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IN HIS OWN WORDS

A treatment for multiple sclerosis that upsets Big Pharma

BY PHILIP LILLIES | JULY 16, 2010

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In a breakthrough in the treatment of multiple sclerosis, last summer Dr. Paolo Zamboni, a vascular surgeon from the University of Ferrara in Italy, made public the results of findings from his study of 65 MS patients.

Dr. Zamboni and colleagues investigated CCSVI -- Chronic Cerebrospinal Venous Insufficiency -- a condition characterized by blockages in the veins causing problems in the blood flow drainage from the brain and/or spinal cord of sufferers. This condition has been shown to contribute in a significant way to the many symptoms of multiple sclerosis. It can be relieved by angioplasty, which is a simple surgical treatment that removes the blockages.

Despite the results of Zamboni's and other significant studies, my research into the media's coverage of angioplasty as a treatment for multiple sclerosis reveals that the mainstream media, with some notable exceptions (examples of which are [here](#), [here](#) and [here](#)), is generally presenting arguments that are favourable to maintaining the pharmaceuticals' monopoly on treatment options (examples [here](#), [here](#) and [here](#)). Overall, the media has failed to do its journalistic duty to research all sides of the issue. They have failed to take the numerous testimonials and positive research results seriously and are failing to take into account the costs and benefits of angioplasty versus those of MS drugs that in the end offer little to no long-term benefits.

Pharmaceuticals provide **millions of dollars every year** to MS Societies in the U.S. and Canada, and the MS Societies in turn advertise the drugs developed by the pharmaceuticals and encourage their members to have full confidence in these drugs, even when alternative treatments, such as diet and angioplasty, might be more effective in alleviating the symptoms of the disease.

In fact, the MS Society of Canada claims to receive less than two per cent of its funding in pharmaceutical grants -- see Myth #2 in the link above. Additional direct assistance to the MS Societies of Canada and the US would be in the form of free education materials, speakers, and expertise, as well as paid advertising in MS Society newsletters; however, total assistance would certainly be a relatively small percentage of total budget, hundreds of thousands in Canada and millions in the U.S., but direct assistance is perhaps not the main source of influence on MS Society decision making.

Eminent neurologists and MS research foundations also receive **extensive funding from pharmaceuticals**, as revealed in a full disclosure article critical of CCSVI treatment that appeared in the **Annals of Neurology** (Khan et al, January 2010, Annals of Neurology).

In addition to funding their research, the pharmaceutical industry also influences through leaders -- see below -- through an educational organization known as the "Consortium of Multiple Sclerosis Centers." **Page two of the report** explicitly states that the CMSC is a partner with the pharmaceutical industry, other non-profit advocacy and services organizations (which would include MS Societies), and MS professional organizations.

Seven of the 11 authors of the report (including the first four, senior authors) disclosed receiving significant financial support from pharmaceuticals that produce drugs for MS. In addition, the pharmaceuticals are key players in an organization known as the "Consortium of Multiple Sclerosis Centers" whose main function is to influence MS thought leaders such as neurologists, researchers, and directors of MS Societies.

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A Civil Society Response

The medical establishment, in general, is hesitant to embrace a finding that would shift some of the burden of treatment for MS from neurologists to interventional radiologists, vascular surgeons, and experts in blood flow and imaging. One can only speculate about why this shift is so difficult for them.

One factor might be professional pride, but a more important factor might be the re-training that is necessary, both for doctors and technicians. As it stands now technicians lack the training to detect the blockages, even when they have the latest Doppler ultrasound equipment; and surgeons are flabbergasted at the thought of performing interventions on veins, which unlike arteries, are pliable and difficult to manipulate.

The upfront investment required to support the required changes, which would affect personnel and equipment, is also an impediment to recognition of CCSVI treatment by provincial health plans. So despite the enthusiastic support of both the **Liberal** and **NDP** health critics at the federal level, without federal financial support, changes at the provincial level may be slow in coming. In fact, the upfront cost would quickly be recovered as use of MS drugs became less common.

It is not surprising, then, that the mainstream media, when it follows the lead of the medical establishment and the MS Society, presents a biased picture that does not contribute to our understanding of the costs and benefits of CCSVI treatment. MS patients demanding the right to angioplasty for CCSVI are often depicted as a mere advocacy group attempting to badger the scientific community because of their hope for a miracle cure. The hundreds of positive reports and internet videos depicting MS patients who have benefited substantially from the treatment are dismissed as mere testimonials with no scientific merit.

Then there are the weasel words that are used to depict MS patients as emotional, subject to the whims of an unpredictable disease characterized by attacks and remissions, which renders them susceptible to quackery, psychological boosterism, and the much touted "placebo effect." Angioplasty itself is often referred to as "the liberation treatment," which suggests the wild and radical aims of those advocating for it. Research directors working on projects funded by pharmaceuticals and spokespersons from the MS Society are frequently quoted speaking out against the treatment without regard for the inherent bias such spokespersons would be expected to have.

The Canadian Medical Association Journal recently featured **an editorial** in which it argued that the medical establishment was on the side of the plain folk, guarding them against being overwhelmed by unproven therapies that had not been evaluated for safety and effectiveness, while preventing public monies from being diverted for use in untested procedures.

The truth is that despite concerted efforts to depict it otherwise, the issue here is not one of science but one of ethics. There is already ample evidence that the treatment has a high probability of being beneficial to a large number of MS patients. Detractors, however, raise the question of whether the costs outweigh the benefits. There is, in fact, ample evidence for those willing to take the time to look for it that this question has been amply answered in the positive (see **here** and **here**). Angioplasty, which is a medical procedure of long standing, can easily be adapted to treatment of CCSVI, and the treatment works. Why it works is still undetermined, but no one is arguing that it works by some mysterious energy or élan vital. There are several promising leads (such as build up of iron within the brain) that can be the subject of future scientific investigation. Patients themselves are amassing the evidence of success on the electronic bulletin boards of websites like "**This Is MS.**" The videos are very moving, and it is hard to dismiss them as anything but overwhelming evidence for the effectiveness of the treatment.

Detractors like to point out that the benefits of the treatment cannot be considered long-term because veins are subject to collapse after stretching. However, even if the veins collapsed again and needed to be re-stretched annually, this would still be more cost effective than most MS drugs, which cost up to \$30,000 per year and marginally slow the course of the disease at best.

In fact, recent studies have suggested that the so-called CRAB drugs have no statistically significant long-term effects. CRAB drugs are Copaxone, Rebif, Avonex, and Betaseron, the standard drugs used to treat MS. They are administered by injection and cost up to \$30,000 per year. Because we don't have a pharmacare program in Canada, the cost of these drugs can be a considerable burden to those lucky enough to be able to afford them at all.

In addition, using vein stents (no this is not a new technology either) could eliminate the need for additional treatments.

CCSVI itself is characterized in the mainstream media as unproven and controversial. Maybe, after all, it is a fairly normal condition. However, CCSVI is not controversial. It has been unanimously recognized by an expert international body as an undesirable congenital malformation. In 2009, at a conference on venous malformations (UIP09), experts from 47 countries voted unanimously in favour of officially including the stenosing lesions found in CCSVI in the phlebology consensus **document and guidelines**.

How dangerous is the treatment? As of today, the treatment has been applied over 1,000 times with reports of only one death following improper placement of **a stent**. Many MS patients, whose lives are in ruins, are willing to take the risk. And the risk can be compared with the risk of taking MS drugs, which are very unpleasant and hardly risk free. For example, a common drug for MS causes liver damage. Another recent study suggests that there are two types of MS -- similar symptoms but different diseases -- and if you treat one of the types of MS with one of the commonly prescribed CRAB drugs you may actually make the disease worse.

The medical establishment is demanding double-blind testing on the Zamboni method, which works well on drugs but is almost impossible to do with a surgical intervention. There is, of course, the questionable ethics of not correcting obvious problems once the surgical intervention has begun. In addition, given that the patients are not under general anaesthesia during the procedure, and in light of the fact that most doctors are probably lousy actors, the blind is going to be hard to maintain.

The University of Buffalo has received funding to try a **double-blind test on a small sample**, but any results are almost certain to be contested. The small sample size itself creates a problem because of the danger of sample bias, which is all the more likely as MS, unlike say breast cancer, is such a multi-faceted disease. Ideally you would want patients that were similar in background, venal malformations, and symptoms, except some would be given the treatment and some not. Unfortunately, this similitude is going to be impossible to achieve.

Double-blind testing does make sense for drugs, where the blind is relatively easy to maintain and ethics may be less of an issue when the benefits of the drug really are uncertain. It would seem that more usual for surgical interventions is to try it if it seems to work, and evaluate based on tracking of results over multiple treatments.

Perhaps this is what Dr. Zamboni means when he says that every Canadian should be given the treatment but also that the treatment should be given in a context of scientific study. This try-and-track approach was used with the original angioplasty procedures that were performed on arteries in the 70s, for example. It has also been used with radical mastectomy for breast cancer and caesarean sections, both of which have lately been given a serious re-evaluation. One notable procedure that the try-and-track approach was used on was scoping of knees. Now, after over a million trials, it would seem that scoping is being rejected as a valuable treatment.

Blind testing of drugs seems to suffer from a problem that is the contrary of the try-and-track approach. Once a drug is approved it may readily be prescribed for conditions that don't meet the test specifications. Notably, it may also continue to be prescribed even when tracking suggests that it may be dangerous under certain conditions. This appears to be the case with one of the commonly prescribed CRAB drugs, which as mentioned before under certain conditions may actually make the disease worse.

There is also a danger that the medical establishment will dismiss the benefits by setting the bar too high. Keeping in mind that the only long-term benefit of the CRAB drugs appears to be modulation of the attacks (so that the disease progresses just as quickly but with less serious attacks and remissions), we should not expect immediate and obvious benefits from every treatment. Benefits may, after all, be both restorative and preventive. Those in the early stages of the disease might not perceive any benefits even though unblocking their veins might prevent future deterioration. Those in the middle stages of the disease are most likely to notice perceptible benefits. Those in the final stages of the disease, after their muscles have atrophied making recovery impossible, might not notice any benefits, but at least they would benefit from prevention of further deterioration.

Some patients **have complained** that perceived benefits are fleeting, lasting merely months. Indeed, if their veins collapse again they may need to travel once again to Europe to have the treatment redone. Unfortunately, travelling abroad can easily cost \$15,000, so can't be repeated too frequently. The solution is, of course, to make the treatment locally available, then it would cost only a few thousand dollars at most. Even if this procedure

needed to be repeated annually, it would be much cheaper than treatment with MS drugs, which costs tens of thousands of dollars annually.

The MS Societies of Canada and the US have tried to accommodate pressure from the medical establishment while appeasing patients by providing \$2.4 million of support to seven small basic research projects **over the next few years**. However, the paltry amount of funding and the focus on basic research has simply further raised the ire of the MS community. **Not one of the projects** is focused on improving intervention techniques, and some of them, such as testing for similar conditions in the brains of Alzheimer's patients, would appear to be aimed primarily at fortifying the arguments of detractors. In addition, some of the projects appear to have been chosen because the researchers have not in the past worked with Dr. Zamboni, which might seem logical, except that part of Dr. Zamboni's contribution was precisely in the area of techniques for the detection of venal blockages.

At this point, based on the evidence of thousands of case histories and several scientific studies, the science points to a cost/benefit trade off that is wildly on the positive for providing the treatment. The benefits would accrue not only to MS patients but to society as a whole which needs otherwise to pay for their MS drugs and accommodate their incapacities. The research at this point needs to focus on refining the technique. And despite how the mainstream media tries to depict it, pressure from advocacy groups is being correctly aimed, not at short-circuiting the scientific method, but at overcoming the intransigence of the medical establishment.

Philip Lillies is a community and labour activist, secretary to the Moncton chapter of the Council of Canadians, secretary to the Moncton District Labour Council, and vice-president for the Public Service Alliance of Canada to the New Brunswick Federation of Labour. He lives in Moncton, New Brunswick, with his wife, Anne, who is afflicted with multiple sclerosis and is on a waiting list for angioplasty at a treatment centre in New York State.

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