



The Scottish Parliament  
Pàrlamaid na h-Alba

(For official use only)  
PUBLIC PETITION NO.

**PE1353**

<b>1. Name of petitioner</b>
Audrey Barnett
<b>2. Petition title</b>
CCSVI liberation treatment for MS
<b>3. Petition text</b>
Calling on the Scottish Parliament to urge the Scottish Government to carry out or encourage urgent research into Chronic Cerebrospinal Venous Insufficiency Liberation treatment for Multiple Sclerosis and make it available to sufferers as soon as possible.
<b>4. Action taken to resolve issues of concern before submitting the petition</b>
<p>People throughout the country have been trying to get doctors, MP's and the MS Society to take action through writing letters, e-mails and personal contact. Both the UK and Scottish Governments are taking advice from the MS Society and this advice is being passed on to the NHS.</p> <p>I have personally discussed CCSVI with my GP's and MS nurse but they are unable to do anything as the NHS is not yet recognising the treatment. I have written to a number of MPs in my area and others throughout the country have done the same. The response is pretty standard and is almost identical to the MS society's response: they are willing to give funding to anybody who will do the research. The Scottish Government Minister for Public Health, Shona Robinson MSP, sent a letter to Councillor John Finnie listing all the research the SCottish Government is doing and confirming that it is not looking into CCSVI.</p> <p><a href="http://www.ms-ccsvi-uk.org/home/open-letter-to-pm.html">www.ms-ccsvi-uk.org/home/open-letter-to-pm.html</a>: This link will take you to the CCSVI-UK website, it will show you the statement that the UK Government gave in response to the 10 Downing Street e-petition and CCSVI-UK's response to that. This statement from the UK Government is pretty much word for word the same as the response everybody who has written to their MP has received.</p> <p><a href="http://webarchive.nationalarchives.gov.uk/+http://www.number10.gov.uk/Page23057">http://webarchive.nationalarchives.gov.uk/+http://www.number10.gov.uk/Page23057</a> (UK government's response)</p>
<b>5. Petition background information</b>
<p>Chronic cerebrospinal venous insufficiency (CCSVI) is described as a chronic problem (ongoing) where blood from the brain and spine has trouble getting back to the heart.</p> <p>It is caused by a narrowing in the veins (stenosis) that drain the brain and the spine. Blood takes longer to return to the heart, and it can reflux back into the brain and spine or cause oedema and leakage of red blood cells and fluids into the tissues of the brain and spine.</p> <p>Blood that remains in the brain too long creates a delay in deoxygenated blood leaving the head ("<i>slowed perfusion</i>"). This can cause hypoxia, a lack of oxygen in the brain. Plasma and iron from blood deposited in the brain tissue can also be very damaging leading to iron</p>

along with other unwelcome cells crossing the crucial brain-blood barrier. ([www.msarc.co.uk/index.cfm?fuseaction=show&pageid=2944](http://www.msarc.co.uk/index.cfm?fuseaction=show&pageid=2944))

The blood deposits iron, which is toxic, in the brain causing lesions. The deformity can be easily treated using a balloon angioplasty and in many cases inserting a stent to keep the vein open and the blood flowing freely. This procedure has been carried out on many MS patients in many countries around the world and has produced amazing results. According to the Multiple Sclerosis Surgery website, CCSVI Treatment is available in countries such as France, Germany, India, Italy, Poland and USA ([www.multiplesclerosissurgery.com/where-tested-ccsvi.html](http://www.multiplesclerosissurgery.com/where-tested-ccsvi.html)).

Dr Tom Gilhooly talks about CCSVI and the LDN 2010 Conference  
([www.youtube.com/watch?v=auxeta2giw&feature=related](http://www.youtube.com/watch?v=auxeta2giw&feature=related))

Dr Zamboni in Italy discovered that in many cases MS patients have deformities in the jugular veins and it is these deformities which prevent the blood from flowing freely back to the heart.  
([http://neurologicalillness.suite101.com/article.cfm/dr\\_paulo\\_zamboni\\_offers\\_hope\\_to\\_ms\\_patients](http://neurologicalillness.suite101.com/article.cfm/dr_paulo_zamboni_offers_hope_to_ms_patients))

CCSVI liberation treatment is a completely new way of treating MS. Until now all we have are the options of steroids, pain relief and disease modifying drugs (these only reduce the number of relapses a person has). The liberation treatment is carried out by balloon angioplasty (a surgical procedure to inflate balloons into the blood vessels which opens the veins and improves drainage from the brain), an everyday operation in this country for other conditions.

The only way anybody can have the tests and treatment is to have it done privately and pay for it. The NHS is not willing to carry out the tests or treatment as it is not yet a proven treatment for MS in the UK. However the NHS is not currently carrying out clinical trials and there seems to be no urgency to do so, this despite the amazing results in other countries as already mentioned. It will take several years for these trials to be carried out so they really need to be started now. The point of this petition is to get the Scottish Government to step in and get things started. The only option for those of us with MS is either to pay for private scans and blood tests and for the balloon angioplasty, anybody who is not able to do that will have to continue to live with their disabilities and has a high chance of getting worse. Hopefully the treatment will become available to them before it's too late. My Aunt had MS and she lost her battle last year, she died in February 2009. Different clinics in different countries all charge different amounts. I am registered with the Essential Health Clinic in Glasgow and the full package of scans, tests and balloon angioplasty will cost £5,590 but am sure the cost to the NHS would be far less.

At the moment many people are on disease modifying drugs at a cost of approximately £15,000 per person. If these drugs were not required that would be a massive saving to the NHS. There would also be a saving in the long run in a doctor's time if patients symptoms were relieved.

CCSVI treatment is not carried out on the NHS in the UK. It is needed now as every day people with MS are struggling to carry on with life and in many people their MS is progressive, many becoming housebound, bedbound, wheelchair users etc and needing a lot of help and care. I had to give up my job as a civil servant 2 years ago because of my MS. This operation gives me hope that I will be able to come off benefits and return to work. There are 10,500 people in Scotland with MS, 100,000 in the UK as a whole - imagine the savings to the economy if even some of these people were able to look after

themselves taking the burden off carers, and if some could come off benefits and return to work, becoming tax payers again! I'm sure you'll agree that can't be a bad thing.

MS is more prevalent in the UK, Scotland in particular than anywhere else in the world. In Scotland 1 in 500 people have MS compared to 1 in 800 in the rest of the UK.

([www.msrc.co.uk/index.cfm?fuseaction=show&pageid=2325](http://www.msrc.co.uk/index.cfm?fuseaction=show&pageid=2325))

The venous connection to MS- a timeline

([www.msrc.co.uk/index.cfm?fuseaction=show&pageid=2953&CFID=4018683&CFTOKEN=25470490](http://www.msrc.co.uk/index.cfm?fuseaction=show&pageid=2953&CFID=4018683&CFTOKEN=25470490))

The MS Society says that more research has to be done before it can recommend this treatment. It is willing to give a grant if anybody submits a viable research plan to it. However as so much of the research done in this country is carried out by drug companies who would not make any money out of this treatment, who is going to do the research?

The problem is that this treatment is not going to make money for anybody, it is likely to lose money for the drug companies and they are the people who do most of the medical research. At the moment many people are on disease modifying drugs which cost around £15,000 per person per year. If these were no longer needed the drug companies would lose a lot of money. Therefore there is no incentive for anybody to do the research. The Government - Scotland and/or UK - would have to take action to get research done. Perhaps one NHS hospital could do the treatments on a trial basis seeking volunteers who would sign a contract stating they are accepting the treatment at their own risk and do not hold the NHS liable if it does not work or anything goes wrong. I know I would volunteer!

- Patient Comments

([www.msrc.co.uk/index.cfm?fuseaction=show&pageid=2956&CFID=4018683&CFTOKEN=25470490](http://www.msrc.co.uk/index.cfm?fuseaction=show&pageid=2956&CFID=4018683&CFTOKEN=25470490))

*"I recently underwent surgery to treat severely occluded jugular veins in which 3 stents have been placed to keep the blood flowing properly. Since the operation I have noticed improvements in various MS symptoms. This is obviously early days but it is EXTREMELY exciting. I am the first UK patient to have had this treatment at Stanford University, California.*

[www.youtube.com/watch?v=TtSzGQ\\_0l\\_4](http://www.youtube.com/watch?v=TtSzGQ_0l_4)

**6. Do you wish your petition to be hosted on the Parliament's website as an e-petition?**

**YES**

**7. Closing date for e-petition**

31 August 2010

**8. Comments to stimulate on-line discussion**

Angioplasty's are carried out every day in this country to clear damaged or blocked veins in patients who do not have MS. Although it cannot be called a cure for MS, there have now been many people with MS to have had amazing improvements in their condition in other countries. This should be enough evidence for Scotland to take action and get the NHS to start doing research urgently. It is discrimination to not treat blocked/deformed veins in a patient because they suffer from MS. From a financial point of view, if we are given this treatment we may need less drugs and social security benefits, who knows, we might even become well enough to return to work and pay tax and national insurance – that can only be good for the economy.