

*Everyone knows very well that Tysabri wasn't my drug of choice. I was never used to taking drugs before MS came into my life and it was a real shock when I realized that doctors wanted me to take them from that moment on for the rest of my life.*

*After trying Copaxone, Avonex and Rebif, and more than enough steroid treatments, I had to make a very hard decision: I had to take Tysabri to give a chance to my MS to slow down.*

*Because I believe in the power of the mind, and loving the care that I was receiving at Hopkins, in Baltimore, I decided that I was going to go every 28 days to receive my Tysabri infusion over there.*

*Choosing to make such a long trip (4 and a half hour ride each way) has become a little tradition for me and for my husband and while neither of us looks forward to it because it means that I am taking Tysabri for another time and I get closer to the many risks that this medicine offers, we have found a way to enjoy the experience.*

*We drive down on Tuesday afternoon after my husband is done with work and we stay at a hotel in the city of Baltimore that is not very far from Johns Hopkins. We have dinner on the way and we get to the hotel at about 11 o'clock or later.*

*I have been taking Tysabri for 16 months and, in this time I have created little traditions that I try to stick to every month and at every infusion.*

*The ride from my house in Connecticut to the hotel in Baltimore is usually a very pleasant drive. As many of you already know, I am not a big fan of the eighteen wheelers that populate the American highways, but I try to bear their presence the best way I can.*

*While I stay in the car for most of the trip, I try to drink anyway to keep my veins plump and my body hydrated and I am quite lucky because I usually don't have to stop and go to the restroom more than once or twice during the trip. I usually drink a liter of water when I know that I am getting closer to a highway stop.*

*I drink a lot at the restaurant where I stop to have dinner, especially because it is usually not too far from my destination.*

*An hour or so before arriving to Baltimore, I have another little "tradition": I take one of my favorite music cds made by Elisa, an Italian singer (she comes from the same town as I come from in Northern Italy) that sings many songs in English and I listen to it until I get to the hotel.*

*In the morning of my infusion, after a quite difficult night (I never sleep more than 4 to 6 hours on those nights) I am up and ready to go. I usually bring some fruit with me to have for breakfast and I get ready in a short time, making sure to remember to smile... Since Dr. Greenberg is not present any more because he works at Southwestern Medical Center in Dallas, going to Hopkins is definitely not the same for me but I try to remember him and keep his memory with me.*

*When I arrive at Hopkins, after parking usually on the roof because the lot is completely full, I check in and I go to the 5<sup>th</sup> floor of the outpatient center that is two steps away from the building that represents Hopkins to the world.*

*There I check in again and I am ready for the infusion at my usual 10 o'clock appointment. The infusion center is a very small room (way too small) and offers seating to 4 patients at the time.*

*While I love the care that I am able to get at this hospital, I don't have anything good to say about the infusion center. Actually, I have been very outspoken about the inadequacy of the hospital to offer a good experience to its patients.*

*The room is too small for the many MS patients that come to take Tysabri every month (there are more than 100 of them and the number continues to grow). The door is not wheelchair accessible and the family members have no room to sit and be close to their loved ones.*

*It breaks my heart every time I see young patients that are already using wheelchairs to get around that are not able to enter the infusion area on their own. There is simply not enough room for them to move independently anywhere around there! (Please, check the letter I wrote to Dr. McArthur, Director of the Neurology Center in March of this year).*

*The welcome that I get every time I arrive to the infusion center is always bright and cheery thanks to the two nurses that take care of us patients during the infusion.*

*Krissie and Alpa are always smiling and are ready to joke and to make the atmosphere light and fun for everyone!*

*When it's time for the infusion, after I say hi to the other patients that are present at the same time as me (some of them change every month) I sit in one of the four chairs and I prepare myself for the infusion.*

*Very rarely I have listened to music or used the computer. Most of the times, I chat with other patients and I spread the word about CCSVI and Dr. Zamboni's discovery. I remember that Dr. Greenberg had told me about the monthly Tysabri get together and how people got to meet once a month to share experiences, news and complains. I enjoy chatting with others and I am always willing to welcome a new person that I didn't meet before to the group because this allows me to see that MS people have many things in common and that we are all quite strong, most of us lean to optimism and we are all doing the best that we can do with what we have to deal with.*

*My infusion lasts an hour and then the saline start running through my veins. This part takes about 20-30 minutes and then I am ready to go.*

*I am never in a rush though because I really enjoy being there and I take my time before leaving the center.*

*Usually, right after the infusion, I meet my friend Maria for lunch at a Panera or at an Italian American deli that is not too far from Hopkins.*

*Maria has been searching for an MS diagnosis (or any other one!) for quite some time and we became friends more than a year ago. Meeting her after the infusion is something that I really look forward to and that I really enjoy.*

*Lately, I met another friend that lives in the city of Baltimore and that makes videos on youtube like me. Her name is Judy (donotconcede) and we already met a couple of times both for dinner and for lunch and had a very nice time! I enjoy meeting with her too and she is a new person that makes my trip and my Tysabri "tradition" well worth it! After lunch, I usually get on the road. As soon as I take a seat in the car and I turn the music on (this time, it could be Tiziano Ferro-an Italian singer that I love very much) I start feeling extremely tired and I start hurting like my body was just hit by a bus! Sometimes, the pain starts right there and then or the morning after the infusion but most of the time my only major side effect is the tiredness that I feel as soon as I sit in the car. If I would be outside in the fresh air, walking and talking, I doubt that I would feel this way but, somehow, sitting in the car and starting my ride back home brings out the fatigue. Since I don't ever sleep in the car (and I never did in my life!) I listened to my music and look out of the window. After a couple of hours, tired of feeling so out of energy and feeling like I would close my eyes and never open them again, my husband and I stop at the rest stop on the highway and we get the only coffee drink that we will get during the entire month! We go to Starbucks and we choose a drink that will get me going for the rest of the day! From that moment forward, I talking up a storm and I sing and as soon as I get home, I am ready to move, to unpack, to warm up dinner that I had prepared before leaving to go to Baltimore and to put away everything I used during the trip! Not only I am a very neat person, but I don't want to have things around that would remind me too much that I received another dose of Tysabri and that another month has gone by already!*

*I feel that time has been flying now that I feel much better and that I am back to living again and I wish that wouldn't be this way because I know that I won't be able to take Tysabri forever and that I will soon get to my two year mark, .. and I will have to make a serious decision. . .*

*The day after the infusion, I wake up in pain but, as soon as I get upset, I refuse to take any drugs to help with it and I go and exercise, I feel much better and the pain goes away! I believe in moving and in avoiding as much as possible to take other drugs and this has been working for me for the past 16 months!*

*I know that I might be making more out of this than most people do, but, again, I have a different background, I come from a different world and I am not used to using drugs (and I never will be!) and I will do my very best to do as many things as possible in the natural way. I actually grew up thinking that the drugs are my enemy and not my savior! (And it's not the answer to everything like the TV commercials want you to believe!).*

*I know the reason why I am taking Tysabri, but I don't have to like it! I am aware of the risks and I don't have to like them. But I do understand that I have to take this medicine for the time being and, having the traditions that I created for myself, make things go a lot smoother and they are a lot more enjoyable!*

*So, once again, I believe that, no matter what we have to do that we don't want to, there is something that can make us look forward to being a part of that experience. Meeting my friends for lunch after the infusion, being in a place where I am able to remember a nice doctor that taught me so much more than he will ever know, finally spend "quality" time with my husband in the car and being able to chat and talk to him and have his full attention, being inspired by the young MS patients that I see every month and that remind me WHY I have to take Tysabri and being in a city that I have mixed feelings for.*

*Tysabri has become a sort of tradition for me. I enjoy going to Baltimore every month and I enjoy everything about this experience... but I am not crazy about putting this drug into my body!!*