



Charity Intelligence Canada

# **CCSVI in Canada Donor Choices for Underwriting Medical Research**

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Charity Intelligence today announces it will be building a syndicate of donors to underwrite the costs of CCSVI research in Canada. This syndicate will be a “pure play” with donations directed exclusively to medical research institutions with the capabilities to perform control studies investigating the CCSVI theory.

Interested donors can give to a specific research initiative, either the St. Joseph’s - McMaster initiative in Hamilton, ON or UBC in Vancouver, BC. Alternatively, Ci recommends a diversified approach to mitigate the inherent risks of medical research funding.

Ci has the capabilities to facilitate giving issuing tax receipts. We hope that Ci’s offices can remove the administrative burden on research institutions, enabling them to focus on the medical work at hand, and simultaneously ensure accountability to donors. We believe donating through Ci will guarantee that donations will have maximum impact in speedily getting CCSVI trials underway.

Time is of the essence. MS is a devastating progressive disease leading to permanent brain damage. Each year Canada spends \$1.1 billion assisting people with MS. Each year people with MS face growing disabilities and death. The question as to whether CCSVI is a valid theory can only be answered as quickly as funding is received.

We can wait for governments to respond, we can wait for others to provide the funding. We can wait for other countries to proceed. Or we can donate today to get CCSVI trials underway in Canada.

This power lies in the hands of donors. Ci hopes that this research report can help you make an informed giving decision that will have impact for Canadians in need.

Charity Intelligence Canada is a Canadian registered charity. Small donations are best made on-line by donating through Ci’s website to Ci’s CCSVI Research Syndicate provided by Canada Helps. Cheques in excess of \$1,000 can be mailed to Ci’s office, eliminating transaction costs.

We estimate that the syndicate has a total capacity of \$1.5 million. If additional funds are received beyond immediate needs, donors will be contacted to choose how they would like to reallocate their donation.

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**Become Informed. Give Intelligently. Have Impact.**

## Executive Summary

Recent developments in the research field of multiple sclerosis present a historic opportunity for donors to have high impact in their giving.

Since multiple sclerosis was first diagnosed in 1868, there has been no cure and no effective treatment abating this disease's progression. The leading thinking until recently was that MS is an autoimmune reaction, where the body begins attacking itself. This conventional wisdom has been contradicted by the published findings of Dr. Zamboni, of the University of Ferrara in Italy, proposing that MS is vascular in nature.

Multiple sclerosis is a debilitating disease that causes progressive disability. It is the number one neurological disease affecting young adults in their prime, with most people initially diagnosed between the ages of 20 and 40. Most people suffering from MS are unable to work 10 years after diagnosis, many living years with growing disabilities. It is also highly prevalent in Canada, affecting an estimated 44,000 to 78,000 Canadians.

Current drug treatments are ineffective in abating this disease's progression, and are expensive. The Canadian Institute for Health Information estimates that MS costs Canada \$1.1 billion each year.

Dr. Zamboni's research has sparked a drive around the world to thoroughly investigate these findings and see if they can be replicated. The questions are simple: Do people suffering from MS have blocked veins in the neck and upper chest and will alleviating these blockages reverse or reduce the progression of MS?

Undertaking the research to answer these questions requires funding. To date, the Hamilton initiative has raised \$50,000 out of a needed \$500,000 for the first phase of this research. The Vancouver/Saskatoon trial has received upwards of \$10,000 out of a projected \$1,060,000. The MS Society of Canada may award each of these initiatives \$100,000 in July 2010. For this research to get underway in Canada, Canadian donors will need to contribute.

And Canadian donors should contribute. CCSVI has promising initial results for people with MS. Last year Canadians donated \$62 million to charities in the MS field. Donors should re-direct some of this funding to underwriting CCSVI research by making restricted donations to the research initiatives planned to test this theory.

“We continue to believe this research will be integral to changing the way MS is defined and treated.”

– Dr. Robert Zivadinov,  
Buffalo Neuroimaging Analysis Center

Ci conservatively estimates that CCSVI, if found to exist in only 15% of Canadians suffering from MS, and where a simple non-invasive procedure using angioplastic surgery for \$1,000 can temporarily alleviate symptoms for 5 years, could produce cost savings of \$290 for every \$100 donated. If Dr. Zamboni's initial results hold true, a \$100 donation could produce over \$3,000 in savings to Canadians.

This is a unique time. Millions of dollars have been spent seeking a treatment for MS, with limited results. Today an opportunity has arrived to advance scientific knowledge, to socially invest in progress that could, if proven valid, save Canada over \$400 million annually, and assist in the advancement of effective treatment for people suffering from MS.

## Multiple Sclerosis: Overview

Multiple Sclerosis (MS) is a chronic, progressive, and disabling disease. MS is identified as the world's most common disabling neurological condition in young adults. The World Health Organization reports the total number of estimated people diagnosed with MS in the world is approximately 1.3 million.<sup>1</sup> People are typically diagnosed with MS between the ages of 20 and 40 years. Women are diagnosed almost three times more frequently than men.<sup>2</sup>

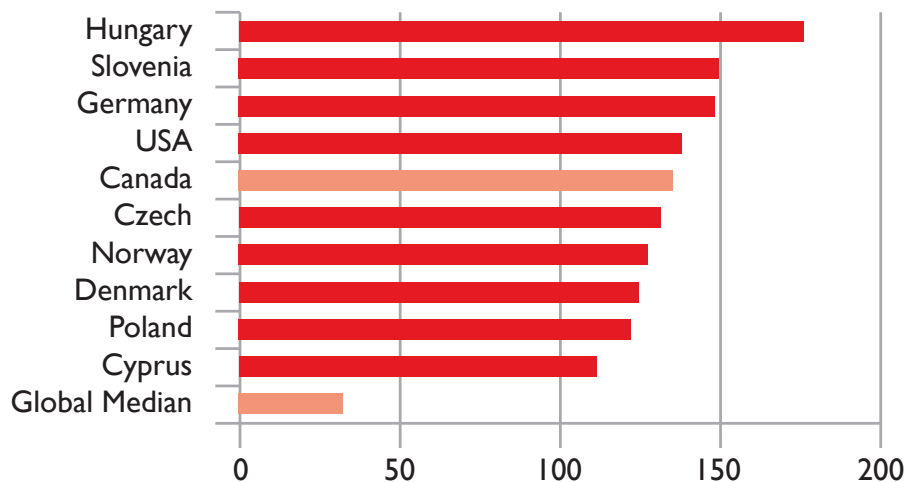
MS is identified by neurological symptoms in the body, with new symptoms occurring weeks, months, or years later.<sup>3</sup> Because the disease is progressive, the symptoms continually worsen, creating debilitating effects on individuals suffering from the disease for the rest of their lives. The course of the disease is unpredictable in any given person. Since the discovery of MS in 1868, there is no consensus on what causes Multiple Sclerosis.

## MS in Canada

The exact number of Canadians living with MS is unknown. Based on regional and international estimates, the number of Canadians with MS ranges between 44,000 and 78,000.<sup>4 5</sup>

Canada has the 5<sup>th</sup> highest number of MS sufferers per capita in the world (see Figure 1).<sup>6</sup> Saskatchewan has the highest prevalence of MS in Canada.<sup>7</sup> Worldwide, MS is most prevalent in Central Europe and North America.<sup>8</sup>

Figure 1: Estimated Prevalence of MS by Country (per 100,000)



Source: World Health Organization, 2008.

“It is our duty to find the answers.”

– Dr. Alex Rauscher,  
University of British Columbia

## Types of Multiple Sclerosis

People diagnosed with MS experience different symptoms and the disease progresses at varying rates. Initial diagnosis describes two types of MS:

**Relapsing-Remitting MS** is initially diagnosed in 85% of people suffering from MS.<sup>9</sup> People diagnosed with relapsing-remitting MS will typically experience a new or worsened symptom attack over a few days, remain constant for 3-4 weeks, followed by partial or complete recovery over the course of one month, where the symptom disappears for months or even years.<sup>10 11</sup> Roughly 15% of people diagnosed with relapsing-remitting MS will experience minimal disability 15 years after diagnosis.<sup>12</sup> Half will develop progressive MS 10 years after diagnosis with increasing disability (commonly referred to as secondary-progressive MS).<sup>13</sup>

**Primary Progressive MS** is less common and initially diagnosed in 15% of people with MS.<sup>14</sup> Primary progressive MS is characterized by a slow, nearly continuous worsening of symptoms from the onset with no distinct period of recovery.<sup>15</sup> A small percentage of people have a type of MS that results in rapid disability and death in a shortened period of time, or steady worsening with clear relapses of symptoms.<sup>16 17</sup>

## The Human Costs of MS

### Health and Employment

MS has devastating effects on an individual's quality of life for many years. Symptoms of the disease range from mild numbing, pain, and extreme fatigue, to more severe symptoms of paralysis, blindness, or loss of bodily function.<sup>18</sup> Simple tasks such as walking, reading, or holding utensils become impossible feats. Up to 60% of people with MS are no longer able to walk 20 years after onset.<sup>19</sup> Half of all patients with MS suffer some extent of brain damage.<sup>20</sup>

People with MS are often unable to work full-time and many experience total disability. Roughly 70% are not working 5-10 years after they are diagnosed, which is significantly higher than adults with other disabilities.<sup>21</sup>

### Life Expectancy

MS shortens the life expectancy of most people with MS by 6-7 years compared with the general population, with 40% of people living into their 70s.<sup>22 23</sup> However, two thirds of deaths are directly related to consequences of the disease.<sup>24</sup> MS is a progression towards an early life of dependency on others. Furthermore, the unpredictable nature of new or returning attacks creates a life of living in uncertainty. Nearly 50% of people with MS experience depression, almost 3 times the rate of the general population.<sup>25</sup> Intent to commit suicide occurs in 30% of MS sufferers, with suicide rates being up to 7.5 times higher than the general population.<sup>26 27</sup>

## The Economic Costs of MS

Adjusting for inflation, it is estimated that the associated costs of MS (health, mortality, and morbidity costs) totalled \$1.1 billion in Canada in 2009.<sup>28</sup>

Annual direct service costs of hospital care, physician care, and drugs accounted for \$165 million (42%, 9%, and 49% respectively).<sup>29</sup> In Ontario it is estimated that disease-modifying drugs can cost upwards of \$40,000 per MS patient per year.<sup>30</sup> These cost estimates exclude additional or alternative therapy costs that people with MS pay.

Indirect costs accounted for \$960 million; 79% of which were from loss or decrease of employment and productivity, coupled with an increase in social service costs, like pension and disability claims.<sup>31</sup>

## Current Treatment & Symptom Management of MS

The cause of MS is unknown and there is no known cure. People with MS are currently treated for their symptoms. Quick and early intervention is critical as significant brain and nerve damage is evident in MRI scans before a patient recognizes symptoms.<sup>32</sup>

Since the 1990s, medicine has helped to slow the level of disability, progress, and symptom severity in some patients with MS.<sup>33</sup> These medications are only available to patients with the relapsing-remitting form of MS. MS patients are injected daily or weekly.<sup>34</sup>

Clinical trials have shown these drug therapies are only modestly effective for relapsing-remitting MS patients.<sup>35</sup> No treatment has been proven effective in primary progressive MS.<sup>36</sup> Additional symptom-specific medications and alternative therapies are currently used in combination for the treatment of progressive symptoms in patients with MS.

## The Autoimmune Theory & Multiple Sclerosis

The prevailing theory in MS research is that MS is autoimmune in nature. This theory states that the immune system attacks the central nervous system. Over time, it continues to increase damage and scarring to the optic nerves, spinal cord and brain, producing the worsening symptoms associated with MS. As the disease worsens and more damage is caused, more severe symptoms appear. Permanent neurological damage occurs as the disease advances.<sup>37</sup>

The trigger for this autoimmune attack has not been identified. MS research is investigating the environmental, viral, and genetic factors that might prompt these attacks. In addition, other areas of research in the autoimmune theory focus on immunology and stem cells.

“...there are millions and millions of dollars donated to MS Societies ...and right now, 99.9 per cent of that money goes somewhere else.”

– Dr. Mark Haacke,  
McMaster University

“...I am confident that this could be a revolution for the research and diagnosis of multiple sclerosis.”

– Dr. Paolo Zamboni,  
University of Ferrara

### A New Approach: Chronic Cerebrospinal Venous Insufficiency

In 2007, Italian vascular surgeon Dr. Paolo Zamboni tested a century-old concept that MS was vascular in nature, rather than an autoimmune disorder. In tests, Zamboni discovered a condition called Chronic Cerebrospinal Venous Insufficiency (CCSVI). CCSVI refers to a condition of a narrowing or blockage of the primary veins in the neck, chest, and/or spine, reducing the efficiency of blood draining from the brain to the heart.<sup>38</sup> As a result, blood often flows backwards into the brain, pushing into tissue around brain vessels causing inflammation as well as cell and brain damage.<sup>39</sup>

The study's findings propose a radical shift in conventional theories and approaches to understanding and treating MS. The absence of CCSVI in people without MS and evidence that malformations of CCSVI precede the development of MS (and not the consequence of MS), suggests that vein blockages are perhaps the cause of MS rather than a coincidence. If proven, this research would reveal that MS is not an autoimmune condition but a vascular disease.<sup>40</sup>

### Ongoing Progress

The CCSVI study is being replicated worldwide. This is required due to the limitations of the study. The diagnostic protocol/procedure for identifying patterns and extent of CCSVI in patients was performed only once and by a single team of investigators. Therefore it does not meet statistical and professionally-acceptable standards of reproductability.<sup>41</sup> It needs to be thoroughly investigated whether or not Zamboni's observations and diagnosis would be made if investigators reviewed the patients a second time. Furthermore, would the same observation and conclusion be made if two or more investigators were to review the patients a second time? The investigative team also noted a need for longitudinal studies, and advanced MRI analysis to determine the complexity of primary-progressive MS and various patterns of CCSVI in people with MS. Replication using a matched control group for treatment would also further validate findings.

## Preliminary Findings of CCSVI: Extracts from Medical Journals

Dr. Zamboni's first study used Doppler ultrasound to assess the heads and necks of 89 MS patients with relapsing-remitting and secondary-progressive MS, and 60 without.<sup>42</sup> Problems associated with CCSVI (narrowing, twisting, blockage, or absence of veins) were found in the participants with MS, in theory leading to plaque deposits, brain lesions, and scarring associated with symptoms of MS, which was not evident in those without MS.<sup>43</sup> To date, Dr. Zamboni has scanned the heads and necks of over 500 MS patients finding the same concurrence in almost all cases.<sup>44</sup>

In 2008 and 2009 Dr. Zamboni, Dr. Galeotti, and Dr. Menegetti published in medical journals additional findings of a pilot study they conducted on CCSVI and its prevalence in patients with MS. Identifying 4 patterns of CCSVI vein blockage, they decided to perform experimental treatment surgery to unblock the veins to release blood flow.<sup>45</sup> Similar to angioplasty, used to open blocked blood vessels to the heart, doctors inserted and inflated a balloon catheter in the narrow or blocked area(s) of the vein in 65 participants with MS. The balloon allowed the blood to flow freely and drain from the brain. The percentage of active lesions fell from 50% to 12% in comparison scans taken 18 months later.<sup>46</sup> These results suggest that the additional treatment of CCSVI reduces the aggressiveness of the disease.<sup>47</sup>

This finding was further confirmed by the number of patients who showed no relapses after endovascular surgery. In the 2 years before surgery, acute MS attacks were found in 50% of the patients, while in the 18 months following surgery 73% of the patients had no more attacks.<sup>48</sup> All participants reported significant and persistent improvement in cognitive and motor activities.<sup>49</sup>

In participants with progressive forms of MS, the same effect was not achieved, but the surgery apparently stopped disease progression.<sup>50</sup> All participants had improved quality of life.<sup>51</sup>

Dr. Zamboni et. al.'s findings suggest that the experimental CCSVI surgery is most effective in patients with minor damage and blockage to the veins. People with progressive MS may require a more sophisticated procedure, such as the use of stents to open blocked veins. This has not yet been proven to be a safe treatment in patients with progressive MS. The risk of re-narrowing or blockage is 16 times higher in the jugular veins than in the azygos vein, pointing to the need for more sophisticated and efficient tools to approach treatment of the former.<sup>52</sup>

“...this particular research is having an impact like no other we have known.”

– Dr. Robert Zivadinov,  
Buffalo Neuroimaging Analysis Center

### Preliminary Findings

The Buffalo Neuroimaging Analysis Center and the Jacobs Neurological Institute at the University of Buffalo have a CCSVI study underway. This centre is associated with Dr. Zamboni and reported that in scans of 16 MS patients and 8 controls, all MS patients and zero controls had CCSVI. They plan to announce shortly the findings of CCSVI prevalence in the first stage of testing that comprised 500 patients.<sup>53</sup>

Unconfirmed reports from a blog site associated with the False Creek Surgical Centre, a private facility in Vancouver, BC, reports having scanned 45 people. It has found significant narrowing of veins in 6 patients, and vein abnormalities in 15 other patients which may or may not be significant.<sup>54</sup>

Although we have not heard that they have plans for a study, Canadians can also have screening done at Westmount Square Medical Imaging in Montreal, Quebec.

### Funding CCSVI Research: A Potential High Impact Giving Opportunity for Donors

The CCSVI findings create an exciting time in MS research around the world and a new opportunity for donors and foundations. Donors can directly fund the preliminary research into the prevalence of CCSVI in MS patients. 12 organizations are rumoured to have submitted applications to the MS Society of Canada for funding to validate or invalidate the CCSVI study findings of Dr. Zamboni et al. Ci has attempted to contact anyone we thought or were referred to as potential applicants across Canada. To date, Ci has identified 2 separate initiatives seeking funding to undertake CCSVI research in Canada.<sup>55</sup>

Ci estimates large potential returns on donations if the clinical treatment of CCSVI proves to be effective, even for a minority of Canadians suffering from MS. This return is in addition to the potentially significant improvement in quality of life for MS sufferers. Obviously, funding medical research is a high-risk but potentially high-reward gamble. Yet Ci believes that even if funding allows the Canadian initiatives to proceed, and these studies find no evidence of CCSVI in relation to MS, this knowledge alone is a valuable investment in advancing medical research.

Estimates of the total cost to complete the diagnosis of damage to the veins (the presence or absence of CCSVI) and the minimal invasive surgery would be \$1,500 per MS patient.<sup>56</sup> There is potential for large cost savings to Canada and to many individuals with MS if replication of the study can be carried out and positive findings reproduced.

Ci conservatively estimates that if only 15% of the Canadian population with MS is found to have CCSVI and a successful procedure can be performed on only 25% of those with CCSVI (where success is defined as improving life to the extent that the cost of MS for an individual is reduced by 50% for 5 years) a \$100 donation would yield a \$290 savings to Canadians. If results are more in line with Dr. Zamboni's preliminary findings, a \$100 donation could yield a return of over \$3,000.

“...Even if it is 10 or 20 per cent of these people who can be helped, that needs to be investigated.”

– Dr. Mark Haacke,  
McMaster University

**Table I: Ci Projected Returns on Social Investment**

	<b>Optimistic</b>	<b>Conservative</b>
% with CCSVI	90%	15%
% Success rate	85%	25%
Return on \$100 investment	\$3,090	\$290

### Donor Risks

Funding medical research is inherently a high-risk venture. It costs a lot of money with the rare occurrence of a medical research finding improving health. Ci believes that these high risks are somewhat mitigated by the CCSVI screens seeking to replicate a preliminary idea already put forward, rather than re-inventing the wheel. Furthermore, the costs of undertaking these screens is reasonable.

Undertaking a sufficient sample size of images is relatively simple. The problem may be in consistently applying standard protocols to ensure analysis is correct. With many different centres undertaking screens, there is a higher probability of different results.

In medical research, Ci believes the largest cause of delays in producing results is typically the lack of people willing to be involved in clinical trials. Given the MS community's response to the CCSVI news, Ci does not foresee this as an investment risk. Medical sites are currently overwhelmed with inquiries from people with MS asking to be involved.

As in making any donation or investment, the ability of management to execute the plans in a cost-efficient, timely, and transparent manner is always an inherent risk.

There are large stakes involved in the pursuit of scientific knowledge. Doctors and organizations may have varied motivations for undertaking CCSVI research. Funders need to be aware of the different associations of organizations and their specialized fields. Ci trusts that the research will be conducted with the highest professional integrity, but cannot independently verify this.

Furthermore, it is unknown at this stage what accounting and auditing controls are in place to verify the use of funds for designated purposes.

Despite these risks, the potential benefits and reasonable costs of validating CCSVI warrants the need for study replication and examination.

### **Donating to Current Canadian Research Studies**

To donate to one of the Canadian teams planning to research CCSVI, donations can be either flowed through Charity Intelligence (at 100% flow-through) or donated directly to the initiatives. If your donation is made directly, to ensure that it has the most impact, please specify that it is for research into CCSVI. For the Hamilton initiative, donations can be made to St. Joseph's Healthcare. For the Vancouver/Saskatoon initiative, donations can be made to the UBC Faculty of Medicine.

If other Canadian institutions are conducting, or planning to conduct, research into CCSVI and require funding, please contact Charity Intelligence.

Table 2: Comparison of CCSVI Canadian Research Teams

	<b>Hamilton CCSVI Study</b>	<b>Vancouver/Saskatoon joint CCSVI Study</b>
Study Size	100 MS patients 100 matched controls	100 MS patients 100 matched controls
Team	9 members The Brain Body Institute (St. Joseph's Health Care & McMaster University), Hamilton General Hospital	8 members University of British Columbia MS Clinic (Vancouver Coastal Health Authority), UBC Faculty of Medicine & University of Saskatchewan
Team Strength	Multidisciplinary team with track record in evidence-based medical research, for-profit experience	Multidisciplinary team, MR & MS research track record, database of MS patients to address genetics of CCSVI
Ethical Approval	Approval to move forward	To be submitted, pending approval
Pre-study plans	N/A	Pilot study: Protocol test of 10-15 subjects (pending UBC Clinical ethics approval) prior to starting Phase I (evidence must support moving forward)
Study Location	Hamilton Citywide: MR imaging at St. Joseph's, Ultrasound at Hamilton Health Sciences McMaster	Two province site study: 2/3 participants tested at UBC, 1/3 Saskatchewan
Estimated Cost of Phase I: Diagnostic (staff, testing, misc.)	\$400,000	\$660,000
Additional funding for Phase I: Diagnostic Screening	With additional funding of \$100,000 to hire an additional technician, Phase I may be able to be completed in a shorter timeframe	Hardware upgrade to enable increased quality of image in less time and scan the veins in the stomach. The study is coupled with other ongoing research and clinical trials, namely if CCSVI is correlated with genetic, environmental, or epigenetic factors. Est. cost: \$500,000
Total	\$500,000	\$1,060,000
Funds raised to date	\$50,000	\$10,000
Phase I Diagnostic Protocol	<ul style="list-style-type: none"> <li>• MR machine (3T)-research dedicated</li> <li>• Ultrasound</li> </ul>	<ul style="list-style-type: none"> <li>• MR machine (3T)-research dedicated</li> <li>• Ultrasound</li> <li>• Catheter Venography</li> </ul>

The information and opinions in this report were prepared by Charity Intelligence Canada and its independent analysts. Factual material information is obtained from reliable sources or received from the charitable organization. Information may be available to Charity Intelligence Canada or its analysts that is not reflected in this report. Charity Intelligence Canada and its analysts have made endeavours to ensure that the data and opinions in this report are accurate and complete, but accept no liability.

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