

MS-CCSVI-UK Newsletter

www.ms-ccsvi-uk.org

Ella in Katowice

Ella Findlay travelled to Poland to get tested for Chronic Cerebro-Spinal Venous Insufficiency (CCSVI). She wanted to find out if she had a problem with the veins in her neck after hearing of the research carried out by a vascular specialist Dr Paolo Zamboni in Italy, who used ultrasound and magnetic resonance venography to examine the blood vessels leading out of the brain of hundreds of patients. He found that the majority of people with Multiple Sclerosis he treated had defective circulation in their neck - a defect he has called CCSVI.

Ella was pleased that she had Dr. M. Simka, the most experienced doctor in this, to examine her because if it hadn't been for his experience at treating patients she may well have come home without any treatment at all. Dr Simka said that it wasn't very obvious at first sight where the problem was.

He eventually found the severe stenosis, in the right jugular vein between the jaw and ear, with the help of a venogram. Dr Simka and the surgeons then proceeded with the procedure called Liberation which in her case involved being injected with an 'X-ray opaque dye' and then a deflated balloon is guided from the groin area up to the point of constriction and once there is inflated to widen the vein.

She spent the night in the unit and was released the next morning with a series of 7 blood thinning injections to avoid the formation of blood clots. The procedure was carried out under a local anaesthetic and Ella reported that there was only a small amount of discomfort and a loud pop when the balloon was inflated. Two



Ella Findlay: Liberated in Katowice, Poland

days later she had recovered sufficiently to take part in a tourist excursion to Krakow. After a further two days, she flew home, arriving back in Farnham at midnight. She was up and off to work the next day, reporting to her mother that she had walked further than she had done in 9 months and on her own to boot. Since then there have been some steady changes for the better, the latest being her ability to cope with her life 'normally' whilst taking antibiotics given to her for a UTI. Ella is pleased that she took the risk of going to Poland. What is life worth if you are not prepared to take a risk to live it?

Since this was first written Ella has seen the improvements slip away and has requested a check up at the Polish Clinic to see if her vein has restenosed. This may happen in some cases. It is important to understand that this procedure does not guarantee a positive result for everyone.

New Website: a resource for change.

MS-CCSVI-UK formed at the beginning of January 2010. Initially a group of people came together on Facebook but quickly realized that more internet space was needed under the control of the group in terms of content and vision. The website is online but still

under construction. Eventually we see it as a resource for people to learn about CCSVI, a place to find useful tools to raise awareness about it and a place where you can have your say. There will be downloadable articles and papers, sample letters to

write to your doctors and MPs, information to give to your doctor and medical specialists such as MS nurses and Neurologists. Here we will also try to provide easily understandable explanations of CCSVI and the Liberation procedure.

<http://www.ms-ccsvi-uk.org>

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CCSVI News

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- New website: a resource for change
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Inside and outside Hotel Zaleze

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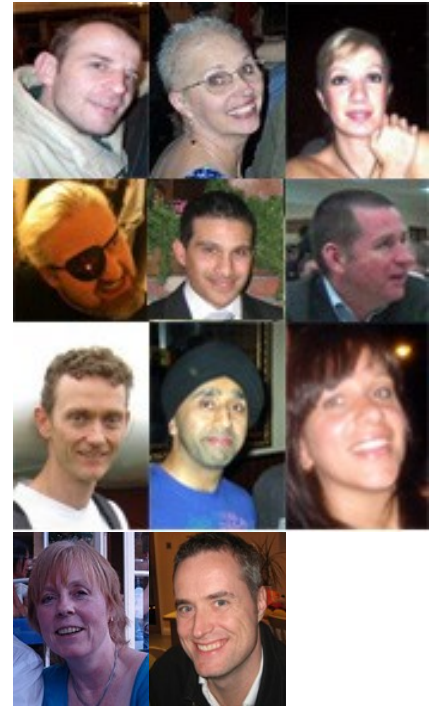
Meet the team

Here is the MS-CCSVI-UK Team, there have been other people helping us in the past couple of months but who have had to drop out, we are very grateful for the help they gave us.

- **Gary Barclay:** Top Boss, Team Leader and Networking wizard.
- **Michele Findlay:** Team Leader, Admin and Publicity
- **Krystalla Michael:** Communicator, gifted PR person, Inbox manager.
- **Harvey Kennett:** Video maker, humorist and wise man.
- **Omar Majdi:** Facebook Manager and Media magician.
- **Colm Mclaughlin:** Forum and Facebook monitor.

"Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has." Margaret Mead

- **Martin Jones:** Document and website content editor.
- **Parminder Nagra:** Media and Marketing consultant.
- **Nicki Christou:** Data handling and researcher extraordinaire, ideas generator.
- **Anne-Marie Anderson:** Website administrator, content generator.
- **Mark Holder:** IT specialist.
- **Jarrold Robinson:** Website designer. IT consultant.
- **Team members who have left:** Diane Parkinson, Ben Parker, Soon-dri Slathia-Foster.



World Wide News

Tribute to Tiger Tim

Glasgow's top stars are to appear on stage at a special benefit night for one of the city's best-loved entertainers. Pop stars such as Marti Pellow, Midge Ure and Hue and Cry will appear on the bill at the Pavilion theatre in Tribute To Tiger Tim. All proceeds will go to a special benefit fund to send veteran DJ Tim Stevens, who is battling multiple sclerosis, to Poland for radical new treatment. Source: *Evening Times* © 2010 *Herald & Times Group* (05/03/10)

UBC researchers planning to study CCSVI theory

A medical centre in British Columbia says it wants to become the first in the country to test the controversial theory that multiple sclerosis patients have blocked veins, preventing proper blood flow from the brain.

Source: *CTV News* © 2010 *CTVGlobe-Media* (03/03/10)

The severity of chronic cerebrospinal venous insufficiency in patients with multiple sclerosis is related to altered cerebrospinal fluid dynamics .

This study demonstrates that venous outflow disturbances in the form of CCSVI significantly impact on CSF pathophysiology in patients with MS.

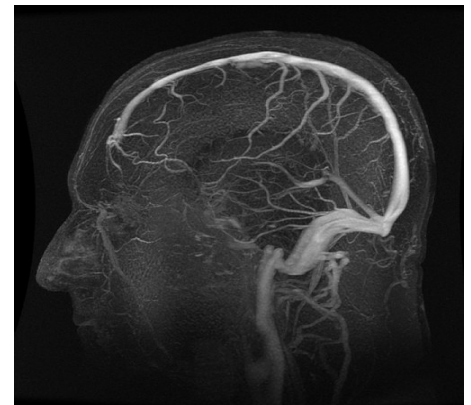
Pubmed PMID: 20018140 (28/02/10)

Controversy: Neurologists or Vascular Specialists

The question most often being asked on Facebook at the moment is why don't we ask Vascular Surgeons to treat CCSVI. Across the world people are taking their treatment and their future into their own hands and going to their local hospitals to ask interventional radiologist and vascular surgeons. Some of these people have been successful at getting their diagnosis and the treatment they needed. However many people have met with resistance and rejection. They have been given a

variety of reasons for this rejection; from profession protocol, through safety of patients to uncertainty about the benefits MS patients might get from this procedure.

To finally answer these questions clinical trials should take place and the UK should not be relying on the research carried out in other parts of the world. Here at MS-CCSVI-UK we want our own research to take place so that this treatment can be provided by the NHS in the near future.



Who should be treating the patient with vein stenoses? Vascular surgeons or Neurologists?