

July 15<sup>th</sup>, 2009

Dear Friends,

*Many times, I wonder how I can pay attention to my disease when I have so many things to be happy for...*

*How can I be paying attention to all of my many and scary symptoms if I am always so happy and if I continue to find reasons to go on and to look at all the small things that have the power to bring me so much joy?*

*How can I focus on the stiffness of my neck, the pain along my spine, the heaviness of my legs when I can think of the many and wonderful experiences that I am able to have every time I travel and every time I go to Johns Hopkins to receive my Tysabri infusion?*

*There is something special about that place for me.*

*I don't know if it's the sense of hope and care that I see everywhere or if it is the people that work so hard to be there for you, to take care of you, to do their best to help you better deal with the challenges of the disease.*

*I would say that it's both!*

*This month I received my 6<sup>th</sup> Tysabri infusion.*

*Six months have gone by and with each passing day, I find myself realizing more and more that this medicine is allowing me to be relapse free and, even if not without its problems, it's allowing me to live without feeling like I am sick every single moment of my day.*

*But going back to the feelings of happiness that I have inside of me, I would like to share a very special day that I had on the anniversary of my 6<sup>th</sup> Tysabri infusion.*

*I had planned to fill my day with special meetings that I had been looking forward to for the whole month.*

*I started by going back to Kennedy Krieger (the place where I did my rehab last year after my July relapse) to see my wonderful physical therapist that I remained friends with.*

*I got to talk to her about many different things and I was able to spend a very nice time before having to go back to the infusion area at Hopkin's Outpatient Center.*

*A few minutes before the infusion itself, I was supposed to meet with Jacqueline Redmond, the very kind and caring woman that works for the University and that collects the funds that I raise.*

*Because I had the most wonderful time talking to my friend Cara and because I had to walk back between two buildings that, while not too far from each other, took me some time to get to, I was late for the appointment and I found out that she had to leave to be a part of a meeting.*

*I was so sorry!*

*I am known to be a very punctual person but, this time (and many more times than I would like it to be now that I have MS!) I was late and I didn't have a chance to see her. I had more funds to give her and I had hoped that after her meeting, I was going to find a way to meet her somewhere in the hospital.*

*Feeling quite bad with myself for missing her, I went into the room where I do my infusion and I started smiling to the people that were present and to my funny and cheerful friend Chad.*

*Remembering what Dr. Greenberg had told me about feeling that there was a Tysabri club in that room, I smiled even more and I became ready to be part of that club by sitting in the comfy chair and getting ready to have my blood pressure checked.*

*While this was going on, with the back of my ear, I heard one nurse mention that she had just seen Dr. Greenberg in the hallway.*

*Knowing that I have some cognitive problems and that I am not always understanding things right the first time, I asked my husband Keith if I had heard the right thing. He looked surprised too, but he smiled at me and he shook his head and he said that yes...Dr. Greenberg was in the hallway.*

*I don't know what happened to me (and I refuse to think that it is the MS that made me jump up and that made me react in such a joyful way!).*

*I just know that I got up, took the blood pressure things off of my arm (what if I would have had the IV in it???! I can assure you that everyone present in the room wondered the same thing!!!) and I "ran" out of the room to get to the hallway!*

*I actually think that that was the moment that I walked better than I ever did in the past 2 years!!!!!!!*

*As soon as I got to the hallway, I saw him on the side and, still not sure that this was really happening, I waved with my hand and I stood there in disbelief for a few seconds.*

*I saw my husband following me into the hallway and then back to the infusion room where I went to announce to everyone that Dr. Greenberg was back!*

*I am not sure why I did that... Maybe, saying those words allowed me to realize that he was really there, present, back at Hopkins and that I wasn't dreaming!*

*Then I got back out of the room and, this time, I waved at him again and I made sure that we could say hi to each other.*

*After a warm hug, I started thanking him for the many e-mails that he still writes to me and for continuing to care about me and about my MS journey.*

*After a few minutes chatting with him, I saw Dr. Calabresi walking toward us and he welcomed me with a "Ciao, come stai?" that made me smile even more!*

*I didn't think that it was possible to smile more than I was already smiling, but now I know that I can do more!!!!*

*I was so happy that I can't even describe how well I felt!*

*I forgot about the neck stiffness, the electrical shocks along the spine, the strong back and head pain and the "inside shakiness" that I mention so often and that rarely leaves me alone. Every symptom subsided. Every symptom didn't seem to be strong and present any more and the only thing that I could think was... "What if happiness can be a cure???"*

*"What if feeling this way could cure my MS?"*

*"How can I pay attention to anything else but feeling what I am feeling now while I stand here with two people that I truly admire and that, just by looking at them by and receiving their smiles, make me feel so much better???"*

*I just smiled and smiled and I kept on smiling!*

*I probably said many silly things and things that might not have made much sense but, if I really did so, I know that I did it with a big smile!!!!*

*Not even for a second I wonder if what I feel for my doctors is strange or not "normal". Not even for a second I think that I shouldn't feel this way!*

*I have MS, I have an active one that seems to be just "as passionate as I am", I deal with a lot every day and I have new challenges every day that I have to learn to accept and to live with and finding people that I can give my friendship to, my support and my smiles to is the BEST thing for me.*

*Finding reasons to smile is priceless and finding people that truly care about patients like me and that take from the bottom of their hearts of the job they chose and that they seemed to be born to do is also priceless.*

*While my behavior and my way of thinking might seem to be over the top, I can assure you that many other people feel the same way about these doctors and that I am not the only one reacting like this to their presence.*

*I call them "heroes" and I am sure that there are many people that see this as a strange way to refer to them.*

*Just like I mentioned in one of my first letters and right after meeting Dr. Greenberg for the first time, I feel that this society chooses to pay attention to the "wrong" people.*

*We make people into celebrities because they did something on television or at the movies and we are not capable to see that the real celebrities are in our own backyards.*

*Calling my doctors "heroes" comes from seeing and paying attention to the fact that they actually chose to study rare diseases that not many people care about, they chose to be a part of a world that won't be "star worthy" and that won't give them too much glamour.*

*I call them heroes simply because I look at their hearts and not at their status or at their fame.*

*I feel that someone that chooses to study MS, TM and the many other serious neurological diseases deserves to be called a hero.*

*I don't expect them to do anything more than to be exactly who they are.  
I don't mean to put pressure on them because of the title I give them. I know they will work hard and that they will do their very best to find a cure for these diseases and I know that they will continue to be special and caring doctors and I also think that this is enough and that there is nothing else and nothing more that can be asked of them.*

*My day was a special one.  
The infusion went well and it went too fast. Many of the other patients laughed thinking about me "running" out of the infusion area to go say hi to Dr. Greenberg and all of them wondered if I would have done the same if I would have had the IV in my arm!*

*I am embarrassed to say that I probably would have! 😊*

*Joy and happiness are feelings and emotions that are so different in all of us and that cannot be judged or touched by others.*

*I am blessed to have found another reason to smile and to be happy.*

*I am blessed to have something that makes me feel good while I am going to a hospital to receive a medicine that I know can help me or hurt me at the same time.*

*And I feel blessed to have the gift of looking at every little thing that has the power to brighten my day and to know that I can take it, make it mine and carry it with me through the hard moments of my journey with MS.*

*Thank you Dr. Greenberg and Dr. Calabresi for caring so much about your patients and for giving me another reason to smile!*

*Hugs to all,*

*Angela*

