

## Your questions answered

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STATEMENT BY MS AUSTRALIA – ACT/NSW/VIC  
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There has been a lot of media attention and hype surrounding CCSVI as a possible cause, with a subsequent treatment (or cure), for MS. This statement reveals the latest facts about CCSVI and MS.

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### What is CCSVI?

CCSVI stands for 'chronic cerebrospinal venous insufficiency'. It describes a situation where there is reduced blood flow from the brain and spinal cord over a prolonged period of time.

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### Why is it relevant to MS?

The concepts surrounding CCSVI and MS are based on a small study conducted last year by Italian doctor Paolo Zamboni and his team. Using ultrasound technology, the investigators examined cerebral venous drainage (blood flow from the brain and spinal cord) in 65 people with MS, compared with 235 people who were healthy or who had other neurological disorders.

The results showed a strong correlation between having MS and signs of venous insufficiency (reduced blood flow). The investigators called this 'chronic cerebrospinal venous insufficiency' (CCSVI) and suggested that the reduced blood flow from the brain and spinal cord may trigger the inflammation that is known to cause damage in the central nervous system of people with MS.

A further study from the same group in Italy looked at the effects of draining the excess blood from the brain. As part of the study, the 65 people with MS (who had all presented with 'blockages' in the initial study) underwent angioplasty – an invasive technique that widens obstructed or narrow blood vessels using a small balloon at the end of a catheter.

Following the surgery, the group reported some positive results, including a reduction in new lesions. However, in 47 percent of participants, the internal jugular veins returned to having restricted blood flow.

Similar research is also underway internationally. For example, in February this year, the University of Buffalo Medical Center in New York issued a press release describing preliminary results from an ongoing study led by Dr Robert Zivadinov into the prevalence of venous obstruction in people with MS. Dr Zivadinov presented data on the first 500 participants in this study, 289 of whom had MS. Results were less dramatic, with ultrasounds revealing blockages in 62 percent of people with MS, 26 percent of healthy participants, and 45 percent of people with other neurological disorders. ▶

## Can treatment for CCSVI cure MS?

The research to date has had many limitations and is not yet complete. The concepts surrounding CCSVI (including the effectiveness of treatments) are still relatively new and need to be validated by large-scale clinical trials before they can be established.

To date, two treatments have been used for people with MS who have been found to have CCSVI. The first was catheterisation of the blocked veins (the insertion of a small tube to open the vein, as used in Dr Zamboni's study) and more recently by stenting the blocked veins (the insertion of a small valve into the blocked area of the vein).

While both of these surgical techniques are commonly used in heart surgery, the effectiveness and level of benefit versus the risk is yet to be established for treating MS. For example, while the people treated by Dr Zamboni's team did experience some improvement in their MS, there are a number of factors which make it difficult to know what this means.

It is known that in almost half of the people treated, the blockage re-formed. We also only know the effects after 18 months of participants having the treatment (i.e. we do not know the long-term effects).

In April this year, MS Research Australia (MSRA) released this statement: "While the early data is interesting, the proposed mechanism is highly speculative. The main limitations are that the study is done on a small number of people and on those who already have clinical MS. It is, therefore, not possible to distinguish whether the venous obstructions are the cause of MS or are part of the physiological changes in the central nervous venous system resulting from MS".

There are also well documented patterns among people with MS, such as the reduction of inflammatory activity in people over 50 or the geographic distribution of MS, which does not appear to fit with CCSVI as the primary cause of MS. If it is to be scientifically established that CCSVI causes MS, these and other well documented factors would need to be explained in a way that is consistent with Dr Zamboni's theory.

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## If the treatment for CCSVI cannot cure MS, can it treat MS?

Treating CCSVI may lead to improvements for people with MS, but the information to date does not prove this. The study reported by Dr Zamboni and his team only included 65 people with MS. While it is documented that on average the group treated for CCSVI experienced improvement in physical and psychological measures of their health, the treatment was more effective for the people with relapsing/remitting MS.

It's also worth noting that all people with relapsing/remitting MS who were treated for CCSVI continued to take their immunotherapy medications, which are well documented as producing the types of improvement seen in this study. Before it can be established that treatment for CCSVI is an effective treatment for MS, there needs to be more extensive research demonstrating more significant results. ▶

## If there is a chance that treatment for CCSVI could help, why not give it a try?

In addition to knowing whether a treatment is effective, it is also important to know whether it is safe. Because of the large number of people who experienced re-blockage after being treated by catheterisation, more recent treatments for CCSVI have used stents.

However, there are several uncommon but potentially fatal outcomes from inserting stents into veins. To date, one person with MS treated for CCSVI using this method has died, and one other needed emergency heart surgery. Treatments being performed were not part of a clinical trial and have since been halted.

The risk of serious negative outcomes does not necessarily mean that treatment should not be considered, but it is essential that the decision is looked at more carefully. In order to make an informed decision about treating CCSVI to improve MS, it is recommended that treatment should not be considered until properly conducted clinical trials have established the need.

Decisions about any treatment should also be done in careful consultation with your neurologist and healthcare team.

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## What is MS Australia's position on CCSVI?

With a complex disease like MS, it is important to consider all possibilities when searching for causes and treatments. Dr Zamboni's theory about CCSVI and MS is taking a new approach to MS research.

While existing data suggests that there may be a relationship between CCSVI and MS, there is not enough information to understand what the relationship is, or what it means for treating MS. Again, further research needs to be undertaken before establishing the need for treatment.

MS Australia, through its research arm MS Research Australia (MSRA), is contributing to the worldwide effort to gather this information.

In December 2009, a trial coordinated by Professor Bill Carroll, Scientific Advisor for MSRA and Chair of Research Committees for MS Australia, began in Perth. If successful, this trial will be expanded.

Due to the limited amount of information available about CCSVI and MS, and the potential dangers of being treated for CCSVI, it is strongly recommended that people with MS do not seek surgical treatment for CCSVI outside of controlled clinical trials. We will keep you updated as more information comes to light on CCSVI and MS.

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## Further information and reading on CCSVI

- **If you want to know more about the implications of CCSVI for your MS**, the best person to talk to is your neurologist.
- **If you would like to know more about CCSVI research**, please contact MS Research Australia on 1300 356 467, email [info@msra.org.au](mailto:info@msra.org.au) or visit the 'News' section of their website at [www.msra.org.au/news-media/news.php](http://www.msra.org.au/news-media/news.php)
- **The National MS Society (USA) website**, research section: [www.nationalmssociety.org/research](http://www.nationalmssociety.org/research)
- **The MS Society (UK) website**, news and events section: [www.mssociety.org.uk/](http://www.mssociety.org.uk/)
- **The MS Trust (UK)**, research news section: [www.mstrust.org.uk/research/news](http://www.mstrust.org.uk/research/news)
- **For all media enquiries**, please phone the media manager at MS Australia – ACT/NSW/VIC on (02) 9646 0600.

## Bibliography

- Ascheiro A, Munger KL. Environmental risk factors for multiple sclerosis. Part I: The role of infection. *Ann Neurol* 2007; 61:504-13.
- Ascheiro A, Munger KL. Environmental risk factors for multiple sclerosis. Part II: Noninfectious factors. *Ann Neurol* 2007; 61:504-13.
- Khan O, Filippi M, Freedman MS, Barkhof F, Dore-Duffy P, Lassmann H, Trapp B, Bar-Or A, Zak I, Siegel MJ, Lisak R. Chronic cerebrospinal insufficiency and multiple sclerosis. *Ann Neurol* 2010; 67(3):286-90.
- Multiple Sclerosis Research Australia (MSRA). Update on CCSVI and MS. Sydney: MSRA, December 2009.
- Samson, K. Experimental multiple sclerosis vascular shunting procedure halted at Stanford. *Ann Neurol* 2010; 67(1):A13-5.
- Singh AV, Zamboni P. Anomalous venous blood flow and iron deposition in multiple sclerosis. *J Cereb Blood Flow Metab* 2009; 29:1867-78.
- University of Buffalo. First blinded study of venous insufficiency prevalence in MS shows promising results. News release. Buffalo: University of Buffalo, February 2010.
- Zamboni P, Galeotti R, Menegatti E, Malagoni AM, Tacconi G, Dall'Ara S, Bartolomei I, Salvi F. Chronic cerebrospinal venous insufficiency in patients with multiple sclerosis. *J Neurol Neurosurg Psychiatry* 2009; 80:392-9.
- Zamboni P, Galeotti R, Menegatti E, Malagoni AM, Giancesini S, Bartolomei I, Mascoli F, Salvi F. A prospective open-label study of endovascular treatment of chronic cerebrospinal venous haemodynamics in the assessment of multiple sclerosis. *J Vasc Surg* 2009; 50:1348-58.
- Zamboni P, Menegatti E, Galeotti R, et al. The value of cerebral venous haemodynamics in the assessment of multiple sclerosis. *J Neurol Sci* 2009; 282:21-7.

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