

October 2008

Dear Friends,

*It's important for me to tell you about many more wonderful experiences that I was able to have while being both at Kennedy Krieger and at Johns Hopkins this past September.*

*In fact, during the two weeks I spent in Baltimore, I was able to meet many of the people that I have learned to admire and respect in the past two years.*

*On very short notice, Dr. Greenberg agreed to meet me once again and spent more of his time explaining the need for taking stronger medications and listing the many options that I have left and that are available at this point. He made sure I understood that, from now on, whatever medicine I will decide to take next will possibly have serious side effects and they are not known too well because they haven't been studied for too long either.*

*This next series of medicines will be presenting many risks. My time with the interferons is over and I have to move forward and try something else.*

*Being able to talk to him helps me a lot but, this time, our conversation was quite different from the other ones.*

*At the end of our meeting, he said that he had some bad news and some good news to give me.*

*Thinking he was going to talk about my MS, I would have never expected to hear him say that he was going to leave Johns Hopkins and go back to Texas to open a new Transverse Myelitis Center at the Southwestern Medical Center in Dallas.*

*I was so shocked I didn't know what to say. I just opened my eyes in disbelief and I didn't know what to say any more. I was speechless for many seconds and I felt my eyes tearing up wondering why this had to happen to me and why I was going to have to say goodbye to the most incredible doctor I had ever met!*

*I have to say that his kindness touched me once again, not only because he decided to do this in person, knowing exactly the type of person I am, but also because he sensed right away my disappointment and my being so hurt.*

*He also gave me the greatest gift he could have ever given me.*

*Knowing very well that my interest in Johns Hopkins all started thanks to Dr. Peter Calabresi, he made sure to tell me that he had chosen me between his numerous patients (500 to 600 of them) to be moved to the care of Dr. Calabresi.*

*He told me that, if I wanted to, I could have him as my new doctor!*

*I have to honestly say that at the moment he told me the news, I didn't really consider it good news because I felt that I had already found the best doctor ever and I didn't*

want to lose someone like him. I felt that I had created a good relationship with him and that I had found someone that knew exactly who I was and that understood my level of sensibility.

It took me a few hours to realize the beautiful gift that he had given me and, from that moment on, I felt a little bit better!

I felt that it was very kind for him to come and say goodbye to me the day before I was done with my two week rehabilitation program.

He came to check up on me and to see how I was doing and he caught me while I was playing/exercising on an arm bike. When I would move the arms, the screen in front of me was moving a car. Now, we all have to remember that I don't drive...

I didn't do a bad job but I wasn't the best driver on gameland that's for sure and I was able to have a lot of fun while joking with Dr. Greenberg.

It's so easy to talk to him and to have fun because he is so very personable and super friendly!

Talking about other people that I admire, I was able to make another dream come true when I finally met Dr. John McDonald.

He is an extraordinary doctor and scientist that works at the center in the research field.

His story and his acclaimed career is quite long and quite amazing.

In 1998, Dr. McDonald was named Medical Director of the Spinal Cord Neurorehabilitative Unit at Barnes-Jewish Hospital in St. Louis and Section Head of Spinal Cord Injury Program at Washington University. There he spearheaded development of what is now a leading spinal cord injury neural restoration program. It was there that he developed the "activity-based restoration" therapies designed to help patients with long-term spinal cord injuries recover sensation, movement and independence.

He is most known for the therapy approach that was publically acknowledged as producing the substantial recovery of actor/activist Christopher Reeve that became one of his very dear friends.

While he might be most acclaimed for this, his work touches many more lives.

While I don't know him personally, he is one of the doctors that I most admire down in Baltimore.

When I had the opportunity to meet him while I was with Mike, my occupational therapist, I felt happy once again because I had the chance to tell him how much I admired his work, his views and his speeches, which I found amazing!

In fact, joking with Dr. Cristina Sadowsky, who works with him at the center and who is the clinical director, I often mentioned to her of using McDonald's Johns Hopkins Rare Disorder Symposium speech to exercise after my relapses!!!

*I suggested that they should work on creating an exercise video with his voice and his words when he talks about the importance of exercise and, while she mentioned that to him as a joke, I still think it's a great idea!!!*

*The courage and the hope that he puts in every single word he says is so powerful and so inspiring that I felt it was the right thing for me to push me to keep on walking and it gave me the strength to believe that I could make it through anything and that I could get better...*

*The day I met him, like I said, I was sitting at a small table with Mike, the very kind occupational therapist that took care of me for two weeks.*

*The gym wasn't too busy that day and when I saw him walking into the room greeting everyone present with a clear "never give up!" I smiled and I was still shocked to see him finally in front of me!*

*He went to say hi to everyone present and he walked around saying that we come from all over the country and the world and from every walk of life. He said that we should never give up and that, by working hard, we would all reach our goals.*

*His very simple, but right-to-the point words touched me once again and when it came time to talk to him, I felt comfortable enough to tell him that I admired his work, his way of speaking and his support of others to push forward and to never give up hope. I shook his hand and I was able to take a picture with him thanks to Keith that ran in the room almost as soon as he saw him coming into the gym. He kindly accepted and he continued to be very pleasant and very hopeful.*

*Another person that I saw every day while I was at Kennedy Krieger, but that I didn't get to be introduced to, was Patrick Rumfield.*

*I had found him on the internet and I read about him during the many hours, days and weeks that I needed to recover from my many relapses.*

*While I had read about him, I didn't know that I was going to find him there and I wasn't even sure about who he was at first because I didn't remember his name.*

*When I saw him for the first time, something clicked in my head and I started wondering if I knew him and then, after telling Mike that I felt like I knew that man already, he explained to me who he was and it all started making sense to me.*

*Patrick Rumfield is the walking proof that it is possible to recover from spinal cord injury.*

*If you would see his spine MRI, you would think that he would be in a wheelchair, but he is not and he is walking really well like nothing happened to him.*

*Injured in an alcohol-related car crash in 1974, Patrick Rummerfield's spine suffered four crushed cervical vertebrae. Doctors saw little chance for survival and they told him that he would die within 72 hours.*

*And he didn't.*

*His extraordinary self-will, positive attitude and spiritual guidance gave him the push to go on and after seventeen years of intense physical therapy, he was functioning with almost complete normalcy.*

*He is now credited as the world's first recorded fully-functional spinal cord injury quadriplegic. His determination to "never give up" became the cornerstone of his new life and he is a great example to all of us and mostly to the people that have suffered spinal cord injury.*

*His remarkable story is so powerful that, even if I didn't meet him personally, but I simply received his many kind smiles every morning when I would be ready to do my therapy, it gave me a lot of hope.*

*While spinal cord injury is very different from the type of damage that Multiple Sclerosis gives to the brain and to the spinal cord, I do feel that exercise is just as important for people suffering from this disease as it is to benefit the people that deal with a life changing experience such as a spinal cord injury.*

*While they do have a long journey ahead of them, spinal cord injury is a one time even while Multiple Sclerosis is an on going debilitating disease.*

*We might get better after a relapse and work hard to go back to normal but then we can get hit again and we might be forced to start all over to regain what was lost during the latest relapse.*

*This has happened to me twice in two years and I know the frustration that I felt in having to go through the same rehabilitation, the same experience and the same uncertainty as I felt the first time around, but I wasn't ready to give up then and I am definitely NOT ready to give up now!*

*The International Center for Spinal Cord Injury at Kennedy Krieger in Baltimore is a place where it's impossible to give up because you are surrounded by so many people that BELIEVE that you will make it and that work hard to make sure that it happens.*

*I will never forget my experience at the center and I will never forget meeting my unsung heroes...*

*Love to all,*

*Angela*