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Thursday, May 6, 2010

Chair

Mrs. Joy Smith

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● (0730)

[*English*]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): Order, please.

Welcome. As the national health committee of Canada, we have had discussions in our regular health committee on this issue of neurological diseases. We have created a subcommittee to do a study on this. I know all members around this committee table are very keen on making sure that we do continue this. I've heard it from you and I've heard it from the members here.

This morning we have one hour in this subcommittee, because we do have another committee following this. So I'm going to give each of the presenters five minutes. Please send any documentation you might have to our clerk, and she'll make sure it is distributed to the health committee so that the dialogue will go on through the printed media.

We will begin with the Multiple Sclerosis Society of Canada and Mr. Yves Savoie, the president and chief executive officer. You have five minutes for your presentation, Mr. Savoie.

Mr. Yves Savoie (President and Chief Executive Officer, Multiple Sclerosis Society of Canada): Thank you, Madam Chair.

[*Translation*]

I will address you in French, to begin with, if you don't mind. Thank you for your invitation to appear this morning. It is greatly appreciated.

The Multiple Sclerosis Society of Canada is the leading national organization supporting people affected by this progressive disease. Our mission is to find a cure for this disease, to stop MS and to improve the quality of life of people affected by it. Thirty thousand people with MS are members of the Society, right across the country.

We are pleased to be able to work very closely with other organizations that support people with neurological diseases, including Alzheimer's and Parkinson's, to foster a better understanding of these illnesses and support the development of policies that meet the needs of Canadians affected by neurological diseases.

[*English*]

Neurological diseases will, within 20 years, be the leading cause of disability and death in our country.

I have colleagues who have joined me and will speak to issues that are important as we come to Parliament Hill today. They will speak on issues of income security and support for informal caregivers—family members and friends—and I'll reserve my final minutes to speak to the area of research.

Research into understanding the cause, how to prevent, and the eventual cure of MS has been at the heart of our work in our 60 years of history. We have funded $120 million in health research, and that grows by about $10 million a year.

The Neurological Health Charities Canada coalition is advocating with the federal government for the government to develop a brain strategy that would, among other things, bring focus on research on neurological disease. I think we can, as Canadians, find tremendous pride in the leadership of researchers in this country in MS research, and more broadly in the area of neurosciences. The Canadian Institutes of Health Research, in their most recent strategic plan, acknowledged this as a priority, reflecting the tremendous strength of research in these areas.

You have all heard, no doubt, of the very exciting new pathway for discovery and new therapy in MS, now very well known as CCSVI, which speaks to the obstruction of veins that drain the blood from the brain. It is important to underline that the society, with a call for research applications, responded vigorously and without precedent by launching a request for proposals from Canadian researchers just in the last months. On June 14, I will be delighted to be in a position to announce the results of that competition.

CCSVI is, I think, a very compelling example of the appetite of Canadians to see very, very rapid translation of new discoveries into treatments that provide benefit and improvements to our health as Canadians. This is at heart the central issue that we face in this context, combined with the need for evidence about that benefit. That is why we have pressed on the accelerator with our own commitments to research, and it's why, in our meeting with the Minister of Health at the end of the day today, we will be asking her, as we announced yesterday, for an incremental commitment of $10 million that would be added to the parliamentary budget appropriations for the CIHR as a designated CCSVI research fund.

The model for this, by the way, is available in a similar supplemental appropriation to the CIHR for research on medical isotopes.

This idea of the translation of research into benefits for Canadians in terms of improved health is also at the heart of a very important strategy of the CIHR called the “patient-oriented strategy”. That strategy is fundamentally about equipping Canada to make sure that new discoveries don't stay in the lab or in the researcher's mind but that they come as quickly as possible to benefit Canadians and become available through our health systems throughout the country in a way, obviously, that makes them publicly available to everyone.

With that, I thank you, members of Parliament, for your time and for this opportunity for a conversation about these important issues.

Merci.

● (0735)

The Chair: Thank you.

We'll now talk to Mr. Denis Baribeau, who is the representative of social action and government relations for the Quebec division.

[*Translation*]

Mr. Denis Baribeau (Representative, Social action and government relations for Quebec Division, Multiple Sclerosis Society of Canada): Good morning and thank you for giving me this opportunity to address you today.

My name is Denis Baribeau and I work as a volunteer at the Multiple Sclerosis Society of Canada. I have the good fortune to be married and the father of two young adults, aged 18 and 21. I was born in Trois-Rivières, Quebec, where I still reside.

In 1982, shortly after graduating with a degree in civil engineering, and shortly before I was to be married, I experienced my first symptoms of multiple sclerosis. Because of diagnostic methods in use at the time, following my first episode, doctors could only assume that I had MS. Then a second episode occurred several years later, which confirmed the diagnosis. At the same time, I consider myself to be lucky because, although I regularly use a wheelchair, I am not affected by the extreme fatigability that afflicts many people with multiple sclerosis. In many cases, that fatigue prevents people from working, even part time.

Since I was diagnosed with multiple sclerosis, I have only missed five days of work—something which happened after a third episode left me partially paralyzed on my left side. But that does not mean it has been easy: I have had, and still have, to fight to keep my job and convince my superiors that I am still able to carry out my duties, even if they see me sitting in a wheelchair. At one point, I was very concerned that I would lose my job and, as I sought employment elsewhere, more than once I came up against people's prejudice. Even though my résumé interested potential employers, their vision radically changed when they saw me come in in a wheelchair. Even today, as an engineer by training who works as a technician, I am regularly invited to sit exams towards a promotion which I pass. And yet, when the time comes to fill positions that would be suitable for me, I am always ignored.

I am very happy to have been able to keep my job until now. You can believe me when I say that I don't see myself as a home husband. I am aware of the fact that many people don't have the opportunities that I have had. I regularly meet with people who have MS, who have lost their jobs and didn't have the energy to defend themselves. Now it is even more difficult for them to re-enter the workforce.

One of the recommendations being made by the MSSC is that people affected by multiple sclerosis or any other neurological disease receive support through more flexible employment insurance sickness benefits. We would like recipients to be able to retain their job attachment. That could be accomplished by allowing them to work part-time at the same time as they are receiving partial sickness benefits. The current regulations could be used to allow recipients to receive partial benefits while they are working part-time. That way, they could receive employment insurance for 150 half days, rather than 15 weeks, or 75 days, as is currently the case. Based on my own experience, the ability to retain one's job attachment would mean that a lot more people could go back to work, rather than having to give it up altogether. Making health insurance and employment insurance benefits more flexible is only one of many changes that are needed to support people with episodic or chronic illnesses or disabilities, to provide them with the income security they need. In our opinion, those changes could be implemented immediately.

Thank you for giving me this opportunity to address you today.

● (0740)

[*English*]

The Chair: Thank you very much for coming, Mr. Baribeau. Because you have a little more time, I want to comment that we're good friends with Steven Fletcher. He doesn't have MS, of course, but as the result of an accident, he's confined to a wheelchair. Some of the things you've testified about in your position with MS, he also faced before he came to Parliament.

Listening to your story, it is one we've heard many times. I'm really glad you came here today to put it on the record and give your witness about what has happened to you. I know it must be kind of difficult to be so personal sometimes, but thank you for doing that.

Now we'll go to Ms. Ozirny.

Ms. Joan Ozirny (Chair, Government and Community Relations Committee, Alberta Division, Multiple Sclerosis Society of Canada): Good morning, and thank you.

I'm a volunteer at the MS Society in Alberta, the Alberta division. I've been a volunteer board member for nine years in various capacities and am currently with the government relations committee at the Alberta division.

This morning I want to touch on why we all volunteer for the MS Society when we have MS. For many of us, this is a transient disease, and as you can see, a variety of us in the room have various symptoms. We generally want to make sure that we give back while we're still stable enough to do so. We don't want to look back with regret and think, I should have done that when I could have, when my health was stable.

I was diagnosed 12 years ago, after a very difficult three-year period of being diagnosed, being undiagnosed, and then finally being diagnosed again. That's often the case for people with MS, simply because the symptoms are very transient.

But more specifically, I think the issue is often that because MS is a transient disease, there's a lot of misunderstanding around the tax credit issues and caregiver issues that arise from that. Typically, we don't fit the mould of every other disease those programs are often designed for.

I'll touch a little bit on the caregiver issues further on in my presentation, but specifically, for me, the primary symptom I had to deal with was vision loss. That seems like a pretty severe symptom, but it doesn't necessarily always lead to a diagnosis. Eventually, I was out of the workforce; I was forced to sell my retail business. Prior to being diagnosed, most people will certainly have symptoms over a period of time that they really ignore, or they don't know what the situation is. Given the transient nature of the disease, they certainly get better and go back to doing their daily things.

Right now I'm very fortunate. While I'm no longer in the workforce as a contributing Canadian, as it were, certainly my health is stable and I am able, with the help of disease-modifying therapies, to contribute to the MS Society in a variety of ways as a volunteer. I do have the benefit of a supportive family, which I appreciate, but certainly at one time in my life, many years ago, I was a single parent with small children, so I understand some of the issues that people with limited income are facing and the fact that they rely on programs to help them face their daily challenges.

Some studies have found that up to 80% of people with MS can no longer work. That's a staggering number of Canadians that are no longer able to contribute. The other fact that often isn't talked about much is the really staggering divorce rate amongst people with MS. That in itself places a huge burden on social programs, because the disease generally affects more women than men. That's something to consider when you think about programs specifically for women. So I want to touch on that a little bit today.

As we're meeting with government today, we want to make sure that our income security program for people affected with MS—and also other episodic disabilities and chronic diseases—is geared to actually making a difference.

Finally, I wanted to tell you a story about some people I know. We often hear these stories, but when you actually know people in a situation like this, it's very difficult to present the information. There's a couple I'm familiar with in the Edmonton area. The wife is now in long-term care. And they are a young couple; they are not elderly people, but in their forties.

● (0745)

The wife was diagnosed some years back, about 11 years ago, and her disease progressed very rapidly. In the situation they were in, they were told by social workers that, really, for the wife to be able to access the services she needed to live, they needed to have a legal separation. Think about a couple who are committed to each other and are told that in order to receive the services they need, they are required to have a legal separation.

When I was telling them that I was working on this project right now and was planning to come to Ottawa to do a presentation, I asked them what would really have made a difference. They said, well, think about checking that box—married, divorced, separated—when you're doing your income tax. How about having a box that says, involuntary separation?

The Chair: Thank you. That's something we'll take into consideration.

I'm sorry, but I'll have to go on from here.

We have one more person. I might have to watch your time a little closer, Ms. Radley. You do have five minutes, and you can begin now.

Then, Dr. Duncan, we're going to do our seven minutes, and we're going to push it a bit so we can get through this. Thank you.

Ms. Laurel Radley (As an Individual): Thank you for giving me the opportunity to speak here today, with particular thanks to Dr. Duncan and Dr. Bennett, who made my appearance here possible.

I'm going to speak quickly. There's a lot of information, I think, that needs to be—

● (0750)

The Chair: Could I just interrupt you for a moment?

I don't think you're quite clear about the process for how witnesses come here. All on the committee want to hear as many witnesses as possible. What we do is we sit down and basically any names that have come forward we put on the committee. We've now had more names than we can accommodate this morning, which means that we probably need some more. So rest assured that you have a lot of people behind you. That's all I'm saying.

Okay. I'll start your time again.

Ms. Laurel Radley: Thank you.

I have multiple sclerosis and so does my sister—and so do, probably, 75,000 Canadians. I'm not here to talk about multiple sclerosis; I'm here to talk about a condition called CCSVI, or chronic cerebrospinal venous insufficiency. I'm here to make sure this committee is aware that there's an emergency going on in this country.

There are a few things you should know about CCSVI in Canada today. Studies have been published indicating that more than half of those living with MS are also living with a serious vascular condition. The math is not difficult. At a conservative estimate, more than 40,000 Canadians are likely living with this vascular condition.

In Canada right now, if you have multiple sclerosis you cannot access testing for this serious vascular condition, despite the fact that the testing is an insured procedure. In Canada, if you have medical documentation that you have this condition, you cannot receive a consultation from a vascular specialist if you also happen to have multiple sclerosis, again, despite the fact that these are insured services. People have been refused in every province. I have personal experience of being refused access to a vascular specialist.

With all due respect to Dr. Freedman and the rest of the neurologists who make up the medical advisory committee for the Multiple Sclerosis Society of Canada, I do not want a neurologist weighing in on my medical treatment of a vascular condition, nor do I want my dermatologist to be weighing in on that. I want the access to a vascular specialist to advise me about my vascular health.

Some quick information about CCSVI. It is a vascular condition caused by malformed and severely narrowed or blocked jugular and azygos veins. This is not a new condition. Chronic venous insufficiency is a well-known medical problem in Canada. There are protocols in place to test for this and there are procedures in place to treat this.

Veins that are narrowed and causing damage to other organs such as the heart, liver, and kidneys, are treated by balloon angioplasty all the time in Canada. The only difference with CCSVI is that the organ that is being damaged by blocked veins is the brain. Procedures to assess and to treat this condition are established and are commonly provided to patients who don't have multiple sclerosis.

Some of the symptoms of CCSVI include increased vascular pressure and compromised circulation to the brain. Symptoms from this vascular condition include headaches, coordination and cognitive difficulties, and fatigue. All of these are symptoms that are experienced by persons with multiple sclerosis.

Diagnosis is done by means of ultrasound, MRV, and angiogram. There's nothing experimental or dangerous about any of these investigative procedures. They're done every day in Canada to screen for various medical problems. Treatment is done by way of a safe, common, outpatient procedure called balloon angioplasty. A small catheter is passed in through veins and a balloon inflated to push the narrowed parts of the veins out. The procedure is done routinely in Canada on veins in various parts of the body, notably veins that drain the kidneys, liver, and heart. Patients who receive dialysis have been benefiting from this procedure for many years.

I feel there's a strong risk associated with not being treated when you have CCSVI. Approximately 750 people have received treatment for this around the globe and there has not been one negative result of having treatment for CCSVI with balloon angioplasty. On the risks associated with not treating CCSVI, well, we all know what the risk is. Those of us with multiple sclerosis have been experiencing progressive and irreversible damage to our brains.

● (0755)

I have some recommendations to make. I have some evidence.... I've been talking to people across Canada who are experiencing an inability to receive screening, treatment, and even an inability to get a consultation with a vascular specialist. My GP referred me to a vascular specialist, but he refused to take my referral and told me I had to go to a second specialist in a non-related field. He said he would not accept me for a referral unless I had a referral from a neurologist.

I'm going to skip quickly to my recommendations. Before deciding on committing $10 million to research, I think the government and Health Canada need to advise the provincial health authorities today that it is a violation of the Canada Health Act to withhold vascular medical services from a group of persons based on the fact that they have MS. We demand to have vascular specialists determine if we are eligible for insured services. Safe protocol is in place for investigational procedures and for balloon angioplasty. Stop denying these vascular services to persons with MS.

Today the government and Health Canada need to tell the Canadian and provincial medical associations that they must immediately direct their members to cease discrimination against persons with MS by denying them access to the services of vascular specialists, to establish screening, and to ensure treatment processes, even if we do have MS.

We want this committee to take immediate action to ensure that those most affected are offered immediate screening and treatment on compassionate grounds while tasking the researchers of this committee to undertake a review of research that has already been done, protocols that are already in place for screening, and protocols for treatment—

The Chair: Ms. Radley, you are way over. I am so sorry, and I know you have submitted some sort of documentation, but I would ask that you get this to the clerk and we can get it translated and distributed to the committee members, because it's very important information.

We're now going to begin our seven-minute Q and A, starting with Dr. Duncan.

Ms. Kirsty Duncan (Etobicoke North, Lib.): Thank you very much, Madam Chair. I'd like to thank all of you for coming, and particularly for your heartfelt testimony. You've touched all of us very deeply.

I would like to begin by saying that we absolutely need a national brain strategy in this country that includes awareness and education, genetic fairness, and caregiver support, for a few. I think it's incumbent upon all of us to advocate for a national brain strategy. I also think it is incumbent upon us to explore new, promising research. This was the reason for this subcommittee. It was to bring the scientists, the stakeholders, and the decision-makers together. We know that in brain conditions, time is brain.... The longer we wait, the more damage.... With MS, the earlier we catch it, the better we treat it.

If there is a vein problem in the liver and in the hip region, we image it and we treat it. I want to know why MS patients are being denied this treatment. I will also recognize that there has been controversy, that there was a death related to a stent, but I want to know why MS patients are being treated differently, and I will ask Mr. Savoie, please.

● (0800)

Mr. Yves Savoie: Thank you, Dr. Duncan. As has been identified before, I think it's very important to note that the death followed a procedure that included the use of a stent. With balloon angioplasty, where a spring form is not lodged permanently in the vein, there has not been such adverse effects. So I think that's important to identify, because both procedures are available and one is more risky than the other, as has been identified.

I think the fundamental question we all face here is the question of the nature of the evidence. If you ask the question of colleagues of yours who are physicians and researchers, they will tell you the evidence available for CCSVI, including the protocols for imaging, is in the early stages. That is why a number of medical associations, provincial bodies, and the Alberta Health Services Board have made the decision to not make available what is still an experimental treatment, in their view.

Ms. Kirsty Duncan: Thank you, Mr. Savoie.

I agree concerning venoplasty. This is well known; there was the one death with the stent. Having said that, it was early on, and as a scientist myself, I recognize evidence-based medicine.

I also come back to the point that time is brain, and if we wait for MS, it may mean the difference between someone walking and being in a wheelchair, someone being able to work and not going to work, and someone living alone or in care.

Does the society recognize the consensus document of the International Union of Phlebology that has come out from the expert panel representing 47 countries, which recognizes venous malformations and how to diagnose and treat them? That includes CCSVI.

Mr. Yves Savoie: Unfortunately, I'm not aware of it, and I'd be delighted to have the reference to explore it.

I recognize the urgency, Dr. Duncan. I also recognize the important link that you have made. MS is progressive, worsening, irreversible, and often debilitating. So in the face of treatments that are available and that may be still in their early stages in terms of the evidence base that is available, I understand that people with MS want to seek those treatments today or yesterday. It's an important value for the MS Society—let me just underscore this, a very important value for the society—that the decisions about managing and living with MS on a daily basis are decisions that belong to the people with MS, not to the society. Our role is to provide information, to provide guidance, and to assist people in making decisions.

Ms. Kirsty Duncan: Thank you, Mr. Savoie.

In Dr. Zamboni's work there were the initial 65 patients who were treated; 18 months later they were doing well. We know that in Poland now about 300 people have been treated.

You talked about risk. What is the risk in imaging patients? All MS patients are repeatedly given MRIs. MRV is another MRI. What is the risk in giving them an MRV and a Doppler exam?

Mr. Yves Savoie: In fact the risks are very small; you're absolutely correct.

The question there that has been offered to me and to the society is that in our health system, imaging and diagnostic is usually done as a step to treatment. In this context, because the treatment is not immediately available...it would have to be repeated by the surgeon who would eventually do the treatment in the days before the treatment. While it obviously would answer the question of whether or not the blockage is present, because the treatments are not available, the diagnosis on its own, given that it would have to be repeated, is not easily available through the public health system.

Ms. Kirsty Duncan: Mr. Savoie, I have real concerns here. We are treating MS patients differently. If they had the vein problem in the liver, if they had it in the hip, we would image them and treat them. They are given MRIs all the time, and they should not be treated differently. I think we give them—

● (0805)

The Chair: Thank you, Dr. Duncan. I'm sorry, your time is up.

Monsieur Malo.

[*Translation*]

Mr. Luc Malo (Verchères—Les Patriotes, BQ): Thank you very much, Madam Chair.

First of all, I would simply like to remind Committee members of one thing—and I am always the only one saying this. Health care is, first and foremost, a constitutional responsibility that has been devolved to Quebec and the provinces. In everything that is done or said, it is essential to bear that in mind and abide by that principle. I am always the only one at this table to make that point. Having said that, I have a question for Mr. Baribeau.

I am sure you know that Marie-Hélène Dubé, a woman who has cancer, is currently leading a wide-scale mobilization campaign in Quebec and across Canada to have Employment Insurance benefits for people with serious illnesses extended to 50 weeks, from the current 15, and to ensure that this particular group is treated the same way as other beneficiaries. Based on what you have said, people affected by chronic illnesses, such as yours, have episodes, which means that it is impossible to predict things. What is worse, there is no way to know how long an individual will have to be away from work. I think we have to delve more deeply into the kinds of reforms that are needed to the Employment Insurance program, in order to meet the specific needs of people with multiple sclerosis, in particular.

I would just like to ask for one clarification. What I understood from your testimony is that 15 weeks may be enough over short periods, because an episode may last between zero and 15 weeks, but that we also need to ensure that people can be away from work for short periods, depending on how they are affected by the disease.

Mr. Denis Baribeau: Yes, exactly. With multiple sclerosis, the time an episode lasts is as variable as the people who have the disease.

Mr. Luc Malo: So, an episode could last more than 15 weeks?

Mr. Denis Baribeau: It's possible. There are episodes with complete remissions, episodes with partial remissions and some where there is no remission. In the latter case, the disease is still evolving. Those individuals could retain their job attachment by working half-days, and look after themselves the rest of the day.

Mr. Luc Malo: In your testimony, you seemed to be saying that employers have trouble developing their work plan when members of their staff have this disease.

Do you think that, by relaxing Employment Insurance rules, employers would be more inclined to hire and retain people with chronic diseases?

Mr. Denis Baribeau: Personally, I would say that people who are already employed would derive more benefit from any relaxation of Employment Insurance rules. As I mentioned, when a person arrives at an interview in a wheelchair, employers are generally a little reluctant to hire someone with a disability.

Mr. Luc Malo: Have you ever talked to employers, to try and understand their concerns about hiring someone with multiple sclerosis, for example?

Mr. Denis Baribeau: I have spoken to physicians who deal with headhunter firms or placement agencies. I have been interviewed by potential employers, who told me they would call me back. When they did not call back, I called them to find out what was going on. They said that they had selected another candidate. There is always another candidate.

Is it because the other candidate was better than me? I don't know; I just don't know. For 25 years now, there has always been another candidate.

● (0810)

Mr. Luc Malo: Thank you.

Mr. Savoie, when you talk about funding for research, what are you basing yourself on to say that more funding should be devoted to research on multiple sclerosis, when there may be other diseases that also require funding. So, why should money be spent for research on multiple sclerosis, as opposed to another disease?

Mr. Yves Savoie: Thank you, Mr. Malo.

That is a very important question. The funding is for research on CCSVI, obviously in relation to multiple sclerosis. The reason why are making this request is because this is urgent. Urgent action is required. The Quebec College of Physicians is one of the organizations that has decided not to make this treatment available, out of a need and concern for more evidence of its effectiveness. But, in order to find that evidence, we need to put our foot on the accelerator. That is why I drew the parallel with nuclear isotopes. We are talking about a crisis, something that is urgently needed, and this is a matter of public interest.

With Dr. Duncan and other witnesses, there has been discussion about discrimination in relation to treatment. We are aware of that inequity, which is a glaring one. People here have talked about it as well, because they have experienced that discrimination. That is why we hope the Minister will provide the additional funding—though not in place of other significant investments in research by CIHR—and earmark it for this public interest crisis.

[*English*]

The Chair: Thank you, Monsieur Savoie.

We'll now go on to Ms. Leslie.

Ms. Megan Leslie (Halifax, NDP): Thank you, Madam Chair.

And thank you all very much for being here.

I actually only have two fairly quick questions, and then I may pass my time over to one of my colleagues.

I'll start with you, Mr. Savoie. First of all, I know a lot about your work on poverty issues, and the NDP has always supported your calls for a caregiver tax credit and guaranteed income and things like that.

I've been working with the Alzheimer's and dementia folks in Nova Scotia, and they've called on the Minister of Health to actually hold a summit on Alzheimer's and dementia, recognizing that this is the future of our health care system. It could collapse under the burden of the number of patients we have with Alzheimer's and dementia.

You started off by talking about how neurological diseases will be the leading cause of death. Have the different neurological disease organizations been trying to look together at calling for what you were talking about, Ms. Duncan, a brain strategy? What is happening with that?

Mr. Yves Savoie: There are two things. One is that the initial call was very favourably responded to by the current government, with an investment of $50 million to the Public Health Agency to do research to better understand the distribution of the population. How many people are affected? What are the economic consequences of the distribution?

We don't know those data in Canada, unlike the situation with cancer or cardiovascular health. It's by coming together as a group of neurological health charities that these studies and the Public Health Agency have now focused attention on neurological diseases.

In addition, we have asked for a $2 million commitment and the partnership of the federal government to develop a national brain strategy. That request has been made. This brain strategy would have many components: genetic equity, research in neurological diseases, issues of income security, and obviously the very important issues of impacts on the family.

The caregiving impact is one of them, but there are broader impacts on family structures; one of the witnesses spoke about the rate of divorce, for instance. Those issues are very important.

Ms. Megan Leslie: Okay. Thank you very much. I appreciate that update.

Ms. Radley, I didn't make it to the rally on the Hill yesterday. I was tied up, but my colleague Peter Julian was there and reported back to me about what was going on.

You're here as an individual, and there were lots of folks coming together on the Hill. There is certainly a grassroots campaign happening about CCSVI, but is there a coming together as one group? Is there an organization forming that can be a conduit for us in talking about these issues, or is it still mostly individuals coming together in the beginning stages?

● (0815)

Ms. Laurel Radley: I can tell you that around the planet there are actually organizations that have come together. An organization that's across Canada now has been initiated, called MS Liberation. There is a website. Andrew Katz and Rebecca Cooney have formed this organization and in fact called for the rally yesterday. There's an incredibly active patient—

Ms. Megan Leslie: I'm sorry, could you give me those names again?

Ms. Laurel Radley: Yes, they are Andrew Katz and Rebecca Cooney.

Ms. Megan Leslie: Thank you.

Continue; I'm sorry.

Ms. Laurel Radley: There's an incredibly active group of individuals, and an excellent source of information is a website called ThisIsMS.com.

Ms. Megan Leslie: Thank you very much.

Madam Chair, if I have some time left—

The Chair: Absolutely; you have three more minutes.

Ms. Megan Leslie: Great. I would like to hand the time over to Ms. Duncan. She has quite a bit of passion and expertise in this area.

The Chair: Please. Thank you.

Ms. Kirsty Duncan: Before you do, I want to acknowledge the work of the MS Society and of Mr. Savoie.

While health care is provincial, the federal government has some responsibility involving aboriginal health and the armed forces, and I think the discussion of CCSVI is relevant to the entire country.

I am concerned that the MS Society is not aware of the International Union of Phlebology and its consensus document on the diagnosis and treatment of venous malformations. Data out of Buffalo shows that about 52% of MS patients show CCSVI. The initial data shows treatment relieves brain fuzziness and improves quality of life. Should we not be advocating for anything that improves quality of life? If we look at injections such as Copaxone and interferon, which cost $25,000 a year, do we see the results that we have seen with this initial work?

Mr. Yves Savoie: I think I might suggest that the answer to the question about disease-modifying therapies be given to you by someone who uses them. My colleague Joan Ozirny, who is a volunteer, referred to DMTs earlier. The evidence is substantial, but a personal account might be more useful.

Ms. Kirsty Duncan: Is it one-third, is it two-thirds, that it is reducing the attacks by?

Ms. Joan Ozirny: In my history of MS I've been on three different disease-modifying therapies in order to stabilize. Generally you change when your condition is declining, and generally it's when it's declining rapidly that a neurologist would make that decision.

It's difficult to give you a broad answer, because it's different for everyone. MS is a disease that's individual, so clearly a drug or any type of disease-modifying therapy is going to interact. I think the evidence with all disease-modifying therapies shows that the old ones, which initially came to market in 1998, were about 33% effective. The last one, Tysabri, has a lot of controversy around it as well, and I have had 32 infusions of that drug. My neurologist determined that it was time to come off that drug because of the side effects that are a potential with long-term use. That drug is a very effective drug, with a 70% reduction of attacks. Of course, attacks create cumulative disability; that's basically what I'm saying.

● (0820)

The Chair: Okay, thank you very much.

We're now going to go to Mr. Brown.

Mr. Patrick Brown (Barrie, CPC): Thank you, Madam Chair.

I thank all the witnesses for coming today.

I've been very interested in neurological disorders as well. You have an excellent MS chapter in the city of Barrie. Jeanette Elliott =has been doing great work raising awareness about the need for combatting this very difficult disease. We have a doctor in Barrie, Sandy McDonald, who is one of the top vascular surgeons, who has been working directly on the CCSVI possibility. I know he's very excited about the possibilities there as well.

To follow up on a point that Megan Leslie mentioned first, in terms of your statement about the leading cause of death, is that something that we are anticipating we'll find out through the study?

Mr. Yves Savoie: These are early data, but there is no question that the work through the neurological study will cement that. There are all these questions of burdens of the numbers of people, and the growth in the prevalence rates as our population ages will obviously add robustness to those data. There's no question about that.

Mr. Patrick Brown: Yes. That's certainly the powerful call to arms that you talked about. I know the "Rising Tide" report from the Alzheimer Society expressed similar concerns with an aging population. This is going to be the challenge for our country.

You also mentioned the competition we've completed...and June 14. What was that with regard to again?

Mr. Yves Savoie: This is the date on which we will announce the results of our CCSVI research competition, which was launched early in the new year. On June 14, after the review by a panel of experts—vascular surgeons, interventional radiologists, MRI specialists, and neurologists—we will be announcing a series of research commitments to CCSVI research.

Mr. Patrick Brown: I know the concern. I think Laurel mentioned it, that there wasn't the perspective of vascular surgeons on that committee. Are the perspectives of vascular surgeons being considered?

Mr. Yves Savoie: Absolutely. Ms. Radley is correct that there has not been a vascular surgeon on our medical advisory committee.

The recommendations for funding of research applications come through panels that are assembled for various competitions. In the context of the CCSVI competition, obviously that panel was assembled with the expertise that is relevant to that kind of research, and I note as well that we were the first to launch a competition.

Our sister organization, the American MS society, launched a similar competition, and we have assembled a joint panel, an international one that includes European expertise and expertise from both the U.S. and Canada. The experts that do the review are not applicants, so they're not conflicted.

Mr. Patrick Brown: That's encouraging to hear. I heard the same concern that Laurel mentioned from that doctor. He's concerned there wasn't any perspective being taken into consideration from vascular surgeons, and obviously it would make sense that their input be considered.

The panel looking at this is comprised of a group of doctors?

Mr. Yves Savoie: Absolutely. The list is on our website, so it's public information. I don't have it here. There are about 20 people, I would say. It's a large group.

Mr. Patrick Brown: Okay. That panel is specifically created to look at this?

Mr. Yves Savoie: To look at the requests from both the American and Canadian research competitions in MS. Sorry, it's CCSVI.

Mr. Patrick Brown: You talked in the beginning about the desperate need we have for a national strategy on the brain. I think one of the neat opportunities we have with this committee is that we're looking specifically at neurological disorders. I've heard many times that if we see breakthroughs in research in one of the major neurological disorders, it's potentially going to help all the interrelated neurological disorders.

What opportunities do you see for synergies among all the groups with neurological disorders?

Mr. Yves Savoie: Let me just speak to one area. We talked about dementia. We talked about the very important work of the Alzheimer Society, and they play a very important leadership role in understanding the impact of dementia and loss of cognitive abilities. The reality is that in MS there are also associated issues of cognitive loss and depression.

These questions about those impacts—impacts obviously in terms of personal quality of life, impact on the family unit, on caregivers—are common. You'll readily see that while in MS, it is not one of the symptoms we will speak about first—we'll speak about fatigue, loss of mobility, loss of sight—these other symptoms are also real for many people. That's where those parallels are very important.

For instance, if you think of research on models of care other than the biomedical research, the commonalities there are just incredibly promising in terms of advancing approaches to housing, to our health system, the delivery of services. That's just one example.

There are many examples, including obviously some approaches that are about the medical aspects. Stem cell research has the opportunity to regenerate lost nerves in Parkinson's, in Alzheimer's, and in MS. In this city, there have been experimental treatments in stem cell research. There is lots of excitement about those avenues. There's another area of potential collaboration. We're really excited about the collaboration across the major neurological health charities.

● (0825)

Mr. Patrick Brown: As we look at developing a national strategy on the brain and if this committee down the road was to prepare a report, what do you think is the most important thing to be included from the MS perspective? If we have a national strategy on the brain, specifically with regard to MS, what do you think is of the utmost importance for us to highlight?

Mr. Yves Savoie: I would tell you that the most important thing is really to mobilize the Government of Canada's role in funding research at a much increased pace—much increased pace. Our long-term recommendation is for an 80% increase to the budget of the CIHR—that would bring it to $1.8 billion—because that is fundamental to accelerate the translation of discovery into improved health for Canadians.

The Chair: I'm sorry, Mr. Brown, your time is up.

I want to thank the witnesses very much for coming and giving your testimony.

We just have a few things on this topic that we have to discuss before we go into our next health meeting, which is a two-hour health meeting. So I'm going to suspend this meeting. I'm going to ask that we go in camera.

Thank you to our witnesses again.

Go ahead, please. We're running out of time.

Ms. Megan Leslie: Madam Chair, before we suspend, as this is a neurological disease subcommittee and we'll be looking at all the neurological illnesses, I was wondering if we could ask Mr. Savoie if he could provide us with information about what the groups are doing together. I think it would be very helpful for us.

The Chair: That would be very nice. Thank you very much, Ms. Leslie.

Ms. Megan Leslie: Are you able to?

Mr. Yves Savoie: We'll do that through the clerk.

Ms. Megan Leslie: Thank you.

Mr. Yves Savoie: Thank you.

The Chair: Good day, and thank you.

We'll suspend for two minutes, please. We should have some time to go in camera.

[*Proceedings continue in camera*]

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