

## Chronic Cerebrospinal Venous Insufficiency (CCSVI) – How To Treat It Where To Get Treatment & New Research

By Ian Cook & Judy Graham

In the last issue of *New Pathways* we reported that Italian researchers had discovered that in every single MS patient they studied, there was an abnormality in the veins from the brain to the heart. Ashton Embry PhD called this discovery 'a huge breakthrough for MS.'

But what can be done to treat CCSVI, where can you get this treatment and what more research is being done?



Alex Gibbs, who had the treatment in the USA

### **"It Has Really Changed My Quality Of Life."**

*Alex Gibbs, 38, went to Stanford University in California, USA, to be treated for CCSVI in June.*

*Diagnosed with MS in 2004, Alex is married to Martin, lives in Chelsea, London, and was studying for a MSci in Property. Before the operation, she suffered from walking difficulties, spasms and bladder problems.*

Says Alex: 'I found out about the CCSVI surgery in Stanford though the ThisisMS website. It was very easy to contact the surgeon, Professor Michael Dake –

I just sent his assistant an email!

Immediately after the operation I was able to go out and about again, which was great. It has really changed the quality of my life!

Several MS symptoms improved, especially noticeable were bladder control and much reduced night spasms. Before, my bladder was so bad I hardly dared go out.

At Stanford they looked at my veins with magnetic imaging which found I had severe narrowing in both jugular veins at about ear lobe level.

During the two and a half hour operation they put in three stents to open the veins up and keep the blood flowing properly. Small titanium nickel alloy stents were opened in both jugular veins, having been inserted via the femoral vein in my right thigh.

I was given a relatively mild local anaesthetic. During the operation I was asked to hold my breath at various points. When the stents were opened it was agony! I was then put on a stronger painkiller. It

was painful, but the results are certainly worth the brief pain.

They also gave me blood-thinning drugs because until the endothelium grows over the stents fully there is the risk of blood-clotting. I was on warfarin, aspirin and plavix for two months and continue to take aspirin.

### **Extremely Exciting**

Over the following weeks various more subtle improvements also appeared, notably reduced spasticity, less sensory disturbance and improved gait. It was extremely exciting!

All in all I feel about thirty percent better than I did before the operation. Thirty per cent may not sound like a lot, but I can now sleep without spasms, I can go out and about without worrying about my bladder too much because there is significantly less urgency. I can also void a bit better. I feel less spasticity and there is less stiffness in my walking.

This doesn't mean that everyone

only benefits by thirty percent – I am in touch with several Americans whose MS seems to have been completely eradicated. It's just that I had very many symptoms.

A few weeks ago I went to Spain and was able to walk, with a cane, an amazing 1.4 kilometers – the furthest I have walked in a long time!

More recently I have had a moderate deterioration in all my symptoms and I'm in discussion with Professor Dake about this. This occurred at a time when I switched from drinking coffee to quite a lot of hot chocolate. Since stopping the chocolate the symptoms have improved again.

### What Is CCSVI?

CCSVI is a condition where veins in the head and neck become narrowed. This narrowing restricts the normal outflow of blood from the brain, causing alterations in the blood flow within the brain and a reflux of blood back into the brain – something that eventually causes injury to brain tissue and degeneration of neurons.

Blood which refluxes into the brain contains iron, and according to Dr Zamboni, many neurologists consider iron dangerous because it is linked to neurodegeneration, MS progression, and disability.

CCSVI was found to be strongly associated with MS, increasing the risk of developing MS by 43 fold.

### Treatment For CCSVI

Dr Paolo Zamboni, the Italian doctor behind this radical new perspective on MS, has been treating MS patients with CCSVI with a procedure called liberation.

In the liberation procedure, veins which fail to drain blood properly from the brain causing a breach in the blood brain barrier are opened up and repaired.



*Dr Paolo Zamboni and his daughter Matilde, 21*

It is carried out in day surgery under local anaesthetic. It is safe, uncomplicated and reduces MS symptoms.

Dr Zamboni says: "Treatment for CCSVI such as balloon angioplasty and in some cases the use of stents may improve the relapse rate and quality of life of patients with relapsing remitting MS. It seems an effective treatment for chronic fatigue in patients with primary progressive and secondary progressive MS."

### What Is The Liberation Procedure?

The liberation procedure identifies problem veins by a special type of ultrasound scan known as a Doppler test or study.

After identifying the problem veins, balloon angioplasty is used to open them up. Tightly folded balloons are passed through narrowed veins and inflated.

In more serious cases, stents - expandable metal tubes - are inserted into non-responding sections of the veins.

The liberation procedure is relatively non-invasive and is done in day hospital under local anaesthetic. Blood thinning agents are sometimes used to help improve blood flow

The liberation procedure can

result in patients being freed from some of the most troubling MS symptoms.

Patients have reported improvements in bladder function, walking and chronic fatigue. There have also been reports that relapse rates have been greatly reduced.

Improvements can happen quite quickly after the procedure is done – in a matter of a day or two.

### Getting The Treatment

Until recently, all the liberation procedures were done in Italy. The results of these will be published in December in the *Journal of Vascular Surgery* and wider treatment is expected to follow this.

Professor Michael Dake of Stanford University in California is the first doctor outside Italy to treat CCSVI. He has performed surgery on more than 40 MS patients.



*Dr Gianfranco Campalani, who had the treatment in Belfast*

### Treatment In The UK

The first liberation procedure in the UK was carried out in Belfast in October.

*Case: Dr Gianfranco Campalani, 63, is a consultant cardiac surgeon at the Royal Victoria Hospital in Belfast and has had MS since 1986. He received Dr Zamboni's liberation procedure in Italy in 2007 and then became the first UK patient to have another course of*

*this treatment at the hospital where he works in Belfast.*

Dr Campalani says: "I had spasticity of the back and lower limbs, progressive weakness in my legs and also bladder and erectile problems. My walking ability has decreased steadily over the last 10 years.

I met Dr Zamboni in Ferrara, Italy (my town of origin). I went to his lab to have a Doppler study that showed CCSVI. I underwent the balloon dilatation of both jugular veins at a hospital in Ferrara in 2007.

I felt much improved but six months ago I felt that I was having a subtle setback. Although still much improved, I started to feel that my back was getting weaker and my movements were slowing down.

I had another Doppler study in Ferrara which showed that the flow in the right jugular vein was not as good as it had been following the dilatation.

I persuaded the consultant vascular surgeon in the hospital where I work - the Royal Victoria Hospital in Belfast - to read Zamboni's papers, which he discussed with colleagues. I had a venogram which showed the veins had narrowed again.

He did the surgery free on the NHS. It lasted just over one hour, used local anaesthetic and was painless. I was back home the same day.

Within a couple of days I felt better; my back stronger and my movements quicker."

## Is CCSVI The Cause Of MS?

In a wide-ranging interview with New Pathways, Dr Zamboni said he didn't think matters were quite so simple. He says: "I never stated that CCSVI is the cause of MS. Multiple Sclerosis is a complex illness caused by several different factors and I think CCSVI could be

certainly one of the factors involved because of the very strong association found between it and MS."

He added that CCSVI is peculiar to MS and has not been found in other neurodegenerative conditions.

Dr Zamboni said that the narrowing of the veins (known as stenosis) was most likely congenital ie: there from birth rather than something that happened later. It had nothing to do with infectious agents such as the Epstein Barr virus.

## Research Into CCSVI

CCSVI may be only one causal factor in MS, but MS symptoms may be a result of the narrowing of the primary veins outside the skull.

Neurologists at the University of Buffalo in New York, USA, are conducting more research into this.

"If we can prove our hypothesis, that cerebrospinal venous insufficiency is the underlying cause of MS, it is going to change the face of how we understand MS", says the University of Buffalo's principal investigator on the study, Robert Zivadinov, MD, PhD.

"The prevailing wisdom that central nervous system damage in MS is predominantly the result of abnormal immune responses against the patient's nervous tissue has been challenged by research findings, which have demonstrated a significant neurodegenerative component in MS and the progressive loss of neurons" said Zivadinov.

"However, these inflammatory and neurodegenerative processes occur concurrently in MS and vary considerably among patients, making it difficult to identify the cause, or causes of the disease. Consequently, the origin and development of MS remains poorly understood, and its cause remains elusive."

Michael Cain, MD, Professor and Dean of the University of Buffalo

School of Medicine and Biomedical Sciences, said a positive outcome from this trial would have enormous implications for the treatment of MS:

"Being able to identify those at risk of developing MS before symptoms take their toll could change the lives of millions of persons who now face inevitable lifestyle restrictions."

The new study will involve 1,100 patients diagnosed with possible or definite MS, 300 age-and-sex matched normal controls, and 300 patients with other autoimmune and neurodegenerative diseases. Enrolment in the study has begun and will continue for two years. MS patients from across the US are eligible to take part in the study.

The results of this study may lead to a larger multicentre North-American trial that will evaluate the occurrence of CCSVI in MS.

## Info Box

### Getting Treatment in the UK

Although Dr Gianfranco Campalani received NHS-funded treatment for CCSVI the situation for others in the UK looks less promising. According to the Vascular Society of Great Britain treatment for CCSVI will not be available in the near future in most UK vascular centres although it will be funded by the NHS when there is a "substantial body of evidence" to support it.

As Dr Paolo Zamboni is due to publish his work in December's edition of the Journal of Vascular Surgery this may help build up a "body of evidence".

In the US the situation is better. At Stanford University in California many MS patients have already been treated with more in the pipeline. Many of the accounts of these patients and their treatments can be found at the website <http://www.thisisms.com/forum-40.html> We will be following some of these cases in New Pathways.

Another doctor who has carried out CCSVI procedures is Dr Marian Simka at the Department of Angiology, SANA, Pszczyna, Poland.

There is much useful information concerning information, testing and treatment for CCSVI at the websites:

<http://csvg-ms.net/en>  
and  
<http://www.ms-mri.com/>