

MY EXPERIENCE AT KENNEDY KRIEGER

November 17th, 2008

Dear Friends,

I keep on adding special experiences to the many that I have had during these past two years.

I mentioned it many times before: I feel it's up to me to see and to find the good things in life and I am grateful to be able to do so.

Having another relapse in the month of July of this year, having to take a whole lot of steroids and having to do plasma exchange once more, having to experience the worst head and body pain possible, not being able to spend fun time with my best friend Deborah and give her another wonderful vacation in this country, weren't good things at all and sure, I could have concentrated on all of this if I had wanted to and if I thought I could get something good out of it, but I didn't.

Sure, I could have gotten myself down and felt depressed or I could have let the worries overwhelm me, but I decided to take a different approach in dealing with what happened to me and I decided to see only the good that came out of the experience.

*And this "good" was being able to receive the right help at the **International Center for Spinal Cord Injury at the Kennedy Krieger Institute** in Baltimore.*

Two steps away from Johns Hopkins hospital and from the outpatient building where I go to see Dr. Greenberg, this center was opened only 2 years ago and it accepts patients with spinal cord injury and people with neurological disorders like MS and TM.

After lots of research and after learning about it during the 2006 rare neurological disorder symposium watched online not long after being diagnosed with the disease, I asked Dr. Greenberg to be sent to the center so I could receive the rehabilitation needed to get back to normal as much as possible after the relapse.

Knowing the center very well and admiring the people that worked in it, Dr. Greenberg felt very comfortable in sending me to it and he believed that I would have loved the experience because he knew that I would have been surrounded not only by people that cared, but by individuals that want to make a difference and that believe in the power of exercise just as much as I do.

After the high amount of steroids I had to take and the plasma exchange I had to do to stop the inflammation in my brain, having to exercise and work hard to get my mobility back without using medicine, was really what I needed!

The center is at the second floor of the Kennedy Krieger building and it's quite small. The gym area is not very big at all but the one at the Fairmount location is much bigger and it has a lot more room.

In March of 2009 the center will move to its new location, a big building still under construction few steps away from the original one and where 6 floors will be dedicated to spinal cord injury and to diseases similar to mine.

While the new place will have lots of space, a huge gym, brand new equipment and a big pool, the one that I was able to use wasn't too welcoming itself, but it had the kindest and the brightest smiling people you could find...and this was what mattered the most to me anyway!

The rehabilitation that was prescribed for me consisted in a 2 week intensive exercise program that would include 3 hours of physical therapy and an hour of occupational therapy each day and that would see me involved in many different kinds of exercise. The first week I got to work with 4 different physical therapists that concentrated their attention to my walking and to rebuilding strength in many different parts of my body. From my weak ankle and knee to my abdominals, from my arms and thighs to my fingers and hands, I was able to take the time to concentrate on strengthening myself in the best way possible!

The first week, with the help and guidance of Cara, Mike, Rachel and Scott, I was pushed quite hard and I worked intensely surprising myself with the amount of strength, determination and persistence I had inside of me!

I was pumped up by the environment, by the physical therapists and by the patients present around me that were working just as hard!

Everyone would smile and chat with the other and I got to meet very interesting and very inspiring people that were coming from all walks of life.

During the first week, I also found out what electrical stimulation is and how it can help an individual that presents problems in moving or that can't walk any more.

While it didn't hurt me, I started feeling extra shocks even when the machine was off and after 5 days of that, I brought up my problem to the attention of one of my therapists and we decided to exercise without it from that moment on.

After the 3 hours of physical work, I would go to have lunch at the cafeteria inside Johns Hopkins Hospital and, to get there from the center, Keith and I had to take an underground passage.

Eating at the cafeteria was a pretty neat experience in itself.

I got to see Dr. Carlo Pardos, a neurologist that works with Dr. Greenberg and with many others at the MS center and I got to be surrounded by all sorts of doctors, nurses, family members and patients.

Everyone had a different story to tell and everyone was there for different reasons but I felt a common sense of hope all around us.

With my simple turkey Subway sandwich and my always present bottle of water, I would sit at a table, share my daily experience with Keith and I would look around and feel like I was part of a different world: a world where I could almost touch the sense of strength and hope that was surrounding us.

After my lunch, I would have my last hour of therapy that focused on daily life activities.

Mike, the occupational therapist I met while I was going through my relapse and that took care of my case during my first evaluation, worked with me for the entire two weeks, he taught me a lot and he was a pure pleasure to talk to because he is someone very caring, very personable and friendly.

He had many suggestions, many ideas and he had a real picture of my disease and of the many aspects of what it means to have to deal with it.

During our first meeting, he had asked me to bring him a journal where I would record my days with MS, and since that was something that I started doing from the very beginning and that came natural for me to do, I brought him a copy and I gave it to him.

He read it and paid attention to one symptom in particular that I was experiencing at the moment and he let me know that he wanted to help.

In the last couple of weeks prior to going to the center, I had started feeling something along the esophagus, something strange that would not allow me to swallow without feeling something "stuck" along the way.

I never had problems swallowing in the real sense of the word, but I felt that something was wrong and that this new symptom could be the first sign of a coming relapse.

On the last day of my rehabilitation at the center after Mike scheduled an appointment for me, I was able to go back to Johns Hopkins and have a test done to check my swallowing.

In the presence of many different people that were checking the screen with curiosity and interest, I was able to find out that I was having spasm along the esophagus and that, right after the swallowing process, my throat would react to the spasm and I would feel that strange "something" that I mentioned before.

I had to eat some of the food that I had brought with me and to which was added some barium, a paste that allows you to see things on x-rays and that, while is not a gourmet item, it actually doesn't taste too horribly and didn't represent a problem for me at all! The machine was pretty cool and the test didn't take a long time and it was interesting to hear the doctor talking and explaining what was happening right after every bite was swallowed.

Learning about what was going on with me and my esophagus, made me feel much better. I knew it wasn't a great thing but I also realized that the spasms didn't really change the swallowing process at the moment and that, while there is a medicine that can help the situation (some sodium channel blocker) I didn't have to take it if I was able to live with the symptom.

I was able to live with it, so I didn't have to take the medication and that made me quite glad.

I appreciated Mike's attention to detail and I am very thankful for his help and for listening to everything I said to him during our many conversations.

I had noticed from the first moment spent at the center that the people there REALLY LISTENED.

Wherever you say will mean a lot to someone working at the center and your request will be listened to in every possible way.

I would have a simple conversation with one of the therapists and, in matter of minutes or in a matter of a day, I would receive an answer to a question or I would actually have my little dreams come true.

While during the week, I worked with many different therapists, the second week I spent all of my time with Mike and Cara, a very special, gentle and thoughtful woman that cared a lot about everything I said.

One of the first things that Cara learned about me was the fact that I wasn't used to taking medicine and that I believed in natural ways to heal our bodies.

I told her about believing in exercise and not as much in pills and I shared with her my love of the gentle movements of Yoga.

The day after me saying this, I started my first lesson in Tai Chi!

I have no idea how she picked up on the fact that I wanted to learn about Tai Chi for quite some time and I was very touched by her willingness to listen to me and to allow me to do something I cared so much about.

Without even knowing the extent of how much that meant to me, Cara cared enough about my words by taking them seriously and by taking my "natural" interests into consideration.

The best example of the special care that she gave me is to tell you about a conversation that I had with her in the beginning of our therapy.

During one of our many conversations, I had mentioned my desire to do Yoga outside and how I had talked about it with my Yoga teacher during one of the many free classes that the MS Society offers in my area.

I had told her of my desire to do something as special as Yoga outside in the sun, in the fresh air, surrounded by nature...and the day after mentioning this, I found myself following her all the way outside, to a spacious green area between the many buildings of Johns Hopkins...ready to do Tai Chi!

I was almost speechless!

Well, actually, I don't think I had any problem in telling her what I felt and I didn't have trouble in showing her how much that meant to me!

She listened so much and so well and cared about what I was feeling and what my goals and my dreams were.

Enough to figure out a way to bring me outside after looking all over for the right area that would permit us to do Tai Chi in the sun!

Talk about helping the mood of someone with a chronic disease and that is just coming out of another MS relapse!!!!!!

This made me happy!

Finding myself outside, in the warm sun of an October autumn day, raising my arms to the sky just like I had hoped for so long since being diagnosed with this disease, made me happy!

Following her gentle moves, looking at the flowers that we had on our side and admiring the blue and shining sky, made me happy.

I had no worries any more.

I had no feeling of being sorry for myself. I wasn't wondering what my future with MS would be like.

I was there and that was my moment.

I was outside, in the middle of Johns Hopkins Institution, doing Tai Chi: what more could I ever wanted or asked for?

These are the moments that each one of us would and could take in different ways: this is the way I took it and I will always store it in my heart because it represents something special.

I found the right place for me, once again, and yes, it is in Baltimore.

I found Johns Hopkins and I found Kennedy Krieger and I know that, in both places, I will always be in good hands.

I also found someone that truly listens and that is not afraid to care for others, someone that is warm inside and that has no problems in showing it.

The whole experience at the International Center for Spinal Cord Injury at Kennedy Krieger has given me a type of hope that no other place could have given me.

Seeing the people that, in their wheel chairs, were able to move, straighten their bodies and work hard to better their lives, brought me to believe that, even with MS, exercise can make a difference and can help me fight against the unpredictable moves that this disease will make in my future.

I know that I can count on the most compassionate people, on the better trained physicians and I know that I can be empowered to always do my very best!

...Soon, I will talk about meeting the people that I so admire...

Until next time, please take care,

Love

Angela

