

Up Close and Personal with CCSVI

Ashton Embry, September 03, 2010

My work on MS over the last year has been almost entirely dedicated to finding out as much as possible about CCSVI. We now have enough solid data to say most people with MS have impaired venous drainage and that this problem is an important part of the MS disease process. Furthermore, it is becoming indisputable that the treatment of CCSVI is helping many people with MS to recover various functions and to be relieved of numbing fatigue and brain fog. In fact, some of the recoveries are nothing short of spectacular.

My son has faithfully followed nutritional strategies (Best Bet Diet) for the past 15 years and he has remained in very good health with no MS symptoms. When it became apparent that CCSVI was an important part of the MS disease process, I naturally wondered if my son had impaired venous drainage and whether or not it was causing subtle damage which would one day result in serious clinical problems.

We discussed the question of having him tested and possibly treated for CCSVI in February and, at that time, Dr Simka's clinic in Poland was about the only option. Given his lack of symptoms and the long wait period (2011) at the Polish clinic, we thought we would wait until other options were also available.

Not long afterwards, my son started reading various internet accounts of CCSVI. I can still remember the day he told me that he had various subtle symptoms that were being commonly ascribed to impaired venous drainage. These included very restless sleep, feeling lousy and somewhat listless in the mornings, bouts of severe depression, pressure behind his eyes, explosive nose bleeds, and not feeling well until he had a long hard run and two or more cups of coffee. This was the first time I thought we might want to act sooner than later.

In May, my son had a Doppler scan at a Canadian clinic and that showed some "turbulence" in his right jugular. On the basis of this result and his potentially CCSVI-related symptoms, we decided to

make plans to get a proper evaluation and possible treatment at a clinic. By good fortune we were able to get a booking at Dr Simka's clinic in mid-August due to a number of cancellations.

On Monday, August 9th, my son, wife and I arrived in Katowice, Poland and checked into the Qubus Hotel. There have been a number of published accounts of CCSVI visits to Katowice and our experiences were very similar. One thing I might mention is that, before he had the procedure, eye and neurological exams revealed no neurological deficits. We explained to the neurologist we were there for preventive purposes.

Wednesday morning was the big day when we and five other families went to the hospital for the Doppler exam and the following venography and angioplasty. Soon after everyone was settled, Dr Simka arrived with his portable Doppler machine and he quickly determined that my son's left jugular was completely blocked (no flow) and that the right one was partially blocked.

My wife and I were rather shocked at the severity of his CCSVI and all my son said was "I told you so". We discussed the possible use of stents for the left jugular, and my son decided he didn't want one at this time and we concurred with this decision. Soon afterwards, the first patient walked into the operating theatre and was wheeled out an hour later. We were then told it was my son's turn and in a flash he disappeared into the procedure room. The next, very long, 45 minutes were extremely tense and we passed the time by chatting nervously with the other patients and their partners.

As we were chatting, Dr Simka and his partner, Dr Ludyga, suddenly emerged from the treatment room and said everything went extremely well and that they were able to balloon open both jugulars and restore normal flow. I'll never forget the tremendous feeling of relief and happiness that swept over my wife and me. They then showed us videos of the venography before, during and after angioplasty and CCSVI became a very real phenomenon for us. By the time the show was over, our son was back in his bed and was feeling good enough to have me take his picture that he then started sending out on his iPhone.

The other four patients were treated and, by early evening, the doctors were gone and we were all looking at each others' venography videos on a laptop. All six patients had notable blockages, mainly in the jugular veins but two in the azygos. Four people needed stents with my son and one other needing only angioplasty.

My son felt better almost immediately after the procedure and now three weeks later cannot believe how great he feels. Instead of restless sleep, he sleeps soundly for 7-8 hours and, for the first time, is experiencing long dreams. His morning fatigue is completely gone and he is down to one cup of coffee a day. The pressure behind his eyes has totally disappeared and he says it feels like his eyes might fall out of his head. My son went to Poland for preventive reasons and ended up with some noticeable health improvements as a wonderful bonus.

Of the other five patients treated the same day as my son, only one had a dramatic improvement. He regained his abilities to walk normally, to see better, to be able to balance on one leg, and to type once again at a fast speed. Seeing his improvements was quite amazing and left no doubt as to the benefits CCSVI treatment can potentially bring. The other four only had moderate to minor improvements but all were very glad they had it done.

I learned a few things from this personal experience with CCSVI treatment. My son's nutritional strategies clearly did not do much, if anything, for his CCSVI, but nutrition was able to offset any MS problems despite the presence of significant CCSVI. This alone shows how important it is to use nutritional strategies if one has MS. I also learned that CCSVI causes general problems like fatigue and depression which are common in many people besides those with MS. This certainly raises the question of how many people in the "healthy" population have CCSVI that would be best treated.

I learned that venous angioplasty is a very safe procedure and all the fear-mongering being done by neurologists regarding the dangers of such a procedure has no substance whatsoever. I also learned that almost everyone with MS has CCSVI given that 97% of the 600+ patients treated at Dr Simka's clinic had obvious blockages as seen on venography.

I have also learned that a negative Doppler test does not mean much and my son's results from his Doppler exam done in Canada were not accurate. Furthermore, one of the 5 people treated with my son had a negative Doppler but major blockages were evident on venography. Ironically that patient was the one with greatest positive results after treatment.

In summary, I can say that it is essential for anyone with MS to have their venous drainage checked by venography and treated as required. The gains from such a treatment will greatly vary from patient to patient but there is no doubt everyone will benefit from having proper blood flow from their brains.