

## Ruth's Story - How my wife went from near-death to normal living in a few days - and why The Reformed MS Society was founded



Steven & Ruth

Dear Fellow MS patient or care-giver:

My name is Steven Simonyi-Gindele and I am writing to tell you that my wife, Ruth, was freed from the worst of her MS symptoms on December 29, 2009, thanks to a simple treatment for CCSVI pioneered by Dr. Paolo Zamboni.

She was patient #17 to be treated for CCSVI in Poland, according to Dr. Zamboni's protocol (also called the Liberation Treatment), and for 3 solid months she has experienced a new life of normal living. Her draining fatigue, constant headaches, double vision and other symptoms were gone or have mainly disappeared. This was accomplished through a simple angioplasty that unblocked her left jugular vein and restored regular blood-flow.

I mention this because I am inviting you to join me to help make this safe, simple treatment available to every MS patient throughout the U.S. and Canada. Based on current data, well over 50% of MS patients will benefit from this procedure and return to their former lives. Those with less permanent damage will be helped even more.

But let me start by telling you how Ruth's life changed – thanks to Dr. Paolo Zamboni, an Italian vascular surgeon who may one day receive the Nobel Prize for Medicine.

### **Ruth's life was being destroyed by MS, and I felt helpless.**

I have been an MS caregiver for the past 22 years to my wife. This disease has affected every aspect of our life. It was the unseen third-party in our marriage, always present and always interfering and demanding attention.

Nothing could be done without considering her MS. When we went skiing with our sons, Ruth had to stay behind in the cabin. We would go biking, but Ruth never had the energy to ride with us. The last three years were particularly difficult as her condition worsened: The pain and fatigue became more intense, and consumed more and more of her waking hours.

And it got even worse. During 2008 and 2009, she began looking so pale and ashen when she was sleeping, I had to check to make sure she was still breathing. Every night we would pray and ask God for His help and deliverance from this horrible disease. Day after day, month after month, year after year we prayed. But instead of getting better, Ruth was getting worse, and we believed that only Divine intervention could save her. The \$2,500 monthly drug regimen certainly wasn't helping, but we were afraid to stop the injections fearing more severe and frequent attacks.

The folks at the UBC MS Clinic – one of the leading MS centers in Canada – were kind and friendly but could offer no relief. There was simply no escape from her desperate fatigue, pain and hopeless outlook. We were told that MS was incurable, and Ruth's condition was changing from Remitting-Relapsing (it comes and goes) to Secondary Progressive. (No relief; symptoms always present and getting worse.)

But the worst of all was when Ruth began saying that it would be better if the Lord would take her. She wasn't suicidal. She was just logical. The woman I love was slipping away before my eyes.

## **Then suddenly, out of the blue, our prayers were answered. Finally, an effective treatment for MS was discovered.**

This past November, we watched a report on the Canadian CTV network. It concerned an Italian vascular surgeon – Dr. Paolo Zamboni – and his astonishing work with CCSVI as it relates to MS. (CCSVI = Chronic Cerebrospinal Venous Insufficiency, which is all about blocked blood flow from the brain through the jugular and azygous veins.)

Could this be an answer to our prayers? I moved quickly. Five weeks later, we found ourselves at a small private clinic in the Polish industrial city of Katowice. It was run by two specialists, Dr. Marian Simka, an interventional radiologist, and Tomasz Ludyga, a vascular surgeon. At the time this was possibly the world's only active clinic using Dr. Zamboni's Liberation therapy.

It was an exhausting journey for Ruth. It took two days to travel from Vancouver, but I'll always remember the day, Dec. 29, 2009. That's when we witnessed the nearest thing to a medical miracle we'll ever see. Ruth was the 17th patient treated in Poland – now 300+ have been successfully treated) – and her life was about to change.

The preliminary scanning (to detect the location of the blockage) was followed by the balloon angioplasty -- the CCSVI procedure. The treatment took little more than an hour, the miracle is what happened next.

## **WITHIN THE FOLLOWING 72 HOURS ...**

Ruth had her first good night's sleep in years... her eyesight had greatly improved and the double vision disappeared ... warmth returned to her limbs ... she took a two hour walk around town, the day after the procedure AND she ate a hearty lunch in a small street cafe. I also started noticing some of Ruth's old personality returning, and that was a special treat.

This wasn't a gradual improvement – which would certainly have been fantastic – but this was an **IMMEDIATE change**. Not a perfect recovery, certainly, but perhaps returning to 80% of what's "normal." (She had previously been at about 20%.) And all this happened after Ruth's clogged left jugular vein was opened, and the blood began flowing.

This is a very brief recounting of what happened in late-December '09. Today Ruth is a different person. Three weeks after the treatment, she traveled to New Zealand alone to visit her family, and toured around for two weeks. Her sisters were simply stunned at the improvement. And something else: The day after she had arrived back from Poland, she was driving again - and confidently - including AT NIGHT, IN THE RAIN!

In April of this year, the fatigue and other MS symptoms started returning , and now we are being forced to return to Europe on May 29 for a follow-up assessment and possible stenting. "FORCED"? absolutely, because the MS Society and bureaucracy won't recognize CCSVI as a medical condition. This forces us to go abroad.). The difference is that we now have real hope, knowing that once the vein is unblocked a second time and helped open by a stent, Ruth will again before of these life-draining debilitating symptoms. We can then return to living normal lives which we so much enjoyed for three months.

Ruth has a new life, and I have my "old" wife. But that's not the end of my story, only the beginning.

### **Questions come to mind...**

I had seen first-hand what Dr. Zamboni's pioneering work had done for Ruth, and I wanted to do something to help others. But what, exactly? I wasn't sure, at first, but I certainly had some questions – especially after meeting with Ruth's neurologist. He insisted that lengthy clinical trials were still needed before treatment for CCSVI could be allowed. I disagreed.

And so I found myself wondering ...

- Why is it legal to have a routine angioplasty to treat a variety of medical conditions, but not MS? Treat an MS patient for CCSVI and you can lose your medical license. Why?
- Why do MS patients have to fly half-way around the world for a simple out-patient procedure that could be done in any city in North America? What if a person can't afford the \$10,000 - \$25,000 to have this done abroad – should they just continue to suffer?
- Why have the National MS Societies kept this information about CCSVI secret for so long? Why have they stayed silent? What's going on?!!
- Why this ongoing skepticism towards CCSVI from the MS Establishment? Why are they demanding clinical trials that would take up to 10 years to demonstrate the effectiveness of something that's already working? What's their angle? Who are they really serving? Besides ...
- Why are they allocating so little money for CCSVI trials? Very strange, considering their total take is over \$900 million every year.
- What about the pharmaceutical industry? Its worldwide sales for MS drugs reached \$8 billion in 2008, and is projected to reach \$15 billion in 2014. But if the problem for most MS patients is vascular, which can be treated with a one-hour angioplasty, wouldn't that slash the need for a lifetime of MS drugs? (The yearly cost for Avonex, Betaseron, Copaxone, Rebif, have risen from \$10,000/yr three years ago to over \$20,000 per year now. Tysabri now costs \$28,000/yr.)
- Why should it take an Italian vascular surgeon, whose beloved wife had MS ... working entirely on his own ... delving into research done in the 1970's by an Austrian doctor, Franz Schelling ... to spot the link between MS and blocked veins? Why were these published studies, readily available on the Internet, purposefully ignored?
- Why do they keep saying that treating CCSVI is "dangerous"? Over 750 people have been successfully treated to date. The one death, that is constantly mentioned, was not directly related to the angioplasty procedure. That patient died of a stroke – having had a previous stroke before being treated for CCSVI. The patient's family refused to allow this death to be linked to the patient's CCSVI treatment. ON THE OTHER HAND: How many people die every day from MS? How many people are dying from hospital infections and botched operations?

And the most mysterious question of all:

Why do MS doctors keep insisting that the positive results from CCSVI treatments are all a figment of patients' imagination – that it's entirely placebo-driven. (To which I'd reply: My eyes don't lie. I know what I see.)

And here's another question worth asking ...

Why should so many prominent neurologists, of whom not one has ever been able to help a single MS patient recover, be so adamant in their opposition to CCSVI -- a vascular disease that, when treated, can reduce or eliminate MS symptoms? Shouldn't they be rejoicing when something has finally been found to help their patients? Whatever happened to their heart? Their compassion? I believe that ordinary neurologists, when free to do so, will welcome and support CCSVI.

## **Meanwhile about 3/4 of a million people in Canada and the U.S. are suffering from this degenerative disease that, until recently, was considered basically hopeless.**

They are told to be patient ... trust their doctors' superior judgment ... wait for more clinical trials ... and keep consuming expensive drugs like Avonex, Betaseron, Copaxone, Rebif and Tysabri. (Which only hide the symptoms and solve nothing. And what about the side effects?)

### **... and with a little research the answers become quickly apparent**

We're witnessing a \$17 billion turf war (North America) over money, patients, reputations and careers – with half of that money going for drugs. Trouble is, all of us with MS, or who are MS caregivers, are being caught in the middle.

- The battle is primarily between the prominent neurologists, six or so pharmaceutical companies and the National MS Societies who are currently on the defensive but fighting back hard. In financial terms, they've got the heavy artillery. Against them are a growing number of activist MS patients and caregivers.
- There is an incestuous relationship between the National MS Societies, prominent neurologists and the MS drug companies. Thus MS neurologists prescribe approximately 15 millions dollars in MS medications every year – while drug companies provide research grants, educational trips and other perks. Prominent Neurologists will make over \$1 million in total yearly income – enhanced by assorted professional fees, etc.
- Meanwhile The National MS Societies act as cheerleaders to the afflicted, enablers to those living off MS patients and expert fundraisers with next to nothing to show for it - in helping people get relief from pain and suffering. They receive money from drug companies, give money to their prominent neurologist allies for basic research (much of it useless) and, naturally, are heavily influenced by the neurologists. Yet despite these obvious conflicts of interest, they eagerly claim to be unbiased spokesmen for MS patients and their caregivers.
- Let's not overlook certain politicians who receive contributions from the drug companies and The National MS Societies. They're key players.

Lots of financial filings to pick through, and it all comes down to the money trail: Who gets what? Where does it come from? What are tangible benefits to MS patients?

In the MS World, the MS establishment is well-organized to protect their own self-interests. But somehow you and I – MS patients and caregivers, the people they're claiming to help – are being overlooked and left to suffer. And this is happening when, finally, a treatment that really works could be available were it not for their obstructionism. Don't we deserve something better?

## **Why The Reformed Multiple Sclerosis Society was formed**

I said that I wanted to DO something, and I did. As a first step, I founded The Reformed Multiple Sclerosis Society, a registered, non-profit Charity incorporated in the United States and Canada. We're a grass roots independent patient-focused group fighting for transparency and accountability... for a fresh approach to MS research ... while pushing to break-down the barriers that prevent MS patients from getting treated for CCSVI.

## Why The Reformed Multiple Sclerosis Society was formed (con't.)

So who are we? We are a group of six successful professionals, business owners and executives who decided to fight this legalized neglect of MS patients. All the directors of The Reformed MS Society feel as strongly about this as I do. One of us has MS, two of us are MS caregivers and one is an ophthalmologist with many MS patients. (You'll find our bios on the About Us page of the website.)

We're all motivated to overcome this injustice. After all, something is horribly wrong when tens and tens of thousands of people are suffering and their lives are being unnecessarily wasted, Did you know the suicide rate among people with MS is seven times higher than the national average?

Why this unyielding opposition to CCSVI? Is it professional pride and stubbornness? Greed? Or just plain cowardice on the part of people who know what's going on ... should be speaking out ... but are keeping quiet for their own reasons?

Opponents say that there should first be clinical trials before legalizing CCSVI. But what's wrong about opening blocked veins to allow normal blood flow? Why on earth shouldn't that be GOOD?!! And why is it that safe, proven angioplasties OK for heart conditions, but not for MS? Our opponents constantly bring up one unrelated death but they refuse to accept the 750+ successful CCSVI treatment outcomes claiming that anecdotal evidence is no evidence.

Wouldn't any fair-minded person see this as being totally outrageous? In fact, if ever there was a human rights issue, this is it. I'll repeat: **IF EVER THERE WAS A HUMAN RIGHTS ISSUE, THIS IS IT! And if ever there was an injustice and betrayal of trust, this is certainly it.**

## Here's what The Reformed MS Society will do

You'll notice the word "Reformed" in our name. That's because there's a lot that needs to be changed in how MS patients are diagnosed, treated and represented by their Society.

- We are dedicated to make CCSVI legal in at least one state or province within 12 months – hopefully before the end of the year.
- Change the laws to allow for immediate testing and treatment of MS patients by vascular surgeons and interventional radiologists. (Initially, if necessary, on a compassionate basis.) Already many are available to help and start providing Dr. Zamboni's Liberation Treatment.
- Work with the insurance industry for full coverage of testing and treatment of CCSVI. It could save them billions.
- Provide research funding to develop a new line of stents designed specifically for veins. Current stents are meant for arteries.
- Assist MS patients to find treatment locally and in foreign countries, until such treatment becomes readily available.
- Organize testing and treatment protocols and logistics suitable for wide-scale implementation when laws get changed.
- Work with others to foster vascular research for other neurological diseases.

Bottom line: There are probably hundreds of thousands of MS patients in the U.S. and Canada who could be quickly and significantly helped with CCSVI. Trouble is, too many people and companies have too much invested – in careers and money – to give this up easily. In our opinion, this aspect of the medical system is potentially corrupt and needs to be challenged.

## Searching for hope in all the wrong places.

If you are like me, you have MS, or you're a caregiver to someone with the disease, you live for hope – unless you're gradually losing sight of it.

Hope means finding freedom from pain and suffering, and stopping the steady physical decline. But until now, realistic hope could only mean (maybe) slowing down your decline and stabilizing your condition – nothing more – until some new drug came along that might ease your symptoms. Meanwhile, the National MS Societies keep dangling in front of us the hope for a “cure” in the future.

That's all we have been offered, and that kind of “hope” didn't mean much. But now you've got something more, and you've got a choice:

You can keep following your doctor's advice, keep taking those very expensive MS drugs, and keep hoping for ... what? (No side effects and long-term damage?)

OR you can take personal charge of your disease and ask yourself this question ...

Should you consider using Dr. Zamboni's protocol to learn if you have stenosis and, if the results were positive, to seek treatment for your CCSVI condition?

Putting it another way: Do you have the right to make this decision for yourself – or, as prominent neurologists would claim, you DON'T have that right. Here's what happened to a close friend in mid-April '10: She is a long-time patient of a well known MS Doctor at one of the top medical medical centers in the U.S.. And he turned her down when she asked for a prescription to be tested for CCSVI. No procedure... just to see if her veins were blocked!

It's your choice. But just remember, “hope” is now more than a mirage – it is a reality with the Liberation Treatment for CCSVI.

## Join us! Let's make history together.

The Reformed Multiple Sclerosis Society is building a grassroots organization within the MS community, in every state and province, to push medical and health boards to change their CCSVI policies.

We will push this through the national and local media ... political lobbying in state and provincial capitals ... assisting and working with MS activist groups ... and providing support for pro-CCSVI interventional radiologists and vascular surgeons – our natural allies.

For the first time patients and their caregivers will be organized, and that will make a significant difference. Yes, and this is also a *righteous* struggle – and that, too, counts for something.

Will you join our non-profit Reformed MS Society? Our annual membership fee is \$30, and it will offer you some major benefits.

- You'll be first to receive information on where CCSVI treatment is being offered beyond the U.S. and Canada: Hospitals/clinics; doctors; pricing; contact information; testing equipment; degree of experience with CCSVI; and current waiting time. This information will be constantly changing – events are moving quickly – and the demand for these services will be intense.

- Upcoming clinical trial application forms – including trial protocols, aims, risk, etc.
- “Request for Treatment Forms” for overseas clinics – with possible group discounts and service upgrades, and accessing early treatment slots from cancellations. We maximize our connections.
- Closer to home, as CCSVI becomes available in the U.S. and Canada, we will alert members about co-operating interventional radiologists and vascular surgeons in your region. SIGNIFICANCE: These doctors are currently under a lot of professional pressure, and they want a low profile. Distribution of this information will be locally focused. We will quietly notify members in a doctor’s immediate region.
- “Reformed” members will be notified of late-breaking news concerning CCSVI: It’s legal status and any easing of restrictions; new pressures being applied by professional groups and how they can be confronted; new clinical trials; etc.
- Members can also communicate with each other through our forums, and learn about the possibilities for CCSVI in their local areas -- as interventional radiologists and vascular surgeons become available.

Please join us! We need your help and support – and I’d suggest that you need us, too.

Power to the patients!

Sincerely,

Steven J. Simonyi-Gindele  
MS Caregiver and Founding Director  
The Reformed Multiple Sclerosis Society

P.S. This message is in PDF format so it will be easy for you to save onto your computer. Please pass it on to anyone who might be interested or who needs hope.  
Thanks!

**I am ready to take action**

I want to join as a member and/or  
make a donation