

I met another hero and a wonderful human being...My appointment with Dr. Byung Boong Lee, June 24th 2010

Yesterday I made another small step in the long journey toward the Liberation procedure.

I am often asked why I haven't yet jumped on a plane and gone to many of the countries that offer this type of operation and I can share my thoughts and my opinions with you all, hoping that you will be as understanding and as supportive as I have been to all of you.

I will say again what I have said many times in my videos: we are all different people, with different backgrounds, different ideas, beliefs and different MS courses. While I completely understand why other patients have decided to go somewhere else to be liberated, I am taking a different route for my journey. Many Italian friends have asked my opinion and they have asked me what I thought of theirs: they have accepted mine and I have accepted theirs. I believe that, if we don't support each other with any of the decisions that we take, we are really not helping.

I believe in sharing thoughts and experiences and I like accepting other people's opinions and support them to the best of my ability. I have many Italian friends that went to Poland and I was there to support them and cherish their improvements. And I will do so in the future. But, at the moment, that is not the right journey for me. I am a different person and I am a different patient. I need to create a relationship with my doctor and I would like him to be local or back in my homeland. My dream is to be Liberated in the United States or in Italy. I can never promise anything about how my future will be and knowing very well how the course of my MS is and how things change very quickly for me, I can't be certain that I won't change my mind or that I won't see a need to go somewhere else. At the moment, and knowing the person I am, I prefer to stay local (and Italy is local for me!) and I prefer to follow the footsteps of my heroes.

Yesterday, June 24th, I got to meet another one of the people that I admire and that I have grown to know. Before going forward with my story, I would like to thank Judy (donotconcede on YouTube) for supporting me with this and for sharing her journey with me. I have decided to follow her footsteps because I completely agree with her and with the decisions she made and I approve and appreciate her suggestions as a friend and not only as a wonderful CCSVI supporter.

Yesterday I went to a town in Virginia where I was able to meet Dr. Lee, a world renown vascular surgeon that has a 40 year successful career and he is the President of the World Consensus Conference for vascular surgeons. He was sitting next to Dr. Zamboni at the conference in Montecarlo on September 4th 2009 and he believes that CCSVI is a congenital disease. Some of you might recall that September 4th was the day when experts from 47 countries unanimously voted in favour of officially including the stenosing lesions found in CCSVI in the new Consensus document.

That was a really big day for Dr. Zamboni and his team because his discovery was accepted by the entire vascular world!

Dr. Lee worked for Johns Hopkins for many years and now he spends his time as a consultant for Georgetown and as a humanitarian doing work around the world. He is 71 years old and he loves what he does and he does it FOR LOVE and NOT for money. His interest in CCSVI is very important. He is working with Dr. Zamboni and he believes in his discovery and in his work.

He is writing a new book and he told me that Dr. Zamboni sent him an article to add to it just a few days ago. They are often in contact and Dr. Lee loves my country and has been to Trieste, the town next to mine, and to Slovenia which is only a few steps (literally!) away from some parts of my hometown.

After meeting Cecilia, the very nice woman that Judy told me about and that welcomed me to the office with a huge friendly smile, I finally got to meet Dr. Lee.

I had slept only 4 hours and I was expected to be exhausted but I wasn't...I was happy to be there and I was able to put pains and symptoms aside and to have a wonderful appointment!

He was quite impressed by my organizing skills.

I sent him my medical records color coded by relapse, I had made a time line for my MS history and my search, from the very beginning of my disease, to the vascular connection.

I was able to prove to him that my vascular theory was present from the moment I found out I had MS and I spent 10 days thinking in the hospital bed...He was really nice when he complimented me for speaking English better than he does (he is quite funny!) and he was very kind and understanding.

He told me about his work and how he does things because he believes in them and not for any other reason. He explained something that I never heard a doctor do before: he admitted that he didn't know something and what touched me the most was when he told me that it was very hard for him to say...but that he does it anyway because he understands it's important to admit something that he didn't think of in the course of his career. He said that he never thought about checking the veins, that all of his attention was on the arteries and the pathologies that present problems with them.

He then asked me about Hopkins and if I was aware of their opinion about CCSVI.

I assured him that I am more than aware about the fact that every neurologist at Hopkins is completely against Dr. Zamboni's discovery. He knew that my neurologist is Dr. Peter Calabresi and I told him that I go back to Hopkins to take Tysabri every 28 days and that I have been pushing for a study to be started over there but that didn't really change anything.

I was told over and over that they don't believe CCSVI has anything to do with MS and that it's a waste of time and money to study it. While in the past few months I was told that a study was going to be possible, now I can tell you that no CCSVI study will be done at Johns Hopkins.

Doctors asked him for an opinion but, unfortunately, that didn't change their mind.

We spoke about Dr. Zamboni and how I got to meet him. He told me something that I make a point to share with others constantly...He explained how surgeons shouldn't use stents and how he is against them until they are studied more and better.

About me, after the visit that allowed him to see the outside appearance of my veins, he told me that there is a need for me to get another ultrasound (the first one showed that I have some drainage problems on the left side of the back of my neck while my jugular veins are open and healthy) and the need to check the azygos vein.

He offered to send me all the way to California to have me do an MRV because he described himself as very particular about where the tests are performed.

He wants the best tool and the best doctor ever and he would want me to go to Dr. Dake to have this test done in the future.

He repeated the importance of repeating the ultrasound overtime in case we find nothing wrong with my veins this time.

My ultrasound test is scheduled for the 12th of July, two days before my 19th Tysabri infusion that, as you already know, I do at Johns Hopkins.

Next month, I will spend many days in Virginia, in Washington DC and in Baltimore.

Thank you all for sharing my experience with me.

Take good care and have a nice weekend.

Hugs to all,

Angela