

The

OPTICS

of **Multiple Sclerosis**

a real life view

By Rob Bloom

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CONTENTS

Introduction	i
Chapter 1: <i>The Diagnosis</i>	1
Chapter 2: <i>Shielding the Truth</i>	4
Chapter 3: <i>The Exacerbation</i>	6
Chapter 4: <i>Putting MS in the Wrong Bucket</i>	8
Conclusion	10

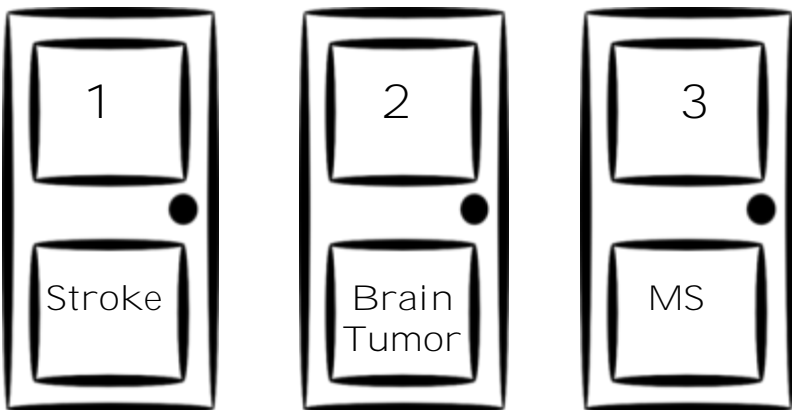
INTRODUCTION

This is a booklet, not a book. It has been written this way to provide a quick read that solely concentrates on the optics of multiple sclerosis to let people truly understand what MS patients are going through on a daily basis and how mystifying the disease seems to be to the majority of those that live outside the boundaries of MS.

When I first went public with my disease, I can't tell you how many people put it in the wrong bucket. They confused MS with Muscular Dystrophy, ALS, Guillain-Barre Syndrome, and a bunch of other auto-immune diseases. Some asked if I would be confined to a wheel chair for the rest of my life, who would help raise my young children, and others simply thought that I was going to die soon. I have even been mistaken for a diabetic when a TSA officer at the airport pulled me aside for having a syringe of Copaxone® in my sports coat. I wanted to be angry, but then I realized he simply was not educated on the disease.

Unfortunately, many of us with MS use a cane, are confined to a wheelchair or rely on a motorized scooter for mobility. There are a slew of us that look good on the outside, yet feel poorly on the inside. Case in point, I use a handicap placard for parking.

On numerous occasions I get out of the car only to be greeted by a nasty stare or hear people purposely talking behind my back. Oh, if they only lived one day with what I am going through. That is what the Optics of MS is all about. It's simply difficult for people to understand that we are leveraging all our internal strength and energy just to get through each day with this chronic autoimmune disease that seriously affects our central nervous system. We are quite a club of 400,000 strong in the U.S. and more than 2.5 million worldwide according to numerous leading authorities.



CHAPTER 1: THE DIAGNOSIS

I remember the diagnosis as if it was yesterday - October 15, 1998. It was a dark overcast Thursday as I drove into Boston to meet with my neurologist and receive the results of my MRI. My doctor was an older gentleman, nearing retirement, and had a rather curt, unorthodox “bedside manner.” Nonetheless, he was highly respected in the Boston medical community, and I was seeking closure on a multitude of symptoms I was experiencing.

What I was expecting to hear was drastically different than what I was actually told. I figured I simply had a bad back. Maybe it was a herniated disc, sciatic nerve or some sort of muscle strain. Instead I was told, “Mr. Bloom, you are symptom-

matic of one of the three things I felt would come back on the MRI; stroke, brain tumor or multiple sclerosis.” I took a gulp, turned to my right and realized my wife wasn’t with me. Why would she be? I was going to be told I had a bad back. I was to receive a script to alleviate pain and do some physical therapy.

I was alone, trying to digest and internalize what I had just been told. I knew a stroke was bad, a brain tumor was really bad, and I had no idea what multiple sclerosis was all about. It sounded awful. I felt like I was on a bad episode of *Let’s Make a Deal*. What door was my diagnosis behind: Door #1 (stroke), Door #2 (brain tumor) or Door #3 (multiple sclerosis). I was thinking to myself, I’ll take Door #1, it’s probably a mild stroke. I’ll be able to recover quickly from it. But no, it was Door #3. It was MS.

I went into a haze. I couldn’t comprehend everything that was being tossed at me. The doctor said, “Multiple Sclerosis is a chronic neurological disease that affects your brain and spinal cord, basically your central nervous system. We need to zero in on whether you have relapsing remitting MS or a more progressive state. We will get you on Betaseron[®], you will need to mix it, you will need to learn to inject yourself every evening, you should be more cognizant of your diet, weight and

alcohol consumption, you will need to get an MRI every year to monitor the damage to your myelin sheath, you will need, you will need.....” Yikes. My world had just changed forever.

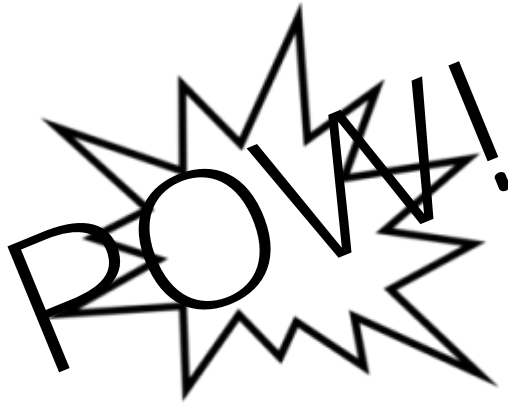
Like so many of us after such a devastating diagnosis, I immediately became a student of the disease as quickly as possible. Now remember it was 1998 and the internet was not as pervasive with content as it is today. There were certainly some good books out there, but most were published in the early to mid nineties. I read them all at least two times, but was constantly on the look-out for a newly published book. It was time to become a sponge on what this disease was all about and what the future would hold for me. I was thirty-nine years old, had two young children, a high powered job and an active social life. I had become the lyrics to a John Lennon song, “*life is what happens to you while you’re busy making other plans.*”



CHAPTER 2: SHIELDING THE TRUTH

I was facing a real dilemma. Who do I tell if anyone at all? I looked good on the outside, but that is part of the optics of Multiple Sclerosis. Sometimes it is tough for people to see or really measure what you are going through. People don't realize what you are struggling with on the inside: weakness, numbness, fatigue, trouble with your gait, difficulty getting a full void when urinating, spasticity, balance, optic neuritis the list can go on and on; not to mention a state of depression that kicks in. And if you try to work through an exacerbation versus taking the proper time to rest and recover, you run the risk of being left with further residual damage.

I have always been a workaholic and an optimist. I figured I could battle through this initial stage, but it was tough. I found myself telling family, friends and colleagues, “I have a bad back, I hurt myself playing street hockey or tackle football with my boys, I slept funny last night,”you get the picture. The only people who knew were my wife, my parents, my three sisters and my in-laws. The lies were starting to pile up, and I found myself needing to discover ways to receive support at work without actually telling anyone what was really going on with me. I would always make sure I had a podium when speaking to maintain my balance. I purchased a rolling briefcase that served as a cane when walking through the office building to get to meetings. I would get into work early and leave late so no one could see me struggling to walk from the parking lot to my office. This went on for years. It was a lot of work to deceive everyone, which gradually took its toll on me. In the summer of 2003 I was working with a new neurologist who basically told me “You have one leg dangling over the cliff.” My recent MRI results were not good. I was on the verge of a major exacerbation if I wasn’t already in it.



CHAPTER 3: THE EXACERBATION

Well, the other leg did go over the cliff. *POW!* I was officially in big trouble. My body's own immune cells had attacked my brain and spinal cord. Most of my right side had gone completely numb and part of my left side was quickly going south. I would wake up in the morning with claws for hands, an incredibly tight spine, and major bladder issues. I was in such rough shape that I literally needed to crawl from my bed to the bathroom, and the energy necessary to do that was beyond comprehension. It was equally as difficult to take a shower and perform simple grooming. My symptoms were surging. It was a terrifying time.

I could not drive. I had trouble navigating the keyboard on my

computer or the clicker for the TV. Holding a knife, fork, and cup was a challenge. I was now totally reliant on a cane to get around the house. Simple things that I took for granted such as raking the leaves, taking out the garbage, tossing a football around with my young boys were not possible. I was a mess, both physically and emotionally.

It was time to aggressively attempt to halt further progression, alleviate the pressure on my spine, and gear up to become independent again. A series of three-day-a-week pulse steroid treatments began, complemented by an increased dosage of Neurontin[®], bladder control medications, and physical therapy. Looking back, I probably should have begun steroid treatments earlier, but I was hesitant due to the side effects, the stigma of intravenous treatment, and simply admitting to myself that I needed serious help.



CHAPTER 4: PUTTING MS IN THE WRONG BUCKET

With an exacerbation the magnitude of mine, there was no hiding behind the shield any longer. After almost 5 years of concealment, it was necessary to go public and tell family, friends, and closest colleagues among a company of nine hundred, many of which I had been working with for over two decades.

Good news travels at a pretty good speed, but bad news travels at warp speed. As I started to tell people, the news went viral in a matter of hours. I held a big job, but I had a bigger job ahead - how to handle the onslaught of family, friends, and colleagues reaching out to me. Everyone's thoughts and well wishes

were deeply appreciated but all the cards, e-mails, and phone calls were overwhelming. Overwhelming to the point that I didn't want to connect to anyone. I felt like a politician that just lost a hard fought election. I needed seclusion, but as I read through all the kind wishes, one thing stood out. I found that a great deal of people had no idea what MS was or had mistaken it for another disease. As I mentioned in the foreword, they put MS in the wrong bucket. I kept on saying to myself and my wife, "How could so many people be so confused about multiple sclerosis?" Then I realized why should they be educated on the disease? I wasn't, until forced by necessity. There is such a small minority of people globally living with the disease that unless you are directly impacted, your focus is elsewhere.



I'm not a diabetic.

CONCLUSION

The need for more awareness, education, and understanding of the optics of multiple sclerosis spawned this booklet. Being mistaken for a diabetic at the airport was probably the tipping point. It's certainly a mystifying disease. There is no answer for how or why I got singled out. People need to realize that you do not recover from MS. You figure out how to manage your symptoms and how to cope with the challenges that MS brings. You grind through it realizing some days will be better than others. The biggest fear is never knowing if an exacerbation will hit again and if your symptoms will stockpile. Scary stuff. I can't tell you how many people wished me a speedy recovery. A speedy recovery? This is not like recovering

from a broken leg or bypass surgery. There is no “set” recovery period. There is only having a great support team and living with the optics of multiple sclerosis.



About the Author

Rob Bloom can be reached at opticsofms@comcast.net. In fact, he hopes that each and every person who takes a few minutes to read and digest the *Optics of Multiple Sclerosis* will reach out to him. Rob was diagnosed with MS in 1998. Since 2008, he has been a patient at the largest independent multiple sclerosis center in the world comprised of the Tisch MS Research Center of New York (www.tischms.org) and its clinical counterpart, the International Multiple Sclerosis Management Practice (www.imsmp.org).



You can follow Rob on Twitter: @Optics_of_MS

