

October 6th, 20007

Dear Friends,

after finishing my very long and detailed report in Italian for friends and family members, a report that ended up being 11 pages long (which is not much compared to my usual reports... but, don't worry, the English one won't be that long!), here I am, ready to finally tell you about my experience at the amazing Johns Hopkins Hospital. To do so, I have to go back in time and tell you how I got to know about it and how it became very important to me.

Right after my first attack, last October, and after coming back from the hospital, still feeling quite sick, but with a great desire of learning about my disease, I found myself on the Internet, looking for better information about it and for ways to prepare myself to accept my future with MS.

While having a general idea of what MS is by living in my country, where the disease is very well known and talked about, I wanted to make sure to fully understand it and to see if there was something that I could do to help myself in any way.

In my country, while most people know and have heard about Harvard, Yale and Stanford Hospitals and Universities, most people don't know about Johns Hopkins and they don't seem to know too much about it.

I was one of them, and when Keith, last year, during our trip to Baltimore to celebrate Independence Day, while driving in the car, pointed to the hospital telling me that it was a very famous one in America, I just looked, smiled at it and simply said "neat" and went on to looking at other things.

I never would have thought that, only 3 months later, that same hospital would have come into my life, become so important and give me so much hope.

One of the first websites that I went to was the MS Society's one.

Knowing that it must have been a good and known one, I decided to take a look and I found myself learning and learning more and more about not only the disease itself but, and especially important to me, what I could do to help myself in dealing with it.

Wherever I read and found something that I agreed with and that made sense, I followed it.

It is since then that I drink cranberry juice while avoiding certain infections and it is since those first days, that I understood the impact that the MS Society has in this country.

While looking around on the website and while being very happy to find a section where it's possible to listen to medical talks and speeches, I found an area where I got to finally meet Dr. Peter Calabresi and I got to listen to his words.

From that moment on, finding something special in his simplicity, in his humbleness and in his honest approach to things, I knew that he was going to represent a lot to me one day.

It wasn't until later on, after listening to more and more podcasts, that I realized that there was a group of doctors (at the time I didn't know they were somewhat connected to each other) that were just simply amazing.

The way they spoke, the way they explained themselves, the way they were able to get my attention, made me realize that I had found something very special.

Peter Calabresi's words touched me from the beginning.

He said that he listens to the patients, that he gets ideas from them, that when he sees the people that he can't help, the only thing he wants to do is to go back to the lab and work harder and harder to find a cure for this disease.

I know that I am unusual (I never said I was "normal"!) but his words really and deeply touched me.

He didn't have to say what he said.

I listened to many scientists talk throughout this past year, and I have yet to hear or to meet someone that is so touched by this disease and that knows how it changes and affects people's lives, from the emotional point of view, like him.

Everywhere I turn and everywhere I look, his name comes up and it's always described as an incredible person, a very personal doctor, someone that remembers everything about you, someone that really cares about you and that really wants to do everything possible to find a cure and help you in the real sense of the word.

In the passing weeks and months, and while getting better and better at understanding medical terms and difficult expressions and while learning how to navigate the internet better and better, I found myself learning something new that made a difference in me and in how I started to look at things...

I learned about a hospital that seemed to have it all and that it seemed to be able to offer all of the scientists that I had met and loved during my studies.

From Calabresi itself to the famous Douglas Kerr, the scientist that is dedicating his life to helping people with Transverse Myelitis and that connected the spine of paralyzed mice making them walk again, Benjamin Greenberg, the doctor that I chose to meet after finding out that Calabresi wasn't taking any more patients, and one other incredible doctor whose name is John Mc Donald and that works at the Kennedy Krieger Institute.

While I had to give up on being able to meet Calabresi, I found myself asking over and over to have an appointment with Dr. Greenberg and I never gave up because I really didn't want anyone else and because I just felt that I had to meet one of my "heroes"! After watching the latest symposium on the computer, I got to meet all of them and I got to learn about their work, their dedication and their commitment to finding a cure for many serious neurological diseases.

In the past few months, while working on raising money for Dr. Calabresi and finally reaching a total of 7,290 dollars, I have been able to dream about going to Johns Hopkins and meeting some of my "heroes".

Like I have explained many times to my Italian friends, society seems to like to make our idols, the wrong type of people.

Actors, singers, sports athletes seem to become more important than the real idols, the ones that don't entertain us, but the ones that HELP US.

I do believe that working at saving lives and at bettering the lives of sick people deserves more attention than a perfect acting role in a movie...and I have completely changed my philosophy about this and I am making sure that people of this caliber and with this type of career, will be recognized, even if it's only by me!

Since the beginning, even if I had never met them, I made sure to write to them and thank them for what they are trying to do and I am making sure that they know they are appreciated.

Well, I felt that I had to tell you all of this before explaining my visit to Johns Hopkins and, because most of you are from this country, I won't talk about how the hospital itself impressed me and how I liked some of the style of the buildings and how I felt in walking around them, observing people, watching every little detail and taking everything in... because you probably know what I am talking about.

While there is always people in a hurry, it seems that a lot of them find the time to stop to smile at someone or to say hello or to give a hug to someone they know and I enjoyed seeing the kindness of some of them just like I enjoyed realizing that I was finally at Johns Hopkins and that I had just made another dream come true.

A couple of months ago, after trying to collect more donations for my fundraiser, I got to get in contact with the person that works at Johns Hopkins and that raises money for Peter Calabresi and for his work.

We spoke on the phone, we e-mailed each other many times and we became friends.

She was the person that welcomed me to Johns Hopkins.

She thanked me for my work and for my efforts, she invited Keith and I to lunch and she brought me a couple of the best gifts that I have ever received!

One was a t-shirt of Project Restore, which was created to raise funds and bring awareness to MS and to Transverse Myelitis, a sticker with the name of the hospital, which I had requested for another project of mine, and the latest research articles that Calabresi, Kerr and Greenberg wrote.

During lunch, we talked and shared ideas and thoughts, I was able to ask many questions and to learn more about what's being studied right this moment by all the scientists.

After lunch, I received a tour of the old part of the hospital, which is incredible and where I was finally able to see a painting of Mr. Johns Hopkins, the wealthy Quaker merchant that founded and created this amazing medical institution.

Finally, Kim, the lady that I have become friendly with, brought me to see a real laboratory in the section where Douglas Kerr works and not only was I able to see his office and be a part of his world for a moment, but I was able to meet two other incredible people that I have learned to appreciate and to admire just as much as I admire the doctors that work with them.

Chitra, a beautiful and brilliant woman from India, made a big difference in the world of science and of medicine.

She welcomed me with her bright and kind smile and she, and her colleague Deepa, showed me around the lab and explained a couple of things for me to learn.

I felt so comfortable with them to feel like I had known them forever and I was able to be open and to really show who I am, without having to worry at all!

While I had shared with Kim my latest idea for a new type of fundraiser, it took me by surprise when she shared the work of my new campaign with the other women.

I was thrilled to see that all of them were just as excited about it as I am and I loved their response: they are going to talk about it on their website and they are going to talk about it in the newsletter which gets sent to the MS patients and to the ones with Transverse Myelitis.

Well, I know that lots of you, don't really know what I am talking about and here, I have to explain something that will take one more page of reporting!

In the month of May, after coming back from my "miracle trip" back to my country, while walking around in the Botanical Gardens in New Jersey and while following the steps of a cute little bunny, I started talking to a woman and her friend who, just like me, were interested in flowers, plants and nature.

What started as a simple conversation between strangers, turned out to be something really special.

We spent most of the morning together and we walked, talked, took pictures and I learned to love a stranger.

Dalia (this is her name) is a special, inspirational woman who had the power to change me, to add something amazing to my life and she was able to open my heart and bring it to wonderful heights.

She told me that I was going to do something in my life, she said that I could do anything that I would set my mind to, she promised to keep in touch and, from that day on, she became someone very important to me.

She wrote to me, every single day.

She sent me inspirational thoughts and poems, medical articles, papers about natural doctors and medicine and she started sending me beautiful pictures of flowers.

I knew she loved to take pictures and, with her very good camera, she takes wonderful shots of the most beautiful flowers around.

I loved to receive them and, while feeling very humble, I started sending her my own little artistic photos, which she then took and touched up by adding to them an extra touch.

This relationship grew more and more each day and it took an even more special turn about a month ago, right after my latest attack, my hospital visit and my recovery.

We had talked about finding another way to help my fundraiser, but I would have never thought that she would send me all of her beautiful pictures, give me the permission to use them and tell me that I could have them printed into cards.

When we needed a logo for the campaign, one of my simple pictures was chosen (it's one of a beautiful butterfly that stopped on top of a pink coneflower in my colorful garden) and the Flowers 4 MS name was born.

Now, this campaign has started and, while I sold a couple of cards by themselves, it was amazing to find out that I could sell entire boxes full of them, raising a good amount of funds for MS research.

Now, this campaign has made another step by being recognised by Kim and her colleagues and it will make another step by going onto the website and becoming a part of the Project Restore newsletter.

When I went to that botanical garden, looking for nature, beauty and color, I wasn't expecting to meet an angel... but that happened and I know, deep in my heart, why and how it happened.

I just continue to believe...

So, going back to Chitra, to Kim and to Deepa, I decided to take a picture with them and I would have never thought that we were going to let me take it in Dr. Kerr's office!

Now, I look at it over and over again and that shot helps me believe that the wonderful experience I had that day really happened!

When the time of my appointment came, I had to leave the two of them and it was Kim that brought me to the office of Dr. Greenberg.

While I was surprised to see that patients, as soon as they arrive, have to take a number (it made me feel like I was in a butcher shop in my hometown in Italy!), I then understood that it is done to protect the privacy of the patients themselves by not naming them at all in front of the many people present.

I did the same, and I had to wait for my number to be called to be able to go and register.

Not long after that, with Kim at his side, I saw Dr. Greenberg and I thought that, while it is a cold thing to be called by a number, it is a very nice touch to have the doctor himself coming and welcoming me to the office.

While I didn't have a good night at all the night before, from that morning on, I didn't feel anything else but happiness and when I saw him, I couldn't feel anything else but more happiness!

I just felt that I had to be myself and I exclaimed: "I know that I have pain, but I really don't feel it at this point because I am very happy to be here!"

He smiled and I knew that the ice was broken.

With calm, expertise, kindness and understanding, Benjamin Greenberg knew exactly what to say to make me feel comfortable.

For 2 hours, he dedicated all of his attention to me, looking right into my eyes for the whole length of time and by adding some few little jokes here and there, just to make me smile.

He talked the same way I learned to love in the many speeches that I am able to see thanks to the podcasts, with the same warm and kind voice and with the same simple way of explaining things.

I was able to ask him lots of questions and he answered them with knowledge and with patience.

I almost knew the next words that he was going to say and that made me realize I might have watched the podcasts a little too much! but that also showed me that my work and my research was very well worth it.

I knew what I was about to hear.

I knew what my options were going to be, but no, I didn't expect that one of the latest and quite dangerous therapies, would have been suggested to me.

While I knew that Tysabri (one of the latest medicines in the MS world that was taken off and then put back on the market, but that still is quite scary to me and that is still possibly not safe) I never would have thought that he was ready to share part of an experiment that I had read and heard about already and that requires killing the complete immune system to recreate one that would be new and that would have hopefully "forgotten" it was sick with Multiple Sclerosis.

We talked about Tysabri, chemotherapy and preparing myself to make a change at the first sign of a new lesion in my brain.

I saw once again the huge lesion that I saw not long ago, the one that caused me this latest attack and that seems to be unusual this early in the disease.

I am a tough case of MS and I knew it from the beginning.

I read too much, I studied too much, I heard too much for me not to know that I wasn't a "normal" case and that I wasn't going to experience the full extent of a disease like this one.

I had prepared myself quite well but, even after listening to all of the news, I just couldn't stop thinking about how this experience was going and I was able to smile anyway, to look at Greenberg straight in his eyes anyway and to feel very lucky... anyway.

After the 2 hours passed, I kept on smiling and I did it even more after I asked if I could take a picture with him before leaving.

The way he answered to that will stay with me for a while.

He just smiled with his big and sunny smile and he posed with me for the photo.

He asked me to send it to him and so I did.

I also wrote to him and he was so sweet to answer me only a few hours later and to joke in response to the ones I had made.

While I told him that he had a great big smile (and how it's not fair that men are always fotogenic in pictures) I admitted I looked sick but, because I am really sick, that that was ok!

He answered by saying that he hopes to be thinner at the time of our next picture!

He was very kind in the e-mail too and he offered to help and to check my next MRI.

The next one will probably be done in the month of November.

If it will present new lesions, meaning that the medicine that I am taking now is not working, like the two previous ones, I will have to make a very serious decision and make another step toward slowing down the progression of my MS.

If it will not present any changes, I will continue to take the European medicine and to monitor my brain activity.

While telling all of the people that I met that day that my "famous" thank you cards were already in the mail, I wrote an e-mail to all of them, just to tell them how much I appreciate them taking the time to meet me.

They answered me in a matter of hours and that, also, had the power to make me feel even happier.

As you see, I didn't talk about my medical situation in the beginning of my story because it is not what my experience has been all about.

It's really not.

While I am concerned and worried, this is not what I have learned, this is not what I am about and I didn't want to simply tell you about my medical situation without understanding that this is the way I am and that this is just another lesson of life that has been given to me.

I don't know what's going to happen to me tomorrow or next week, just as all of us don't really know.

I do live every day like it is a gift and not just another, simple day.

I just learned to realize that what is important in all of this are the people I meet and that I have met and that, now, are part of my life.

People that gave me so much to dream about and that allow me to be happy every day, even while having to deal with MS.

People that, without MS, I would have never have been able to meet.

The pain I feel is only physical, but it doesn't own me and it doesn't own who I am, just like MS doesn't.

I am still the same person I was before "it" came into my life and I won't change just because it is a part of it.

The visit to Johns Hopkins was just one of the amazing experiences that I have been blessed to have in this country and in of the many places that I have visited throughout my life.

I won't forget all of them just because I am sick, just like I won't stop believing that I have been lucky, that I have been blessed and that I have been able to learn how to make myself happy with those famous little things that most people forget to look at.

This is all about my visit to Johns Hopkins.

It was an experience that was added to the many I have been lucky enough to have.

Thank you all for being a part of this.

Love

Angela