my ability to walk and see. How could I argue with their logic?

Still, here I was — empty and shredded yet again. I had no words left and my husband wanted so desperately for me to speak. My body was burning up. I was tired of eating all the time, which was often stuff like what was on the table in front of me.

For a second I even thought, “Maybe my body is not meant to live in this world. Maybe I am just not supposed to live.” That thought terrified me.

Getting out of the Dark

I have never wanted to give up. Something was awfully, terribly, horribly wrong. As I looked from one set of worried eyes to the other, I realized my husband and son were seeing it too.

The time had come and I finally said, “I need to quit Tecfidera.”

Now that I have dropped the Tecfidera, I can see how easy it was to step away and try something new. But when I was in the thick of it, that wasn’t how I felt at all. To me, I was running short on options. To me, the idea of trying Gilenya was, because of my clinical trial results, risky.

Honestly, it still might be. Looking at it now though, I realize things for me had gotten pretty dark. I am not a dark person by nature, so things had to have been really piling up for me to have been feeling as trapped as I had felt.

I am writing this today as a reminder to all of you and to myself to not allow things to get so dark before you turn around and start walking towards the light again. I pride myself in being a person that never gives up, a person that never quits.

Sometimes though, quitting one thing is the only way to continue another. In this case, the med I chose had come to run my life off the rails. My life is more important than that med. My life is worth the risk of trying something scary and new.