

Hello and warm wishes.

Before I begin, I want to pay tribute to all of you, who bravely fight MS every day, and who are fighting so hard for help here in Canada.

I want you to know that working with you has been one of the most humbling experiences of my life, and that I am always an email away to listen, to help.

I thought an up-date on my activities might be helpful to you (the up-date starts from last spring...some of you might want to scroll down to the end for the most recent information):

As you know, I came to Parliament Hill in order to fight for neurological disease, including MS. I was aware there were treatments available overseas that were not available to Canadians. I therefore garnered all-party support for a House of Commons Sub-Committee on Neurological Disease.

On May 6th, myself and Liberal Health Critic, Dr. Carolyn Bennett, wrote an open letter to Federal Health Minister, Leona Aglukkaq regarding CCSVI, but we

have yet to receive a response.

[https://www.liberal.ca/en/newsroom/media-releases/18090\\_open-letter-to-health-minister-leona-aglukkaq](https://www.liberal.ca/en/newsroom/media-releases/18090_open-letter-to-health-minister-leona-aglukkaq)

On May 10th, I asked for an emergency debate regarding CCSVI, but unfortunately it was denied. I immediately asked for a take-note debate.

I have written several Order Paper questions on CCSVI—the Government has 45 days to answer these questions. I will paste the most recent one below; it concerns the CIHR process, as well as follow-up care.

The Sub-Committee on Neurological Disease had four hearings on CCSVI. On Tuesday, June 15th the Sub-Committee heard from Dr. Zamboni (Italy), who pioneered the 'liberation' procedure to treat CCSVI, and Dr. Simka (Poland), as I passed a motion for them to present. The link below will allow you to listen to the session:

<http://www2.parl.gc.ca/CommitteeBusiness/CommitteeMeetings.aspx?Cmte=SMND&Language=E&Mode=1&>

[Parl=40&Ses=3#DT20100615SMNDMEE8](#)

The take-note debate was finally granted by the government, and took place on Monday, June 14th. The link below will give the debate; please scroll down to 7:10pm for the start:

[http://www2.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&Parl=40&Ses=3&DocId=4622318](#)

I travelled to New York City at the end of July to attend the second Professional Symposium on CCSVI so I would know the absolutely latest science.

[http://www.liberal.ca/newsroom/blog/new-hope-in-the-fight-against-multiple-sclerosis/](#)

On August 20th, Dr. Bennett and I wrote another open letter to the Health Minister:

[http://kirstyduncan.ca/LatestNews.aspx?id=1927](#)

On our first day back in Parliament, I read the following statement (1 minute):

[http://www2.parl.gc.ca/HousePublications/Publication.a](#)

[spx?Language=E&Mode=1&Parl=40&Ses=3&DocId=4656017](http://www2.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&Parl=40&Ses=3&DocId=4656017)

On our third day back, I presented the following (5 minute-late show; if you go to the link, scroll down to 6:30)

<http://www2.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&Parl=40&Ses=3&DocId=4658923#OOB-3280397>

I have since presented two more late shows regarding CCSVI.

<http://www2.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&Parl=40&Ses=3&DocId=4699810#OOB-3383977>

(scroll down to ~6:45 pm)

<http://www2.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&Parl=40&Ses=3&DocId=4716906#OOB-3409859>

(scroll down to ~6:45 pm)

On December 7th, Dr. Alain Beaudet appeared in front

of the Neurological Sub-Committee as a result of my motion, in order to up-date the committee on the expert panel established to address CCSVI.

<http://www2.parl.gc.ca/HousePublications/Publication.aspx?DocId=4855965&Language=E&Mode=1&Parl=40&Ses=3>

On the last sitting day of the House for 2010, I read a one-minute statement about the science and the need for follow-up care.

<http://www2.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&Parl=40&Ses=3&DocId=4899600#OOB-3695922>

On February 8th, I hosted Drs Mark Haacke, David Hubbard and Sandy McDonald at a breakfast for MPs and Senators so that the latter could learn the latest science regarding CCSVI. We all called on the Government to ensure follow-up care, and to undertake clinical trials and a registry.

Last week, I spoke in Poland at the request of Dr. Marian Simka on CCSVI and MS.

<http://www.vefconference.pl/page8.php.htm>

I would like you to know that my last words of the speech were to all those living with MS. ‘Thank you for your courage, your tireless efforts ... you inspire me every day.’

On Thursday, March 10th, I hosted MS patients at a breakfast for MPs and Senators so that they could hear the patients’ perspective. My invited guests spoke passionately.

I know the tremendous courage it takes to live with MS, and will continue to advocate on behalf of all Canadians living with multiple sclerosis.

Yours very truly,

Kirsty

Dr. Kirsty Duncan MP, Etobicoke North

Q-9512 — February 7, 2011 — Ms. Duncan (Etobicoke North) —  
With respect to chronic cerebrospinal venous insufficiency (CCSVI), the liberation treatment, and multiple sclerosis (MS): (a) what consensus documents have been published regarding the

diagnosis and treatment of CCSVI, (i) by whom, (ii) on what dates, (iii) what were the recommendations, (iv) were they reviewed by the August 26, 2010, meeting of the Canadian Institutes of Health Research (CIHR) in collaboration with the Multiple Sclerosis Society of Canada (MSSC); (b) why were Canadian members of the International Union of Phlebology (IUP), who were part of the Consensus process regarding the diagnosis and treatment of CCSVI, not consulted during the August 26 meeting of the Canadian Institutes of Health Research (CIHR); (c) what are the details of any plan the government has or is developing to collect evidence regarding the diagnosis and treatment of CCSVI, for example, through clinical trials or the creation of a registry; (d) what percentage of surgical procedures in Canada have been double-blind tested over the last 40 years and, for this percentage, (i) what is the risk of complication, (ii) what is considered an acceptable risk of complication, (iii) how do physicians judge acceptable risk and convey this risk to their patients, (iv) what actions do physicians take to reduce risk if the patient chooses to undertake the procedure; (e) when a medical treatment appears to be potentially effective, is its approval ever fast-tracked by the relevant Canadian authorities and, if so, (i) what are any examples of this in Canada over the last five years, (ii) has this ever happened with respect to MS, (iii) if so, who advocated for a fast-tracking and when, (iv) what process was followed to allow the treatment, (v) who made the decision to proceed, (vi) why was fast-tracking deemed necessary, (vii) what were the known risks at the time of the request, (viii) what, if any, negative impacts

resulted; (f) what are the reasons for the length of time it has taken the relevant Canadian authorities to implement clinical trials or to develop a registry; (g) why did no member of the August 26 group declare any conflicts of interest, either real or perceived; (h) how many liberation procedures did the August 26 group estimate have been undertaken, (i) which countries were undertaking the procedure, (ii) to which countries were Canadians travelling, (iii) were the practitioners considered to be sufficiently trained, (iv) were the procedures in these countries found to be safe; (i) which people, labs and operating theatres had undertaken the diagnosis or treatment of CCSVI in Canada prior to the August 26 meeting; (j) why did the August 26 meeting not include Canadian experts in the imaging or treatment of CCSVI and for what reasons was Dr. Sandy McDonald not included as a participant; (k) why did the August 26 meeting not include international experts in diagnosis and treatment of CCSVI, data presented at international scientific conferences or site visits to labs and operating theatres, which were or had been undertaking diagnosis or treatment; (l) what is a comprehensive explanation of why the inclusion of CCSVI and liberation experts might have biased the sample of the August 26 group and whether such selection is an established practice at all CIHR meetings; (m) what are all the names of the group members who had spoken out against diagnosis or treatment of CCSVI or the liberation procedure prior to the August 26 meeting, what were the details of their positions, and what are their publically-available comments on the matter; (n) who were all the members of the August 26 group and, for each member, what were his or her stated

or declared conflicts of interest or perceived conflicts of interest; (o) what was the August 26 group's assessment of and comments concerning all reviewed published papers, including both positive and negative observations; (p) did the August 26 group find it unusual that two of the reviewed papers had been accepted for publication in only six weeks, (i) did the group review whether this is a common practice in medicine, (ii) did the group consider how and why this might happen, (iii) did the group explore the expertise of those writing the papers, their experience, how their results compared with those of Dr. Zamboni and, if so, (iv) what were the group's findings for questions posed in (iii); (q) which neurologists, present at the August 26 meeting, had followed MS patients who were diagnosed with CCSVI and who had been treated for the condition, (i) how had neurologists followed them (e.g., appointment, EDSS score/another scale, MRI, neurological exam, etc.), (ii) what, if any, evidence did they present of patients' progress following the liberation procedure; (r) did the August 26 group find the reversal in the MSSC's position, who was part of the greater group, unusual, (i) did the group investigate or consider the reasons for this change in position and, if so, (ii) what observations did it make or conclusions did it come to regarding the reversal; (s) did the August 26 group estimate how its decision might impact Canadian MS patients, including (i) impacts on their mental health and how this might impact their disease, (ii) the number of Canadian MS patients who might feel forced to seek help outside Canada, (iii) how air travel, a compromised vascular system, recent surgery, and lack of follow-up in Canada might impact their

disease and, if so, (iv) what are the results of those estimations; (t) what consensus documents are forthcoming, (i) by whom, (ii) when will they be published; (u) what is the work plan for the new expert working group which met for the first time on November 23, 2010, (i) who are the panellists, what are their qualifications and what is their expertise in diagnosis and treatment of CCSVI, (ii) how were the panellists chosen and by whom, (iii) what is the group's mandate and how was it derived, (iv) what is the schedule of meetings, (v) what is the timeline for the group's work, (vi) what evidence will be reviewed to reach any decision about possible clinical trials, registry, diagnosis, treatment, follow-up care, etc.; (v) what was the agenda for the November 23 meeting of the expert working group, (i) what abstracts, documents, and presentations were reviewed, (ii) which Canadian and international experts, with experience in diagnosis and treatment of CCSVI, were consulted, (iii) what Canadian and international unpublished data were explored, (iv) what Canadian and international labs or operating theatres were reviewed and visited; (w) for what reasons is the new group going to analyze interim and final results from seven studies funded by the Canadian and US MS Societies and why are these studies considered more worthwhile cases for analysis than other studies already completed; (x) when will the November 23 expert panel declare and post any conflicts of interest, following the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) guide, on the CIHR website to eliminate the possibility of real or perceived conflicts; (y) further to assurances made by the President of CIHR, Dr. Alain

Beaudet, to the Subcommittee on Neurological Diseases on December 7, 2010, that MS patients who have had the liberation procedure would have follow-up, what are the details of how that follow-up will occur, specifically, (i) how will “a message be sent”, by whom, to whom, by when and what will the message be, (ii) specifically, will all patients who travel or travelled outside Canada be assured that their doctors will see them, that appointments will not be cancelled, that tests will not be cancelled, that they will have access to recommended prescriptions, that they will not lose their long-term care and that they will not be berated for making the decision to have liberation, (iii) how will this be enforced, (iv) what action should MS patients take if they are denied care, (v) to whom should they report a denial of care, (vi) what are the consequences for a physician or health practitioner or organization who delivers care but fails to provide follow-up care, (vii) will follow-up include ultrasound or MRI to image the veins of MS patients and, if so, how often will these imaging procedures occur and who will pay for them?