New Hope for MS Is on the Horizon

by LIBBY SELINSKY

Coming to Terms With the Real Probability of Never Experiencing Another MS Relapse

Not too long ago I wrote to you all about a clinical trial that I had been recruited to join. For those who are not in the know, I have spent the past four months participating in what had become a regular routine of medical tests and blood draws.

I was a regular at the neurologist's office, learning each employee's life story along the way. I confess, I am a talker and I love to learn everything that I can about each person that I meet.

I found myself in a rather strange position with this clinical trial. It is important to mention that I have always considered myself an unlucky person. I have had goodness and pure joy in my life, but the negative events have never been far behind.

Also, I just don't have the kind of experience in the world where life floats in wonderfully and hands me my needs. I usually have to use every ounce of grit that I have to attain goals in my sights.

The All-Encompassing Effect of MS

When multiple sclerosis (MS) rolled into my life, I thought, "Of course I have a chronic illness that will torture my every thought for the rest of my life. Of course it was me. My great-grandmother lived to be 105; no one in my family has any chronic illnesses. Of course I am the one."

Having this disease can make you very dark, if you let it. It hangs around, lurking in the shadows, whispering doubts and pain into your mind when you find a moment to be happy.

Frankly, I never believed the people who said they were relieved to finally have a diagnosis of MS — "At least now I know what it is!" they say.

I am sure there is a level at which relief hits, however; MS is not something that comes easily, to anyone.

Being diagnosed with MS means reevaluating everything you think you know about yourself. It is earth shattering.

Suddenly, all of your plans are upheaved and your identity is shaken to its core. There is nothing that MS does not touch.

It took years to find myself again after I was diagnosed. That confliction of my desires versus my realistic options was prevalent in every choice that I made as a woman, as a mother, as a wife.

Who was I to become? What was I to become? Am I a disabled person? Will I be? Where is my value? When will I sleep again?

Years of my life have been washed away to the doubt and fear of MS. The moments of worry have ticked away time in my life that could have been better spent.

The struggle becomes a salvage effort to shore up what is left and plan for a future that can shine through the loss. When we get to this point of acceptance, this mindset, is when we have finally healed as much as we can and we embrace this new version of ourselves that we have become.

I reached that acceptance a few years ago and my life has been better for it. I have been on a solid track of maintaining my body and ebbing the flow of MS and its aggressive pull on my body.

However, I have become accustomed to waking up five or six times a night. It is hard to believe it, but I have gone nearly 10 years without sleeping through the night.

I have been a happy person who is thriving, but I never healed enough to sleep — until a month ago.

The Return of Luck

Like I said, I never considered myself a lucky person. I need to amend that statement now. I am a lucky person, it is just that my luck comes in extremes, separated by extreme lengths of time.

The phase of clinical trial I was on was a “dosing trial.” This means that I was guaranteed to receive the drug and not a placebo.

I also benefitted from knowing the safety and efficacy of the drug before taking it.

This drug is very safe and I have felt no side effects at all. I take one pill every morning. Oh, and by the way, its efficacy is a 95 percent reduction in disease activity.

My last relapse, in May 2016, was the first one that I had had since September of 2008. I worked very hard to maintain my disease activity over the years and have been very fortunate to have kept my activity low.

Also, the timing of my most recent relapse was the key to where I am now. I walked into my neurologist’s office the morning after his clinic had been chosen to take part in this trial. There are only 24 people in the country who have the chance to participate — and I was patient #1.

Next page: Libby recounts her conversation with her doctor after the study.

New Hope

The past few months have been incredibly emotional; I think I have been kept so preoccupied with the whole process of everything that I really didn’t allow the questions to seep out until a month ago.

I was speaking with my neurologist on my final appointment for the study and the questions came out, one by one.

“My body is responding well to the medicine?”

“Yes.”

“I had only one relapse in eight years when I was on a medicine that reduced my disease activity by only 45 percent?”

“Yes.”

“This medicine reduces my disease activity by 95 percent?”

“Yes.”

“So if I did as well as I have with the medicine that only reduced my disease activity by 45 percent, then I have a good chance of never having another MS relapse again, as long as I am on this new medicine?”

“Yes.”

“Oh.”

That was all I could say — “Oh.”

What could I say? It was such a strange conversation. I cannot count the times I had imagined walking into the neurologist’s office and having him walk up and give me a shot in the arm and then tell me I was cured.

This is definitely not a cure, but it is a new world for me and it showed up in the most unexpected way, and at such an unexpected time. It almost seems too soon or too easy.

So Many Questions

I have been shy to talk about this. I am still trying to figure out what it all means.

Who am I now? Who will I be now? What will I be now? Is this really real?

I have been struggling to accept that this medicine will not make me sick. There are plenty of risks for sure, but so far I have been totally fine, which never happens with MS medication and me.

The last medicine I was on stripped away my immune system to nothing. I am terrified of feeling confident in this medicine, of dreaming of my life again, only to have my body react negatively and find myself back to where I was just a few months ago.

Can I be a person who walks confidently through life? Can I sleep through the night with the knowledge that I will not wake up paralyzed?

A few months ago, the rational part of me was expected to acknowledge I had a solid chance of waking up some morning at least partially paralyzed. That is to be expected when you have MS.

Now, I am finding the rational part of me is expected to revert back to a mindset that almost all of us are born into and carry about ourselves for our lifetimes. I am expected to believe that I will not wake up some morning to realize I have lost the ability to move, to see, to touch, to taste.

I am supposed to go to sleep every night and rest assured that I will feel the same when I wake up as I did when I rested my head on my pillow.

A New Reality

One month ago, I slept through the night for the first time in almost 10 years. I woke up rested. It turns out, for me, sleep is my first step towards accepting this new reality.

I believe it is going to take many years before I will be able to fully accept I’m in the clear. For now, I feel the wealth of luck I had doled out onto me.

Out of the 2.5 million people in the world with MS, I am one of the first handful to be told I have a solid chance to never have another relapse again. I am holding this blessing and loving every moment I can enjoy it, with the

hopes that those moments will keep stretching forward.

This drug is going through the FDA approval process as we speak. They are hoping to have it to market by the end of 2017.

Hang on, take good care of yourselves — hope is on its way. I love this medicine; it has treated me very well, and it has also ignited a competition with other MS drug manufacturers who are racing to get their comparable pills to the market.

A new world is on its way — be ready for it when it arrives.