

*Dear Friends,*

*The best way to give you an example of how unpredictable my disease is, is to tell you what happened just a couple of weeks after seeing Dr. Greenberg and after getting the positive news that the latest MRI showed no new lesions and that my MS was finally slightly “stable”.*

*A few weeks after that pleasant moment, I started feeling the new symptoms of what then brought me to experience the third relapse in the course of a year and a half.*

*Many years ago, with my usual strong desire to get to know this country; I decided to travel to some of the major cities to experience how different they each celebrate Independence Day.*

*Thinking that it would be an incredible experience to be a part of such a colorful celebration, every year I have chosen a different place to go to and be a part of the most interesting American holiday, the one where the spirit and the pride of its people comes out with strength and joy!*

*After having been to major cities like New York, Washington DC, Philadelphia, Rye New York, Westport Connecticut, Salem Massachusetts and Baltimore (and that was in 2006, few months before getting diagnosed with MS and before finding out how important Johns Hopkins would soon become for me) I decided to pick Pittsburgh as the next city to discover for the occasion.*

*Pittsburgh is the second largest city in Pennsylvania after Philadelphia and it's a seven hour drive from my town in Connecticut and, leaving on the 2<sup>nd</sup> of July, Keith and I were able to make it in time to start seeing the city by looking at its tall buildings and its many bridges that decorate the city's three rivers. I learned that there are about 446 bridges and more than 100 high rise buildings in Pittsburgh and many of them are quite colorful!*

*While I wasn't feeling completely myself just like it has been happening since the beginning of my life with MS, I went on with my plans anyway and I started looking forward to learning what the city of Pittsburgh had to offer.*

*For the next two days, I continued to feel “troublesome” and it was on the 4<sup>th</sup> of July itself that I started noticing new symptoms that were getting stronger and that the MS was getting more “active”.*

*Convinced that it must have been related to the heat or to one of the many other things that seem to have an impact on the disease, I went on with my day and I tried not to give too much power to those sensations.*

*I tried to do my best to fully participate to the celebration of the day and I think I did pretty well!*

*I focused my attention on the wonderful colors of the fireworks and on the happy and patriotic music that was being played all around us and I made it through the day.*

*Things were different the next morning.*

*I woke up and I couldn't really move well at all. I couldn't get up from the bed and the right side of my body, the side that never gave me problems before, wasn't responding to my commands.*

*I suddenly needed help to do everything.*

*My neck felt tight, hard like a rock and extremely painful.*

*I needed help to get up from the bed, to move, to take a shower, to go anywhere!*

*I couldn't pick up my feet to take a step and I didn't have much control of my movements once again.*

*I suddenly realized that I was experiencing another relapse.*

*While feeling pretty horrible about bothering him, I felt the need to ask for help and Keith wrote an e-mail to Dr. Greenberg letting him know about my situation.*

*It's important to remember that we were in the middle of a holiday weekend and I continued to feel bad in the course of the 5 minutes that it took for Dr. Greenberg to call us back and offer us his help!*

*I knew I could count on his support because I already knew how incredibly giving and caring he is, but I really felt bad in taking part of his free, family time!*

*He told me to do what I thought: I had to go back home and start getting steroids to help stop the inflammation that was going on in my brain and to stop the attack before it got worse.*

*To do so I had to rely on Yale and that's never an easy thing for me to do...*

*In fact, while I requested the steroid treatment, I was told to wait one more day and see how things were going to progress. Because the next day, while feeling pretty bad, my symptoms didn't worsen, I was told to wait some more.*

*I continued to have difficulty walking and I started experiencing trouble with my balance, I started feeling pain all over my body especially in my arm and neck but I was able to push myself to welcome as best possible my best friend Deborah, who arrived to spend most of the summer with me.*

*Fearing that I wasn't going to be able to offer her the usual vacation that I take so much pride in giving her every time she comes to visit in the summer, I did my very best and I tried to hide some of the new symptoms that continued to appear.*

*My throat, my fingers and the deep state of confusion in my head arrived a day later and the following day the fatigue was more present than ever.*

*The amount of pain I was feeling was increasing.*

*I couldn't sleep because of it and it ended up touching every single part of my body: from ears to fingers, from legs to feet, from head to arms I felt incredibly intense and different types of pain. I didn't really know that we could suffer in such ways and when the electrical shocks began, I actually reached my very own pain threshold!*

*I had electrical shocks in the head that were horribly strong.*

*I noticed and learned that, to deal with them and with their acute, launching pain, my stomach would contract causing me to feel pain in that area too.*

*Then the numbness arrived.*

*It started from the left side of my body, which is my usual side. Then I started feeling numb pretty much everywhere I used to feel the strong pain.*

*Finally, on the 15<sup>th</sup> of the month, I was able to start the five day steroid treatment which was done at home and which didn't seem to make things better. Actually, after a one day improvement, I ended up worsening.*

*I found that I needed to constantly move my itchy legs and the fact that I didn't sleep for entire days, (a normal reaction to having steroids in the body and of refusing to take one more medication to help me fall asleep...) made my fatigue stronger and more debilitating.*

*Just like I found happening during my two previous relapses, the steroids seemed to have the power to awaken previous symptoms and to create new ones, so every moment of every day is actually quite interesting... and it's an ever lasting surprise!*

*Sometimes I felt like my body wasn't real any more.*

*It was hard for me to believe that my own skin could feel so fake, so weird, and so painful to the touch.*

*I often wondered how it was possible to feel like I was a part of a cement block, not able to bend knees and my fingers, not able to chew food without feeling sharp electrical shocks running along my body that would end up in the back of my head.*

*I wondered how someone could feel so horrible and experience such types of unbelievable pain and agony.*

*I soon had to learn about the millions of new ways that I could hurt and suffer. It was truly awful but I had to make it through and, with time, I did.*

*It took three more days of steroids and Greenberg's suggestion to have plasmapheresis done and, after finishing all of that therapy, I was able to start getting some of my body back.*

*The plasma exchange, which I had done as a preventative measure the year before and that ended up not working at all (2 weeks after that, I had my second relapse!) was the right thing to do this time and I was glad to see that, slowly, in a matter of days, I was able to move my left ankle and take better control of my legs.*

*It comes natural to notice how, at every passing relapse, I end up needing more to get things under control and I seem to be requiring more effort from different therapies to get me better.*

*I don't think this is a good sign of things to come, but I am so happy and so grateful to be able to get back to normal every time that I don't really concentrate on the past experiences.*

*I only look and move forward and I can't waste my time dwelling on what just happened to me. I can't afford to do that. When I get better, I go right back into living and I try to do it as well as I can to make sure to appreciate every moment I get!*

*I keep a daily journal of my disease so I will never forget what has happened throughout the course of the years, but I am not about to relive everything by reading it over and over or by thinking about it too much.*

*Today is what I have and I don't want to spend it by thinking about yesterday.*

*What I make sure to pay attention to is the people I meet and the experiences I have every day.*

*Just like I said many times before to my friends, every day, I have to reinvent myself.*

*If I can't do something one way, I have to learn to do it in a different way.*

*If I don't have something or someone to look up to, I will search and I will find one.*

*When I didn't have any heroes and no one to believe in and put my hopes and dreams in, I went and looked for them and I found them.*

*When I have many things that have the power to make me sad or make me worry, I simply look at what I have, at what I achieved, at what I can still do and I never let the sadness or the worry touch me or change me.*

*When I meet the wrong people or I find myself surrounded by others that don't share my passions or my views or that don't let me be who I am, I remember what special people have been teaching me in so many ways and I work hard with myself to follow the right path and the right influences.*

*I learn to adapt every day. I make sure to find something that has the power to touch me inside and I take it in and allow it to become a part of me.*

*For me, it's all about the heart!*

*I call this "reinventing" myself.*

*It's an ever changing process that allows me to refocus moving forward without looking back and while taking one step at a time and creating ways to enjoy myself in the simplest ways possible.*

*I recreate my dreams.*

*I find something else to make me smile. I change part of a passion to fill the needs of my ever changing life.*

*It's a form of survival, I guess and it's something that works for me and that makes my days go by with joy and not with sorrow.*

*Until next time, please take care.*

*Love,*

*Angela*