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Kerri Cassidy for CCSVI Australia, Wednesday, June 27, 2012 at 12:37pm

The Internet is posing a difficult challenge to many areas of life. The Health services are not immune. With the rise of social networking a new dynamic has been introduced where people with Multiple Sclerosis can communicate and compare notes.

What I believe we are seeing through online networks such as You Tube, Facebook and This Is MS is an extensive data base of research where individuals from across the globe contribute their real life experience. Patients can now access the same medical journals and publications as their doctors and often have more time to comb through the treasure trove of literature on any given MS topic.

Values have shifted from viewing the Neurologist as the only source of assistance, to them being one expert out of many consultants on which to base health care decisions. I believe organisations such as MS Australia and Neurologists face the possibility of becoming increasingly irrelevant if they cannot understand the impact of open information in the hands of the people they are mandated to care for. I have been privileged to participate in a Warwick University study into how the sharing of patient experiences and treatment on the internet affects policy, medical practice and patient decision making. The focus of the study is on people with Multiple Sclerosis with the issue of CCSVI providing a clear case in point. Such studies may shed some light on how to tackle this issue more effectively in Australia.

With that as background, it is not surprising that when Paolo Zamboni's theory of CCSVI surfaced in November 2009 that news spread amongst online communities like wildfire. His research suggested that people with MS had impaired blood flow in their brain and spinal cord, primarily caused by blockages in the major veins such as the jugular and azygos veins. The impact of blocked veins on MS was largely unknown but it seemed reasonable to many of us online that should we have impaired venous drainage treating these veins may relieve some symptoms.

Immediately we began to contact our Neurologists for advice and found that they knew very little or were unwilling to discuss this new idea. Being notoriously conservative they upheld the importance of long term clinical trials before recommending treatment of any sort. This of course sounds entirely reasonable, however, at a personal level, I knew I did not require years of research to find out if my own jugulars were blocked.

Returning to my network of trusted online friends I found I could have a cheap, non-invasive ultrasound test to indicate whether I had CCSVI. My GP was great, agreed it was a reasonable course of action and provided a referral. He told me the story of Marshall and Warren and how their research into stomach ulcers was ridiculed for years before it was finally accepted and a Nobel prize granted and this may well be a similar story.

February 2010 an ultrasound indicated that both my internal jugular veins were stenosed, the valves were malformed and I had reversal of blood flow. Simply stated, there was dirty blood being redirected back to my brain. The obvious question was "what damage is this doing?" I needed good advice. The head cardiovascular and interventional radiologist at the Alfred Hospital reviewed my ultrasound and advised that an appropriate method to relieve the narrowing was balloon angioplasty. Angioplasty has been performed for 30 years in Australian hospitals on people with conditions from varicose veins to heart problems. It is a relatively safe procedure with only a local anaesthetic. The professor showed me scans of jugular veins that he had treated in the past with successful outcomes.

When you have MS, every day is dangerous. Tomorrow you could lose your vision, your legs or your bowel function. Many of us are on immune modulating therapies that leave us open to infections and cancers, have nasty side effects and compromise the kidneys and liver. The MS drug I was on has caused a serious brain infection in 242 pwMS, 52 of those people have died. Despite treatment I was still relapsing every 2-3 months. My vision blurred, I could not walk further than 300m, I had chronic fatigue, my hands were weak and uncoordinated, my body jerked uncontrollably. My neurologist compassionately said "Kerri your MS is too active, your prognosis is not good." He indicated that disease modifying drug I was on didn't appear to be helping and all he could really offer me were drugs to manage symptoms.

In January 2010 I suffered another MS attack, I lost ability to urinate and required a catheter: a fearful and undignified experience for a 34 year old woman; a wife, a mother, a business owner, an employer, a volunteer in my local community. That month I closed my Accounting business and succumbed to this disease. This was not me, not who I wanted to be.

When you are suffering, taking dangerous medicine and face a future of decline you want to know if unblocking the main blood drainage pathways of the brain, the brain that causes all your suffering, could possibly help. A relatively cheap and low risk procedure... Why wouldn't you? Why wouldn't you?

In March 2010 I had balloon angioplasty. It took less than one hour, only a local anaesthetic was administered and I was released from hospital three hours later. This picture of a balloon being inflated in my left jugular clearly shows the narrowing in the superhighway of blood flow from brain to heart.

I am no longer on disease modifying or symptom management drugs, I have not relapsed in two and a half years, my mobility is excellent - I regularly walk 5 kilometres, I have no bladder problems, my body does not jerk and I am a contributing member to society once again. The year before treatment I estimate I cost the taxpayer \$60,000, the last year I have cost the taxpayer one MRI. My story is not unique.

57 research papers on CCSVI have been published and more are underway. It is estimated 30,000 people have now been treated worldwide - 400 in Australia. QoL surveys completed by one treating Australian doctor are showing an average 54% increase in quality of life.

In 2010 the Alfred Hospital treated 50 people with MS with angioplasty. The results were so compelling that a clinical trial was submitted and finally approved in April this year. Within 2 days of being announced 250 pwMS had registered. We have raised \$88,000 to date for the Alfred Hospital trial. We value this research – please hear us.

Why has this issue become political?

Because people with MS are being refused help. There are significant barriers in place that deny access to testing and treatment IF you have MS.

Firstly, Neurologists have moved to classify this as an unproven treatment for MS thereby pushing it out of the realm of Vascular specialists and existing standards of vascular care.

As a result Angioplasty that is available to any Australian who has blocked veins, even blocked jugular veins, is not readily available to pwMS. Nor is it available on Medicare, the scheduled fee being around \$1200, less than a month's treatment of my previous MS drug. There is limited treatment privately costing people up to \$3,500. This cost puts the treatment out of reach for most people with MS.

Due to the negativity of hospital neurologists generally, vascular doctors are under pressure from their employers not to treat people with MS, some are laying low watching the research.

The final barrier is misinformation being communicated to people with MS such as angioplasty is a high risk procedure or that treatment is simply not available at all in Australia. Misinformation can be more dangerous than no information. Black markets have sprung up across the world offering CCSVI treatment. Advertising for Medical tourism flashes in the side bar of our Facebook pages every day. Australians, despairing as they cannot get accurate information and support at home, are looking at places like India or central America for a procedure that could be available in their local hospital by the very best doctors.

A Youtube Infomercial for a CCSVI Clinic in Mexico appeared online just last week featuring an Australian with MS. Clearly this is aimed at generating more business from Australia – an alarming reality.

There are hundreds of people living with MS who are being refused vascular care and they feel utterly powerless.

It is this lack of information and support that led to the formation of CCSVI Australia. We are a group of people who have CCSVI and Multiple Sclerosis or care for someone who does. Our core team has 40 volunteers and our wider facebook group is greater than 2300. Our main focus is to raise awareness of vascular abnormalities in Multiple Sclerosis. We collaborate with similar groups in other countries including Canada, the US and UK. We provide information from a variety of sources including published research, medical opinion and patient experience both the positive and the negative. We direct people to places of ultrasound testing and treatment in Australia and have assisted around 400 Australians restore blood flow to their brains and spinal cords. Finally we provide a safe open forum for questions, concerns and opinions so that every person has a voice.

This issue needs to be resolved for the 21,000 + Australians living with MS. It has now been over two years since the first Australians were treated.

We need your help.

Firstly, to uphold the right of any person to seek the opinion of a Vascular Specialist of their choice and, should treatment for vein irregularities be recommended, that it be available under the current Medicare provision Balloon Angioplasty. We ask that questions be raised to the public hospitals of their treatment of pwMS in relation to vascular issues. The discrimination must stop.

Secondly, that research money be made available for quality independent research of CCSVI in MS to contribute to the world effort, increasing understanding of the impact of vascular abnormalities on the brain and spinal cord and the development of best practise to treat them. This will require collaboration between Neurology and Vascular doctors with appreciation for their expertise in their respective fields.

We don't yet know if CCSVI causes MS, it is possible and we need to find out.

I will finish with a video of a well respected heart surgeon living with Multiple Sclerosis and was treated for CCSVI in 2007. Gianfranco Campalani. (MS Wars video 17:32 – 19:12)

I honestly don't know why I need to be here. Jugular flow is imperative to life. It should not be obstructed, not by vascular abnormalities, and certainly not by bureaucracy and medical dogma.