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Chair

Mrs. Joy Smith

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● (0905)

[*English*]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): I'd like to start the meeting so we have the time we need.

I would like to welcome to our committee, from the ALS Society of Canada, by video conference, Mr. Derek Walton.

Mr. Walton, can you hear me?

Mr. Derek Walton (Member of Advocacy Committee, Amyotrophic Lateral Sclerosis (ALS) Society of Canada): Yes, I can, Joy.

The Chair: I'm so glad you could join us.

Mr. Walton, as soon as I introduce the rest of the witnesses, we're going to begin with you. Are you prepared for that?

Mr. Derek Walton: Yes, and thank you.

The Chair: Thank you.

Also with us is Dr. Galit Kleiner-Fisman. Welcome, and congratulations on your brand-new baby.

This lady has just had a new baby, and she's here.

You thought I didn't know that. It was a month ago, wasn't it?

Dr. Galit Kleiner-Fisman (Neurologist and Movement Disorders Specialist, Baycrest Hospital): Exactly.

The Chair: Being a mother of six children, I understand the sacrifice you're making—a month and you're here. Thank you for coming.

From the Multiple Sclerosis Society of Canada, we have Ms. Deanna Groetzinger, vice-president, government relations and policy. Welcome.

Mrs. Deanna Groetzinger (Vice-President, Government Relations and Policy, Multiple Sclerosis Society of Canada): Thank you.

The Chair: And we have Ms. Marie Vaillant, vice-chair of the Ontario division board of directors. Welcome.

And from the Neurological Health Charities Canada, we have Dr. Garth Bray. He's the chair of the scientific advisory committee. We are very pleased you're here this morning, Doctor.

And we have Dr. Ian McDowell, the vice-chair of the scientific advisory committee. Welcome. Thank you for being here.

We are going to have ten-minute presentations. Mr. Walton, we will listen to the other presenters as well, so you can listen carefully to what they say, and then after that we're going to into questions and answers.

The vice-chair is going to be taking the chair at 10 o'clock, because I have to go someplace else, but you'll be guided through everything.

Can we begin with you, Mr. Walton?

Mr. Derek Walton: Madam Chair, honourable members, and ladies and gentlemen, good morning.

My name is Derek Walton. I live in Barrie, Ontario, with my wife and primary caregiver, Diane. Patrick Brown is our MP and a valued friend.

Once again it is my honour to be asked by the ALS Society of Canada to witness today on behalf of all ALS patients in Canada and explain what it is like to live with ALS, more commonly known as Lou Gehrig's disease.

Amyotrophic lateral sclerosis, ALS—three letters that change lives forever. ALS is a rapidly progressive and fatal neuromuscular disease that is characterized by the degeneration of a select group of nerve cells and pathways, called motor neurons, in the brain and spinal cord. This loss of motor neurons leads to progressive paralysis of the voluntary muscles and ultimate death when the chest muscles are no longer able to help the lungs achieve adequate oxygenation. It is a very nasty disease and is one that has been likened to being buried alive.

I am one of fewer than 2,500 Canadians living with ALS. However, unlike 90% of patients who pass away within five years from date of diagnosis, my symptoms are moving very slowly. Although the average life expectancy is just 2.7 years, many of those I have mentored to date have passed away in less than a year.

Sadly, there is currently no cure for ALS. That is why we need more funds for research to find a cure.

Although I was finally diagnosed in May of 2002, I believe my signs started as early as 1998. Unfortunately, ALS is usually determined after all other neurological diseases have been eliminated. I was misdiagnosed for years.

Because my symptoms are moving so slowly, I have used a cane, a walker, a scooter, and most recently a powered wheelchair. We have yet to purchase a customized vehicle, so I still use my scooter when travelling.

In a nutshell, I have been spared the short lifespan the majority of ALS patients and loved ones are given after hearing those three words and those three dreaded letters—“you have ALS”.

I am so thankful this committee has been formed, as, according to the WHO, the prevalence of neurological disorders will dramatically rise in years to come, from both the extension of life expectancy and an aging population globally.

However, I do bring an ask list on behalf of ALS Canada. They ask that the health committee create a comprehensive and coordinated national brain strategy to address the need for caregiver support, income security measures, genetic privacy, prevention, investment in neuroscience research, integrated care, and public education.

● (0910)

The new IBM research and development centre being built here in Barrie is a great start. However, a national brain strategy will greatly help to reduce the social and economic burden of neurological conditions in Canada.

They also recommend that neurological conditions be added to the Canadian chronic disease surveillance system; however, they thank the government for the work to date in achieving this goal through the national population health study on neurological conditions.

The ALS Society of Canada delegates are again coming to Ottawa on June 4th and 5th for our Hill Day, to meet with politicians to discuss compassionate care benefits in more detail. Please join us for our open air vigil on the Hill from 7 until 9 on June 4th.

In closing, I hope my testimony to the committee today has been beneficial and I can leave confident that my lone voice has been heard on behalf of all ALS patients and their families nationwide.

Thank you.

● (0915)

The Chair: Thank you, Mr. Walton. Your coming to committee today makes a big difference. So thank you for the effort you've put in. Your insightful recommendations are much appreciated.

Dr. Kleiner-Fisman.

Dr. Galit Kleiner-Fisman: Thank you very much.

It can start with a slight tremor in the hand, or stiffness, or maybe it becomes difficult to walk. You know there is something wrong, but you're told it's old age or maybe arthritis or maybe it's in your head, which only makes it worse. But sooner or later, the diagnosis is confirmed: you have Parkinson's disease. You, a once vibrant person, are transformed into a full-time patient requiring increasing levels of care from spouse or family members and ultimately long-term care placement as the care needs become too overwhelming for partners and families.

The number of Canadians battling Parkinson's disease is 100,000. It robs each of them, ultimately, of their dignity and of their hope. When they need it the most, our health care system fails them, providing solutions that don't really match the disease and can't help them back to a better life.

But there is another way to dramatically improve the quality of lives of people with Parkinson's disease, while actually saving the health care system money. Honourable members of the health committee, it is this other and more holistic approach that I'm here to tell you about today.

My name is Dr. Galit Kleiner-Fisman. I am a Harvard-trained neurologist who has received further sub-specialized training in Parkinson's disease. I am currently an assistant professor in the Department of Medicine at the University of Toronto and the medical director of the ATC Jeff and Diane Ross Movement Disorders Clinic, a collaboration between the Baycrest Health Sciences and the Assistive Technology Clinic in Toronto.

Those I care for suffer from what are known as neurodegenerative conditions. They are people who have ongoing and progressive damage to their nervous systems, as happens in Parkinson's. Care of people with Parkinson's disease is my life's work. My goal is to provide the best possible care using existing resources.

Right now, each year one in every 100 Canadians aged 65 to 80 gets a new diagnosis of Parkinson's disease. Over the age of 80, that triples to three new diagnoses for every 100 people every year, and that's in addition to the number of people already living with a condition. About 12% of Canadians aged 80 and over currently live with Parkinson's disease, and as our aging population grows this will double to 25%. So think about that for a moment. If you and your spouse live into your eighties, there is a one-in-two chance that one of you will live and die with Parkinson's disease.

Parkinson's affects every aspect of a person. It affects thinking. It can cause depression or hallucinations and problems with eating, voiding, and bowel function. But these non-movement symptoms are frequently not recognized as part of the disease by either patients or their doctors, and are misdiagnosed or left untreated. Untrained in recognizing or managing the complex and debilitating symptoms of Parkinson's, family doctors are caught between the increasing needs of desperate patients and an over-stressed health care system. All too often and needlessly, patients end up in emergency rooms, where they don't get the care that they need. In Ontario, in fact, people living with Parkinson's are admitted to the hospital 40% more often than people without Parkinson's. When they are admitted, they stay 20% longer than people the same age without Parkinson's. Studies have shown that a person with Parkinson's also has a five times higher risk of being placed in a nursing home, and then costs incurred while in the nursing home are also fivefold more compared to residents without Parkinson's disease.

In 1998 the Parkinson Society of Canada reported that long-term disability of Parkinson's patients cost the health care system $560 million. Now, more than a decade later, costs have ballooned to an estimated $750 million.

It is within our reach right now with current treatments already available to better manage symptoms, reduce unnecessary hospitalizations, and delay nursing home admissions, all while saving the health care system money and vastly improving the lives of patients and their families.

At the centre where I work, the Baycrest-ATC Jeff and Diane Ross Movement Disorders Clinic, that's what we do. In our model, the patients don't revolve around their health care professional, we revolve around them. While this model may be novel in Canada, it's not in other countries. For example, in the United States the veterans' health care system established inter-professional Parkinson's centres 11 years ago, and with great results. I was privileged to be a clinician at one of these facilities, called PADRECCs, or Parkinson’s Disease Research, Education, and Clinical Centers, when I was on faculty at the University of Pennsylvania. I saw first-hand how effective these PADRECCs were in addressing the complex needs of Parkinson's patients.

● (0920)

We'd all like to see medical advances in the form of a cure, but the fundamental question that drives our work at Baycrest and ATC is how do we use the medical and non-medical tools that already exist to improve the quality of life of patients with Parkinson's and other chronic neurological illnesses, all while staying within the current framework of our health care system?

Well, it starts with the philosophy of patient-centred care. In addition to the sub-specialist and a family physician who acts as a liaison with community family physicians, we also provide access to allied health professionals, including physical therapists, occupational therapists, specialized nurses, dieticians, social workers, and pharmacists all under one roof. This is called interprofessional care.

At the end of a patient's visit, everyone debriefs and provides recommendations for ongoing management based on collective input. We treat the whole person. As a result, we're more able to accurately fine-tune medications, deal with side-effects, and better manage the symptoms and issues that could otherwise result in a trip to the hospital. The fact is many Parkinson's patients don't get the instructions they need to follow through to better manage their disease. Our patients do, and so do their doctors.

We believe empowering family doctors to better treat Parkinson's disease is important. There's a great shortage of specialized Parkinson's care providers, even in a major medical centre like Toronto. In our model, GPs and patients themselves become more self-sufficient, freeing up the specialists' time to deliver specialized care to more people.

In Canada the provinces administer health care, but federal leadership needs to create the momentum for an integrated interprofessional approach to the management of Parkinson's and indeed for other neurological diseases.

The basic philosophy for our model of care is based on previous ATC models of care and includes the following: patient needs define services; care is organized around solutions; multi-disciplinary teams provide care; and results need to be measured to accelerate learning.

Building on these four fundamental principles, we believe the time has come to set up interprofessional centres of excellence for neurological care across Canada. Through these centres, patients will learn how to better manage their disease, will be seen more quickly, and be able to employ strategies that will keep them out of hospitals and enjoying a better quality of life, all while saving the health care system money.

We need to ensure access for all Canadians and not just those living in large metropolitan areas where centres usually exist. That will necessitate federal support to set up methods that will allow patients in remote areas of the country virtual access to these centres and the related professionals.

We recommend that each centre of excellence for neurological care should include the following components: adequate physical space for patients to see practitioners and where practitioners from all disciplines can come for training, along with the necessary infrastructure; sufficient funding to cover salaries and operating costs; virtual access via video conference for those in remote areas, along with an electronic patient record for virtual collaboration between medical and related professions; a database to share and collaborate with other centres of excellence so as to encourage clinical research; a website for patient education that is accessible in multiple languages and is sensitive to issues related to knowledge translation in those with disabilities; and a research and development program for entrepreneurial development of innovations, such as communication technologies, seating and mobility devices, and environmental aids for daily living, just to name a few.

We need to encourage collaborative partnerships between the public sector and business community as well as private investment to stimulate the economy.

Successful health care delivery models could also lead to social impact investing where private investors help fund not-for-profit projects and the investors are paid a return that comes from the money that projects save the government. Additionally, we need to encourage private donations through matching federal support.

In conclusion, Dr. William Reichman, the CEO of Baycrest Health Sciences, who testified in front of this committee on November 28, 2011, said that for elderly people to stay living in their own homes rather than being placed in nursing facilities requires deliberate, transformative change. We stand on the verge of a crisis. The needs of an aging population threaten to bankrupt our already strained health care system, but with great crisis comes opportunity. Using what we already have and know, we can make life better for neurological patients and their families, while saving money for the health care system.

Thank you very much, and I look forward to your questions.

● (0925)

The Chair: Thank you very much for being here today. You're a real professional, and we all really appreciate your insightful comments.

Now we'll go to our next group: from the Multiple Sclerosis Society of Canada, Ms. Marie Vaillant.

Ms. Marie Vaillant (Vice-Chair, Ontario Division Board of Directors, Multiple Sclerosis Society of Canada): Madam Chair, committee members, on behalf of the Multiple Sclerosis Society of Canada, thank you for the opportunity to appear before you today.

My name is Marie Vaillant, and I am a volunteer for the MS Society. Currently I am a member of the Ontario division board of directors, and I chair the Ontario client services committee.

With me is Deanna Groetzinger, MS Society vice-president of government relations and policy.

The MS Society is a founding member of Neurological Health Charities Canada, so while we will talk about issues that are important to people living with MS, this also impacts people living with other neurological conditions and episodic disabilities as well.

We echo the thanks of other NHCC members to the government for the support of the national population health study of neurological conditions. It will provide crucial information on the incidence and impact of neurological conditions in Canada.

The MS Society agrees with NHCC that it is time to develop a national brain strategy. Such a strategy will help greatly reduce the burden of neurological conditions in Canada. We urge the committee to recommend that a strategy be developed.

Today I will provide more details about one of the pillars of the strategy—income security. Deanna will then provide an update about progress in research on CCSVI and MS.

The MS Society has long been concerned about the toll MS has on the ability of people living with it to remain at work. Many people are diagnosed between the ages of 15 and 40, just when they are finishing school, starting careers, and beginning families. As the disease progresses, it takes a toll on a person's ability to stay in the workforce full-time. Over time, up to 80% of people with MS can no longer work. Unfortunately, for most people, not being able to work means having to live on extremely limited incomes.

Sometimes there is job loss because MS symptoms have become more severe. But at other times it's because of a lack of understanding and accommodation by employers and because of insufficient government supports. Many more people living with MS and other episodic disabilities and neurological conditions could remain at or return to work if greater assistance were provided.

The Chair: Excuse me for one moment.

Dr. Sellah.

Mrs. Djaouida Sellah (Saint-Bruno—Saint-Hubert, NDP): The translator sounds as though she's talking very quickly, so she needs to slow down.

The Chair: Are we going too quickly? Okay.

Ms. Marie Vaillant: I will slow it down.

The Chair: Could you slow down a little bit?

Thank you, Dr. Sellah. I was so involved in this paper that I didn't notice.

Okay, if you could slow it down a little bit, that would be great. Thank you.

Ms. Marie Vaillant: Many more people living with MS and other episodic disabilities and neurological conditions could remain at or return to work if greater assistance were provided. The result would be the retention of experienced employees and less cost to society as a whole.

In my own case, I was diagnosed in 1996 with primary progressive multiple sclerosis while working as a manager with Bell Canada. My director was very understanding and accommodated my needs by allowing me to telework one day a week. In 2002 my MS had progressed and my neurologist suggested I no longer work. Because of my 25 years of service, I qualified for short-term disability for one year at full salary, and then I went on long-term disability. I now receive two-thirds of my salary as a combination of CPP, disability benefits, and employer-paid disability benefits.

Leaving the workforce was one of the hardest things I've ever done. Giving up a fulfilling career in my prime resulted in a period of depression and the need to reinvent myself. This I was able to do through my volunteer work with the MS Society.

I'm quite aware that my scenario is the exception and not the rule for many people living with MS who do not have the benefit of income security. The MS Society believes it is important to tackle the issue in two ways.

First, for people living with MS and other neurological conditions who can no longer work, there is an urgent need to develop a basic income plan for Canadians with severe disabilities. The Caledon Institute of Social Policy has done some excellent work on an innovative approach involving federal, provincial, and territorial governments.

We realize this could take time to put in place, and therefore we suggest there are some relatively easy steps that can be taken right now. These include making employment insurance sickness benefits more flexible, so people who do some work while in the midst of a relapse could choose to work part-time and receive partial benefits.

Currently individuals who qualify for EI sickness benefits receive them for 15 weeks, which equals 75 days. By allowing people to receive benefits for 150 half-days instead of 75 days, people with MS or other conditions would be able to maintain a strong attachment to their jobs and receive adequate income even when they take time off. Employers would pay a lower salary during the benefit period but still retain the services of an experienced employee. There would be no additional cost to EI.

The MS Society also recommends making existing tax credits—such as the disability tax credit, the caregiver tax credit, and the new family caregiver tax credit—refundable. This would put money in the pockets of low-income Canadians.

We are very grateful to the government for the creation of the family caregiver tax credit, since it recognizes the vital contribution spouses make as caregivers. It would be even more valuable as a refundable credit.

Madam Chair and committee members, as a person with MS, I can assure you we want to work. We want to do our part in contributing to Canada. We just need some assistance to help us do just that.

I'd now like to turn the presentation over to Deanna Groetzinger.

● (0930)

Mrs. Deanna Groetzinger: Thank you.

I'll provide a quick update about progress that has been made in determining the relationship between CCSVI and MS.

First, The MS Society is very grateful to the Government of Canada and to all parliamentarians for making CCSVI and MS a health priority. People living with MS need answers they can use to make decisions about their own health. It is heartening to have your support.

On April 18 the Minister of Health announced that there was a fundable applicant for the CCSVI clinical trial. We are anxious for the clinical trial to begin as quickly as possible but understand the need for ethics review by university and hospital ethics boards. The MS Society is looking forward to helping fund the clinical trial as a partner with CIHR once there is final approval. The clinical trial announcement was just one of a number of positive developments to help people with MS obtain the answers that they need. For example, the Government of Saskatchewan has worked with the Albany Medical Center to enable about 86 people with MS to participate in a clinical trial right now. In March, the first group of participants travelled to Albany, New York. This agreement followed an unsuccessful clinical trial process in Saskatchewan last year.

In December 2011, British Columbia launched a CCSVI registry that will follow people who have had the CCSVI procedure outside of Canada. These registrants will be followed for three years to see what happens. In Alberta, the Alberta MS Initiative has been established to learn, through an observational study, about the range of experiences and outcomes following treatment of CCSVI. This is now ongoing. At the federal level, the Canadian Institute for Health Information, with funding from the Public Health Agency of Canada, is developing a nationwide system to measure and monitor MS progression and the impact of treatment, including CCSVI.

The MS Society continues to ask all governments to ensure that Canadians who undergo treatment for CCSVI outside of Canada have access to necessary post-treatment and follow-up care when they return home. We're pleased that most provincial governments have responded positively. In Ontario the government established an expert committee to develop detailed guidelines for physicians to help them treat patients who have had the CCSVI procedure. The Government of New Brunswick chose a different approach. It set up a program to assist people with the cost of having the CCSVI procedure, offering one-time matching grants of up to $2,500.

In 2009 the MS Society became the first organization in the world to issue a request for research proposals to investigate the relationship between CCSVI and MS. We were joined by our sister organization in the U.S., and we were able to fund seven research projects totaling more than $2.4 million to investigate the possible association of CCSVI and MS.

Funding for the projects began in July 2010 and at the 18-month mark the research teams say they are making good progress. More than 800 people have undergone scanning with various imaging techniques, including the Doppler ultrasound technology used by Dr. Zamboni and his collaborators as well as magnetic resonance studies of the veins, catheter venography, MRI scans of the brain, and clinical measures. More details about the project and the progress researchers are making can be found at our website, CCSVI.ca.

With that, we will conclude our remarks. We look forward to any questions the committee members may have.

Thank you.

● (0935)

The Chair: Thank you.

I must say, Ms. Vaillant and Ms. Groetzinger, your input into this committee has been very helpful this morning. Thank you for doing that.

I will now go to Neurological Health Charities Canada. Are you sharing your time, Dr. Bray and Dr. McDowell?

Dr. Garth M. Bray (Chair, Scientific Advisory Committee, Neurological Health Charities Canada): Unfortunately for Dr. McDowell, I'm doing it all.

The Chair: He says rah-rah to that.

Dr. Garth M. Bray: But he's going to answer the questions.

The Chair: We look forward to hearing from you, Dr. Bray.

Dr. Garth M. Bray: Thank you.

Madam Chair and honourable members of the committee, thank you for this opportunity to discuss the national population health study of neurological conditions, which will be referred to as “the study“ for the remainder of this presentation. This presentation will be an overview from the perspective of the scientific advisory committee, the nine-member committee created by the implementation committee after the study was launched. Dr. McDowell and I are members of that committee. Dr. McDowell is a professor of epidemiology at the University of Ottawa. I was a clinical neurologist and laboratory researcher at McGill University and the Montreal General before my retirement.

In at least two previous sessions you've heard from other speakers about Neurological Health Charities Canada and quite a bit about the study. For example, on March 1 Vanessa Foran told you about the history of Neurological Health Charities Canada, known as NHCC, and the genesis of the study. At your April 26 discussion on Parkinson's disease, you heard from Dr. Daniel Krewski, who is a principal investigator on one of the projects of this study. You also heard from Joyce Gordon, who is president and CEO of the Parkinson's Society of Canada, but who is also president of the NHCC and is a member of the study's implementation committee, as is Deanna Groetzinger, who has just spoken.

As Vanessa explained in her March 1 presentation, the study is a collaboration involving a group of neurological health charities, the Public Health Agency of Canada, and researchers in academic centres across the country. Thirteen individual projects, three national surveys, and a micro simulation study are the components of this study, whose broad objectives are to determine as precisely as possible the numbers of Canadians who suffer from neurologic conditions, and to enumerate the impact of these neurologic conditions on the daily lives of the affected individuals, their caregivers, and the broader health care system.

Over the next few minutes my aim is to give you an overview of the anticipated collective outcomes of the various components of this large study.

Eight of the projects in the two surveys will contribute current data on the epidemiology of up to 18 conditions that cause neurologic disabilities in the overall Canadian population. In other words, these projects will assess prevalence, incidence, and co-morbidities. In addition, data from some of the projects will relate to specific subgroups of Canadians: first nations peoples, the elderly, and children.

A second group of projects addresses risk factors. Data on risk factors and the factors that influence disease progression are being analyzed in four other projects of the study. The outcomes of these projects will be important for the prevention and amelioration of disabilities due to the targeted neurologic conditions. The impact of neurological conditions on the daily activities, independence, emotional state, and financial situation of affected individuals is being studied in four of the projects and one of the national surveys. Because neurologic disabilities also have an impact on the lives of caregivers, families, friends, and communities, estimates of such broader effects are viewed as an important additional outcome of the study.

Six projects in both surveys will provide measures of health services utilization, including its availability, gaps in care delivery, and the identification of novel ways of providing appropriate care for persons with neurologic conditions.

The study also has three other potential outcomes that have broader implications. First, new sources of epidemiological data are being developed. For example, two projects are testing the feasibility and validity of using the electronic medical records of primary care physicians as sources of data for surveillance and other epidemiological studies.

● (0940)

Two other projects will develop recommendations on the use of registries for ongoing surveillance of neurologic conditions. These projects are evaluating inventories of existing registries and developing guidelines for the creation of new ones.

A final product of the study will be the micro simulation model. It will combine data from the various projects with projections of population growth and age to predict the future demands on health care services due to neurologic conditions and to indicate the most cost-effective way to deliver these services.

In conclusion, we would like to thank the Government of Canada for its commitment to and support of the national population health study of neurological conditions. To ensure the legacy of the study continues, we hope this committee will recognize the importance—as others have suggested—of adding neurologic conditions to the already functioning Canadian chronic disease surveillance system, and we hope that you will make such a recommendation in your report on these hearings.

Dr. McDowell and I look forward to your comments and questions.

Thank you.

The Chair: It has been an extremely great morning, with a lot of very insightful information that's very useful to all of us.

We'll now begin our round of Qs and As. This is our first round, which is for seven minutes.

We'll begin with Ms. Davies, please.

Ms. Libby Davies (Vancouver East, NDP): Thank you very much, Chairperson.

First of all, to the witnesses and to Mr. Walton on video conference, welcome to the committee today. I think you're all aware that the previous committee in the former Parliament did a lot of work on this, so we're catching up. Having you here today and hearing more testimony is actually very helpful to the study we're doing.

I think we've gone from the broad issues that Dr. Bray has just put forward to some very specific issues.

I wanted to say as a general comment, first of all, that for those of you who have talked about the need for greater supports for caregivers for people with MS and other neurological diseases, I do think that's really important. It keeps coming up, just so you know. Whatever issue we look at in terms of chronic diseases and conditions, it keeps coming up. So clearly, there's a lot more work that needs to be done. I hope very much that will be a part of our report: the need for—as I think you put it, Ms. Vaillant—refundable tax credits.

I know the situation is really tough for people who have lost their employment because of their medical situation, so it's a huge issue, which the federal government can directly assist with. That's not going to be my question, but I wanted you to know that we've heard everything you're saying.

The questions I have focus more on where we're at with the CCSVI. We've all been visited by constituents, by MS sufferers. I have, on many occasions, and I have a couple of things on that. It's fascinating to me to see how the system responded when information about this treatment first came out, whether it was the MS Society, the government itself, or the medical community overall. We do know that the clinical trials are going to begin, so I have a couple of questions.

First of all, are you satisfied that the trials are happening quickly enough? There seem to be so many...I don't want to call them delays, but it's taking so much time. I know that there has been a great impetus to have this move more quickly.

I'm a layperson, but I do have the sense that there has been so much happening in the U.S. MP Kirsty Duncan organized a great session a few months ago at which we had some incredible experts from the U.S. It seemed that there was a lot more happening there in terms of the CCSVI treatment.

So I do have a question about why it took so long in terms of the response here, and, looking back, how you feel about that now. How has the MS Society itself dealt with this issue? Because I know it was quite divisive. There were people who went out and formed their own sorts of networks and so on.

So I do think it's worth exploring this, because to me this was very much a patient-led movement, if you will. It almost became a movement—maybe it is a movement—that compelled us to get on it. I don't think we had ever seen that to such an extent before, at least in my experience, but I haven't been on the health committee very long.

I'd really like both of you to respond to that—and the other witnesses as well—in terms of what's happening in the U.S. and whether Canada is now behind that, and whether you're satisfied with what is contemplated now, both for the trials in Canada and for the monitoring system that's being set up.

I hope that's clear enough for you to answer.

● (0945)

The Chair: Who would like to begin with that?

Mrs. Deanna Groetzinger: I can start, and then we'll see who would care to comment as well.

First, I'll say that we all want this to happen as quickly as possible. But I do understand, and the MS Society does understand, that a process to get good information must be followed. We've been pushing to get as much information as possible, to get a clinical trial started as soon as possible. It's interesting. I mentioned in my remarks that Dr. Zamboni's paper was published in late 2009. There were then media pick-up of that. But even the week after that, we realized that there was something we immediately needed to look into concerning this possible treatment. So we launched our own request for proposals to look at the relationship between CCSVI and MS. We were the first organization in the world to issue a request for research proposals on CCSVI and MS and that possible relationship.

Research does take time. I understand, from conversations—our research department is working closely with CIHR on this clinical trial process—that for research in Canada, this is lightning speed. The government has responded quickly to pressure from people with MS, and thank goodness for that. Thank you all for listening. I'm sure you've all had people with MS in your offices saying that we need to find out answers about this right now. That things have moved ahead as quickly as possible I think is because of the widespread understanding of parliamentarians that this was an important issue.

● (0950)

Ms. Libby Davies: Can I get more specific? Does the MS Society know how many MS patients have gone to the U.S.? I have the perception that there has been a huge number of people, at some considerable cost, I would imagine, going to the U.S. because this new treatment is available when it hasn't been in Canada. It does leave us with the feeling that we are behind. Do you have any idea on how that's looking?

Mrs. Deanna Groetzinger: Initially, I would say most Canadians with MS who were interested in having the procedure were going not to the U.S. but to places in Europe, to the Caribbean, even as far as India. Most recently—and I think it makes a ton of sense—if a procedure is available in New York, and it tends to be the border states, then people are having the procedure in the U.S. It's easier for them to get there. The procedure is more accessible.

But I think we need not confuse treatment and research, because the U.S., being a totally different medical and health care system from Canada—

The Chair: Ms. Groetzinger—

Mrs. Deanna Groetzinger: —it's very different. If I could just say—

The Chair: You're way over time. Can you just wrap up in one sentence?

Mrs. Deanna Groetzinger: Okay, sorry.

I will wrap up by saying that we know a lot of people are going out of country, mostly to the U.S. right now, and we're really grateful that the various registries and observational studies will capture that information.

The Chair: Thank you for your very thorough answer.

Mr. Brown, go ahead.

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

Thank you for all the testimony. I know you were here when we had the subcommittee studying neurological disorders, but I think the fact that the entire health committee is studying it shows how seriously the health committee pays attention to neurological disorders.

To Derek Walton from Barrie, I thank you so much for your testimony. You're always eloquent, and the fact that you've been raising awareness and research for eight years is incredibly courageous and commendable.

For those who don't know, Derek jumps out of a plane every summer to raise funds for research for ALS and has gathered a gigantic following to do this. He has convinced everyone, from representatives from the Argonauts to civic leaders across Simcoe County, to jump out of the plane with him as well. He's asked me to jump out of the plane. I haven't taken him up on that, yet but I'm starting to be pressured.

The Chair: Mr. Walton, I'll put money on that if you get Mr. Brown to do that, okay?

Voices: Oh, oh!

Mr. Patrick Brown: He's raised more for Sunnybrook and their ALS research than anyone else, so you truly are a living legend when it comes to what you've done for ALS. Thank you for your contributions.

Some hon. members: Hear, hear!

Mr. Derek Walton: Thank you, Patrick. It's much appreciated.

Mr. Patrick Brown: I wanted to ask a few questions based on the testimony today, specifically with regard to ALS. I know you worked very closely with Sunnybrook.

You've been doing a lot of fundraising for the research component of ALS. What type of research is being undertaken at Sunnybrook that you think they could use help on? What type of ALS research is occurring in the country that we need to do more of?

We talked about a larger research envelope. What possibilities would exist if there were a larger research envelope for ALS?

Maybe that question could go to Derek and Deanna.

The Chair: Mr. Walton, maybe you can start.

Mr. Derek Walton: First of all, because of the length of time that I have had ALS, I no longer qualify for research trials. That in itself is a little frustrating for me, personally, because the only known drug at the current time that is known to slow down the progression of ALS is a drug called Rilutek or riluzole, and even that, Patrick, only reduces the timeframe by approximately 15%.

Now, Dr. Lorne Zinman, who heads the ALS clinic at Sunnybrook, in conjunction with all other ALS clinics in Canada is actively in the process of researching. They had tried lithium, and unfortunately it proved to not be conducive to ALS symptoms, but they are currently looking at a variety of trials and with a placebo being used within these groups. Usually it's also in conjunction with other ALS clinics throughout North America.

I always feel that because of the small number of ALS clients—I mentioned in my presentation there are 2,500, as opposed to the 100,000 Parkinson's or MS clients—we ought not to be forgotten in the way of research funds.

I really hope that the committee can see a way of advancing additional funds for research, which is badly needed in the ALS community.

● (0955)

The Chair: Ms. Groetzinger, I think you wanted.... Is that okay?

Mr. Patrick Brown: I was going to say that the point of interest from Deanna would be that I imagine the concerns with MS are similar. There are so many good research applications. We hear that with applications to CIHR there are obviously so many they can be attended to. Do you get that sense as well with MS, that good projects that should be investigated are being left on the table, or are we starting to get a much higher percentage of them being investigated?

Mrs. Deanna Groetzinger: Actually, the MS Society itself is in an interesting sort of dilemma, in that we have been very successful in encouraging through an MS research and training network to encourage young researchers to come into MS research. We are now finding that we aren't able to support as many of the good project grants as we were able to, but I think that's a good problem to have. In terms of, as someone mentioned, perhaps more matching of health charity funds with the federal government, all of the new Canada Brain Research Fund, might be an interesting thing to talk about with all of us who are members of NHCC.

Another interesting development I would see is that there's the potential for neurological research, writ large, not just necessarily MS and ALS. We've been able to fund a large research grant on progressive MS, and there it's not an inflammatory process, but more of a neuro-degenerative process, which perhaps is more similar to Parkinson's, Alzheimer's, etc. So I think we're starting to see some cross-linkages among the neurological conditions that may be more similar at certain stages than we thought before. I think this is an exciting new approach to neurological research.

As I said, I think the Canada Brain Research Fund is an excellent example. It's a model we all might want to look for in terms of encouraging research into ALS, MS, or, writ-large, more neurological research.

The Chair: Thank you very much, Ms. Groetzinger.

Now we'll go to Ms. Duncan.

Ms. Kirsty Duncan (Etobicoke North, Lib.): Thank you, Madam Chair.

I'd like to thank all the witnesses for the work you do each and every day, from looking after Canadians, to the volunteer work you do.

Mr. Walton, as always, thank you for the funds you raise.

We hear you loud and clear. We need a national brain strategy in this country.

Dr. Kleiner-Fisman, thank you for those wonderful recommendations around centres of excellence, interprofessional care, and the specific recommendations that you gave.

I'm sure you all know I'm going to discuss MS. One of my greatest goals was to ensure that those living with MS across this country had the same access, whether it was to clinical trials or to diagnosis and treatment.

Ms. Groetzinger, as you showed, that is not the case. We have Alberta doing one thing, New Brunswick doing another. In fact, because action was not taken at the federal level, we actually have patients travelling in clinical trials already, before the clinical trials start in this country, in Canada as a whole.

I'm just going to bring up the issue of follow-up care. It still remains a problem. There is not a week that goes by that I am not contacted by someone who's been denied follow-up care. It remains a problem.

Ms. Groetzinger, could I ask, was the MS Society involved in the consensus workshop on ultrasound imaging used to diagnose blocked veins in September 2011?

● (1000)

Mrs. Deanna Groetzinger: Thank you very much, Dr. Duncan, for being one of the champions in Parliament for people with MS. As I've said before, I think we are moving in terms of research at lightning speed and we're seeing that benefit. So thanks to you and thanks to really everyone across the board.

Ms. Kirsty Duncan: Sorry, I have to move you along. I don't want to be rude.

Mrs. Deanna Groetzinger: Sorry, but I do want to recognize that.

In terms of that particular conference, I'm not a researcher, so I'm not sure who might have been there.

Ms. Kirsty Duncan: Were you aware of the ultrasound workshop?

Mrs. Deanna Groetzinger: Absolutely, but as I said, it wouldn't be me who would be attending that, so I'm sorry, I really can't comment on that.

Ms. Kirsty Duncan: But are you aware of that?

Mrs. Deanna Groetzinger: Absolutely.

Ms. Kirsty Duncan: Thank you.

I have a copy of the briefing that was provided to all MPs here that says this took place. The briefing was given on February 13. Can you tell me why Dr. McDonald was not invited? He was personally trained by Dr. Zamboni. He is the leading expert in Canada and his people trained the folks in Saskatchewan to do the diagnosis. As you know, our folks have already gone to Albany. Why was he not invited?

Mrs. Deanna Groetzinger: Sorry, we weren't involved with that particular meeting, so it would really be more of a question for the organizers of that.

Ms. Kirsty Duncan: Okay. Did the MS Society have correspondence with the CIHR regarding this meeting?

Mrs. Deanna Groetzinger: I am not aware of that; sorry, Dr. Duncan.

Ms. Kirsty Duncan: I'm surprised.

I've just done an access to information and privacy request and I asked for all information—reports, briefing notes, and e-mails—regarding the consensus workshop. The response was that after a thorough search for the requested information, no records were located that responded to my request. So I'll further dig into this. Thank you.

I'm going to continue if that's okay.

On May 5, 2010, the MS Society called on the government to provide $10 million for research into CCSVI. Quoting from the release, it said: “The request for funding comes as Canadians with MS continue to seek diagnostics and treatment for CCSVI elsewhere, paying out-of-pocket for tests and experimental therapies that could be provided in Canada.” And it also said, “The MS community has spoken. They want access to diagnostics and treatment for CCSVI in Canada.”

Has the $10 million ever been given by the government?

Mrs. Deanna Groetzinger: The $10 million, I'm happy to say, would certainly be part of the funding of the CCSVI clinical trial. As you know, there was a fundable applicant, which is great news, so now we'll need to go through the ethics reviews; they have to take place. And most of that, in my understanding—because we don't know the details of that application, we don't know publicly what that budget would be.... The MS Society has said that we'll put in up to half a million to support that clinical trial, and the rest would be funded through by the federal government and possibly provincial partners. That's my understanding.

Ms. Kirsty Duncan: Okay, so the $10 million has never been given by government. Did you continue to advocate for it?

Mrs. Deanna Groetzinger: We are continuing to advocate for clinical trials. Again, I assume that part of the $10 million would be certainly expended through a successful CCSVI clinical trial if we're able to have one.

Ms. Kirsty Duncan: I only have a minute left, so it's going to be quick.

In September 2010 you called me to say that the MS Society was going to give $1 million to trials, and in June 2011 the MS Society committed $1 million to the trials. Is that the same $1 million that was announced in the fall of 2010?

● (1005)

Mrs. Deanna Groetzinger: Yes, that's right.

Ms. Kirsty Duncan: In September we said $1 million. In June there was a re-announcement, and now you've just said it's a half million?

Mrs. Deanna Groetzinger: No.

A half million for this first stage, our board wants to reserve the remaining half million for a phase three trial if phase one and two are successful. It makes sense to us to be careful of our donors' dollars, and to do it in a phased kind of way.

Ms. Kirsty Duncan: I appreciate your explaining that.

I have one last question. I had never heard until today, and maybe you could tell us, that the MS Society put out a request for clinical trials in 2009.

Mrs. Deanna Groetzinger: Sorry, I should correct that if I misspoke. It's not a request for clinical trials, but a request for research into the relationship between CCSVI and MS. It's not a trial.

Ms. Kirsty Duncan: That was done in 2009. Thank you.

The Vice-Chair (Ms. Libby Davies): Thank you very much. You kept good time there.

The next members of the committee are Dr. Carrie and Mr. Strahl, who I believe are sharing time.

Mr. Colin Carrie (Oshawa, CPC): Yes, thank you very much, Madam Chair.

First of all, I do want to thank the MS Society for your partnership, but also for your support. As you mentioned, research in Canada on this issue is unprecedented in terms of how quickly it is moving forward. I do appreciate the positive working environment you have with the federal government. As you said earlier, all members of the House would like to see this move forward as quickly as possible. Thank you for supporting the research and for your support for proper ethical consultation before we move forward with any experimental treatments on Canadians.

My question is actually for Dr. Kleiner-Fisman. First, I want to say thank you very much for being here today, and say hello to Dr. Reichman. When he was in committee I thought he was one of the most forward-thinking witnesses we had.

I have an interest in technology and innovation, and I was wondering what role can assistive technological devices play in the treatment and rehabilitation of persons with movement disorders and Parkinson's?

Dr. Galit Kleiner-Fisman: I really appreciate that question and the opportunity to tell you about what it is we're doing in the very unusual and incredibly successful care model that we're practising at Baycrest. It's actually a collaboration with a private health care clinic called the Assistive Technology Clinic on Baycrest grounds. The way we're working is that I'm actually, as you know, a movement disorder physician. Medically, I see the patients in the Baycrest part of the hospital.

The second part of what we do is the support and rehabilitation of our patients, which is being done on the grounds of the Assistive Technology Clinic. The clinic provides mobility devices, assistive communication, and does all sorts of research in trying to advance various different rehabilitation programs, and we're having incredible success.

What's particularly interesting about this place is that even though I'm doing movement disorders there, it actually started as an MS clinic. It has grown into an ALS and MS and stroke clinic. Really, the final common pathway of people with neurologic disability is the same. It doesn't really matter what the original cause is. People have mobility problems, people have—as you had mentioned—problems related to various social issues and financial issues. So we have a social worker. We distribute.... I think it's the largest distributor of wheelchairs in Canada. People come there when they have nowhere else to go and they get what they need at a nominal fee, if none at all. They are supported throughout their disease, regardless of what stage they're in. We're always there to help them.

It really is a remarkable place. There's a lot of focus on research into cures—and obviously that's incredibly important—but your constituents and my patients are living with their problem right now, and the cure isn't tomorrow. While there needs to be sort of parallel thought regarding research and the future, there also have to be helping people today.

There are resources to help people today, but very few people, believe it or not, have access to those resources. Even for physical therapy, you have to have private insurance to actually get physical therapy. So there are so many barriers to actually living today. What my philosophy and that of the people I work with is—and I think it's a growing philosophy in terms of care of patients—what can we do, what are the barriers we can overcome to help you get through your life today, your activities of daily living? How do we optimize quality of life today? It's true for all of us. We do have assistive technologies, and they are beneficial for patients with neurologic disabilities. I think that has to be a focus of a strategy.

● (1010)

The Vice-Chair (Ms. Libby Davies): Thank you, Dr. Carrie.

Mr. Strahl, there are about three minutes left.

Mr. Mark Strahl (Chilliwack—Fraser Canyon, CPC): Thank you very much.

Thank you to everyone who presented to us today. I'm always impressed at this committee with the level of expertise in Canada, not only the level of education that people have undertaken, but also the personal experience that we have shared. Marie and Derek, I want to thank you especially for opening yourselves up to us and giving us a window into what you face.

One of the things we've heard in different studies, chronic disease as well—Marie, you talked briefly about it—is the issue of mental health as it relates to.... I don't know what it would be called, not a side-effect, but it's a separate issue you deal with. How has the MS Society been able to help with that? Is that a focus of the MS Society, providing the mental health services? Dr. Kleiner-Fisman, you talked about treating the whole person. Is that part of what you do at Baycrest as well?

Dr. Galit Kleiner-Fisman: Absolutely. In fact, I'm very interested in patient input as to what their actual needs are. We recently conducted focus groups and studies and we're about to publish a paper on what patients' perceptions of their needs are, as opposed to what we, as doctors and professionals, perceive as their problems.

I have taken care of people with Parkinson's for many years, and I do my best to be open and sensitive to their issues, yet I was really surprised, as the moderator of these focus groups, what their issues were. Issues one to eight had absolutely nothing to do with their actual medications or their symptoms of Parkinson's. It had to do with their mental health. It had to do with their relationships with their partners and with their families. It had to do with their perception of being an ill person. It had to do with their financial situation and their concerns for the future and planning for the future and for their children.

It was really sobering and interesting to find out what really is on the forefront of people's minds and what we have to give them. It's not enough to give them medicine, that's not enough. It's not enough to just treat symptoms. There are so many. You can't break down a person into how they move, into how they think, and into how they feel. It's all part of one continuum. Those are the issues that are pressing for people, and we have to think about that in terms of resource allocation as well as—

The Vice-Chair (Ms. Libby Davies): We just have a little bit of time, so if we want to hear the MS representatives.... I'm sorry to cut you off.

Ms. Marie Vaillant: It's a very good question. Thank you very much.

There is a fairly high level of depression among people who live with multiple sclerosis. Numbers say about 50% of people who live with MS will suffer major incidents of depression. I got a little choked up when I talked about leaving work. I suffered a major depressive event during that period.

We with the MS Society are doing a lot about awareness of this. I will be giving a presentation tomorrow night as part of a national education event talking about wellness, and the emotional piece is part of it. It's really about education. I was lucky that between them my neurologist and my GP, when I was walking to the MS clinic and breaking down in tears, which is not what I do, said I needed to be on drugs. I was put on therapy to deal with the depression, and it worked.

Really, it's a question of education, and mirroring what Dr. Kleiner-Fisman is saying, the whole cycle of social needs of people with chronic illnesses is much bigger than just the drugs; it's the emotional element of it.

The Vice-Chair (Ms. Libby Davies): Thank you, Mr. Strahl.

We'll now move to our second round of questioning, which is of five minutes. Just keep that in mind: it's a shorter time period to speak and respond.

The first question will be from Dr. Sellah.

[*Translation*]

Mrs. Djaouida Sellah (Saint-Bruno—Saint-Hubert, NDP): Thank you Madam Chair.

I wish to thank all of our guests here today. A special thanks to you, Mr. Walton. I'd like to say that perhaps your skydiving activities have prolonged your life expectancy beyond the norm. I encourage you to keep on fighting.

I am a doctor by trade and so, as you can well imagine, scientific research is of great importance to me. One of the studies on CCSVI subsidized by the Multiple Sclerosis Society of Canada focuses, in particular, on whether chronic cerebrospinal venous insufficiency is a cause of multiple sclerosis.

The study, conducted by Dr. Brenda Banwell from the Hospital for Sick Children, involves examining children and teenagers with MS to determine whether the venous system is abnormal, as children and youth represent a population where the disease process is at a very early stage and are also unlikely to have age-related changes to their blood vessels.

What are the main conclusions that can be drawn from this study on teenagers and children? What other studies on CCSVI as related to MS are being conducted in Canada and abroad? What results have been attained, if any?

● (1015)

[*English*]

The Vice-Chair (Ms. Libby Davies): There's about three minutes left to reply, just so that you know.

Mrs. Deanna Groetzinger: Dr. Brenda Banwell's study of CCSVI possible in children is still ongoing. It's part of the suite of seven studies that the MS Society of Canada and the National MS Society are funding.

The results are not yet available. We were at the 18-month mark a couple of months ago. This summer, we'll be at the end of the two-year mark. The researchers will then bring those findings together. Until sometime late in the summer, I would imagine, we won't have those results. There are seven studies ongoing that are not a clinical trial but are looking at the relationship and at best ways to diagnose this.

Last week I looked at the list of the clinical trials registry, which is a part of the American National Institutes of Health. and there were eight CCSVI clinical trials registered. Interestingly enough, though, three are taking place in the U.S., two in Poland, two in Italy, and one in the U.K. There's one in the U.S., which is in Albany, and one in Italy, which is just getting under way; only those two are actually phase three randomized, double-blind, gold star sorts of clinical trials. The rest are more observational or open label.

So there's a lot of work being done. And certainly with every scientific gathering about MS or specifically about CCSVI there's much more being known. We'll know so much more when the seven studies are completed this summer as well.

The Vice-Chair (Ms. Libby Davies): Thank you, Ms. Groetzinger.

There's about a minute left, Dr. Sellah, if you have another quick question—very quick.

[*Translation*]

Mrs. Djaouida Sellah: Thank you, Madam Chair.

My question goes to Dr. Kleiner-Fisman. You stated that ideally, there would be multi-disciplinary teams so as to ensure coordinated care between the different—

[*English*]

The Vice-Chair (Ms. Libby Davies): There's no English translation. Could one of the interpreters say something?

Yes, now I can hear you.

[*Translation*]

Mrs. Djaouida Sellah: Let me rephrase that. As did most of the doctors and witnesses before this committee, you mentioned multi-disciplinary teams and coordinated care to make sure that patients' needs are addressed. Apparently, this is not the case as only a handful of centres have adopted this approach.

What do you suggest concerning a pan-Canadian strategy? I would also ask that you submit your presentation to the clerk if you please?

[*English*]

The Vice-Chair (Ms. Libby Davies): Just give a very fast response. If you have further information, you are most welcome to submit it to the committee.

Dr. Galit Kleiner-Fisman: Okay, I'd be happy to.

In fact it's an easy question to answer. I've been thinking about it a lot, in the sense that we've established this kind of centre where I'm currently working. It's extremely efficient. Patients have mobility issues; they have issues related to understanding how their medications work; medications interact with other medications. These interactions cause a whole bunch of secondary, other problems. People have problems related to what they eat and how that interacts with medication.

We try to educate them and their families and provide them with resources and with professionals to provide them the information they need so that they can successfully manage their condition. The idea is empowerment for them and empowerment for their doctors. We ensure that nothing gets lost.

● (1020)

The Vice-Chair (Ms. Libby Davies): Thank you very much. Anything that is presented today is on the record, so we can get it from Hansard, but if you have additional information, you could send it along.

Dr. Galit Kleiner-Fisman: I'd be delighted to provide it for you.

The Vice-Chair (Ms. Libby Davies): Our next questioner is Ms. Block.

Mrs. Kelly Block (Saskatoon—Rosetown—Biggar, CPC): Thank you very much, Madam Chair.

I would join my colleagues in thanking you for joining us today. Your testimony has really helped me in understanding some of the issues with neurological diseases and the need for research.

Mr. Walton, I want to thank you so much for sharing your personal experience with us. I want to confirm that I understand you have been living with the symptoms of ALS for approximately 14 years and then with a confirmed diagnosis of 10 years, so I can imagine that you have become a very strong advocate for raising awareness of ALS as well as for fundraising.

You also noted a concern regarding the fact that with a smaller number of individuals living with ALS as compared perhaps with those living with Parkinson's or MS, the funding dollars aren't as readily available for ALS as they might be for other studies.

I'm wondering whether, in the time you've been advocating for ALS, you're finding that the awareness has been raised and that more people are contributing to the funding for ALS.

Mr. Derek Walton: Thank you for your question, because it is very important.

When I was putting my presentation together I asked ALS Society of Canada how they got their research funds. Every dollar comes from donors. That is so frustrating, because they in turn fund Dr. Zinman at Sunnybrook. So donor dollars that are going to ALS Canada quite often finish up at Sunnybrook for their research.

It's been my experience, since I became actively involved in raising awareness, that the message is getting out there. Sadly, there appear to be more cases of ALS appearing on a regular basis. Unfortunately, due to the short lifespan these clients seem to become very isolated, and a lot of times friends will disappear. I'm glad that the other presenters mentioned the depression aspect, because there becomes a sense of unworthiness when you're not able to do normal tasks. That's why I cannot emphasize enough that dollars are required. As much as the national brain study is looking at the overall brain per se, for ALS it needs to identify that naughty gene that is breaking down the motor neurons and give us ALS clients some sense of hope that we are moving towards finding a cure.

Mrs. Kelly Block: Thank you very much.

I'm not sure, Mr. Walton, if you can answer this question for me, but certainly we know with some of the other research that's happened that there are often concentrations of individuals living with a certain disease in certain areas of the country. Is that true of persons living with ALS? Are there some areas of our country that have more persons living with ALS than other areas have?

● (1025)

Mr. Derek Walton: They say, Ms. Block, that it's related more to the size of population than to any specific.... I would say obviously Ontario has one of the highest number of ALS patients because of the overall population.

Interestingly enough, there is a study going on in Italie right now that is looking at professional soccer players, and they seem to think that there may be a tie-in with the pesticides and the fertilizers used on the grass. The U.S. is looking at football with regard to head contact, etc. So there could be these little pockets that have an unusually large number of patients.

There are three kinds of ALS. Familial ALS is inherited within the family, and that represents approximately 5%. There's the worst one of all, which is bulbar, which affects the muscles in the throat. Death comes very quickly in that situation. Then there's the one I have, which has no rhyme or reason. I just try to think positively, but I know that I'm the lone voice. I'm in a 5% bracket now, so please don't look at me as being the normal ALS client. I'm absolutely one of the very lucky ones, if you want to say that, because I do feel lucky. I have a wonderful wife and a wonderful caregiver and a strong support system.

The Vice-Chair (Ms. Libby Davies): Thank you very much, Mr. Walton.

We'll move to our next questioner, Dr. Morin.

[*Translation*]

Mr. Dany Morin (Chicoutimi—Le Fjord, NDP): Good morning.

I'd like to speak to the subject raised earlier by Ms. Vaillant. Although the medical aspect of neurological conditions is quite interesting, this is a matter of provincial jurisdiction. I would like to know what the federal government can do to help those who suffer from a neurological condition or their caregiver families.

Ms. Vaillant mentioned earlier that there is a non-refundable family caregiver tax credit. She believes, as does her organization, that this credit should be refundable.

I'd like to ask other committee members if they agree, particularly in view of the fact that, as she mentioned in her brief presentation, 80% of individuals living with multiple sclerosis are unable to work and thus suffer a loss of revenue. Obviously, if the spouse is the caregiver, he or she must take time off from work to do so.

The NDP is aware that low-income families and even middle-class families cannot benefit from the tax credit. I would therefore ask other members if they agree that the family caregiver tax credit should be non-refundable.

[*English*]

The Vice-Chair (Ms. Libby Davies): Maybe what we could do is go down the panel. If each of you would like to respond quickly, we have about three minutes for a response.

Dr. McDowell and Dr. Bray haven't had a response yet, so if you would like to comment in terms of support for families and tax credits, feel free to add your voice, and then we'll hear from the others.

Dr. Ian McDowell (Vice-Chair, Scientific Advisory Committee, Neurological Health Charities Canada): It seems to make a whole lot of sense to me. When I was working on Alzheimer's disease, we did an intensive study on the costs to caregivers and collected national data on that. We were able to model it.

One of the advantages of the study that Dr. Bray described is that not only does it collect facts and figures about how many cases, but it also feeds those into the simulation modelling that allows us to model the impact of varying policy approaches to things such as caregiver support on an economic basis. That is an additional connection between the more basic science and clinical research and policy formation.

● (1030)

The Vice-Chair (Ms. Libby Davies): Thank you.

Dr. Kleiner-Fisman, did you want to add anything?

Dr. Galit Kleiner-Fisman: Absolutely. In fact, the figure that I had quoted in terms of $750 million, those were the direct costs. Nobody talks at all about the indirect costs, and that's one of the largest areas where there's a huge impact in terms of families.

Parkinson's is not just a disease of the elderly. In fact, it starts in some people in their thirties and forties, in the prime of their lives. There have been studies that have actually shown the near millions of dollars of lost income to the person living with Parkinson's, not to mention the fact that the caregiver has to take time off work. It's a natural assumption that the spouse would take care of the person. One of the major issues related to it, and it all ties in together in terms of depression and relationships between people, is the loss of income and the fact that people lose their sense of self, both the patient as well as the caregiver, who has to now stop his or her career also.

Absolutely, the support of caregivers is key. In the *Rising Tide* report, that was one of the priorities with regard to Alzheimer's disease.

The Vice-Chair (Ms. Libby Davies): Does anyone from the MS Society want to add anything?

Mrs. Deanna Groetzinger: No, we're fine.

The Vice-Chair (Ms. Libby Davies): Then we'll go to Mr. Walton briefly. Mr. Walton, do you want to add anything about family reports?

Mr. Derek Walton: Definitely. We totally agree with the direction that is being proposed.

ALS is a crippling financial burden on families. It has no boundaries. Therefore, ALS clients quite often have to give up work and the caregiver obviously needs tax benefits.

Yes, definitely, we concur.

The Vice-Chair (Ms. Libby Davies): Dr. Morin, you have just about half a minute left.

[*Translation*]

Mr. Dany Morin: Very well.

I’d like to mention a Manitoba government initiative, the intergenerational home forgivable loan program. Each year, this program has the potential to help up to 200,000 families add a second living area to their home in order to accommodate an elderly parent.

Are you aware of this program? Do you think this is a good way to help families take care of their loved ones?

[*English*]

The Vice-Chair (Ms. Libby Davies): Very briefly, please—like, ten seconds.

Mrs. Deanna Groetzinger: Okay.

Our Manitoba division of the MS Society has been working very closely with the Manitoba government on a number of other initiatives regarding caregivers. I think Manitoba has done some great leadership in that area.

Thank you.

The Vice-Chair (Ms. Libby Davies): Thank you very much.

Mr. Lizon.

Mr. Wladyslaw Lizon (Mississauga East—Cooksville, CPC): Thank you very much, Madam Chair.

Welcome to all the witnesses, and thank you.

My first question is on MS treatment. The Zamboni treatment was discussed here this morning, and actually it's been discussed for a while. Where are we in finding, or trying to find, the cause of the disease? Of course treating the condition is one thing, but I think the key to success would be finding a cause. Associated with this would be early detection of the symptoms, or really of the disease. That would probably greatly help in stopping the progression of the disease.

This is to whoever wants to address it. We briefly touched on it at the last meeting with Dr. Krewski and others who were there. Is there any international cooperation in the studies so that we don't reinvent the wheel and every single country doesn't have to repeat the same process of clinical studies? Is there a way of exchanging information?

The Vice-Chair (Ms. Libby Davies): Mrs. Groetzinger, and then maybe we'll also get Dr. McDowell to respond from an overall perspective.

Mrs. Deanna Groetzinger: Perfect.

I'll start by saying that actually, interestingly enough, the MS Society of Canada funds a large research program, and obviously one of the targets we want to support is looking at actually what triggers this disease.

I think it was Dr. Sellah who asked the question about looking at CCSVI in children. Even before that, we'd been funding research, by Dr. Brenda Banwell at the Hospital for Sick Children, looking at MS in children; it's rare, but it does occur. That actually provides perhaps some insight into what might trigger that disease. If someone develops MS at the age of three or five or eight, then their life experiences are.... It's far less complicated than looking at someone who develops the disease at 30.

So yes, there's certainly work on that. It's a complex disease. It's probably a combination of genetics and environment and various other exposures.

I can assure you that on the international level, certainly with MS and I suspect with other neurological conditions, there's a lot of international collaboration, because we certainly don't want to reinvent the wheel.

● (1035)

The Vice-Chair (Ms. Libby Davies): Dr. McDowell, would you like to answer the question as well?

Dr. Ian McDowell: I think one of the skills in developing a national brain strategy will be to pay close attention to the balance between funding the clinical trials of treatments once it is in effect too late—the horse is getting out the door—versus doing etiological studies that may lead to preventive opportunities, which obviously is what we would all dream about.

So establishing that balance I think is going to be very, very interesting—and is a great challenge for you.

The Vice-Chair (Ms. Libby Davies): Mr. Lizon, you have about 30 seconds left, if you want to follow up.

Mr. Wladyslaw Lizon: Thirty seconds: it's not much.

The Vice-Chair (Ms. Libby Davies): I know.

Mr. Wladyslaw Lizon: I would just make a comment on the Zamboni treatment. I strongly believe, and I think it would go for all of us, that MS patients should not be left without hope. Every possibility that can be used to address their difficult condition should be explored.

The Vice-Chair (Ms. Libby Davies): Thank you very much.

Now we'll go to Mr. Kellway.

Mr. Matthew Kellway (Beaches—East York, NDP): Thank you very much, Madam Chair,

Thank you to the witnesses.

This is my first day as a member of this esteemed committee, and I didn't realize how esteemed it was. Everybody is a doctor, it seems, around the table. I had no idea. I'm not a doctor, but I do look forward to working with everybody on the committee constructively. To pick up on Dr. McDowell's statement, we have many challenges before us in the health field, so I come to the committee with a great deal of enthusiasm.

To my colleagues, thanks for the welcome.

Dr. McDowell, you mentioned research on Alzheimer's. We heard from Dr. Kleiner-Fisman today about an interdisciplinary model dealing with neurological disorders that impact on mobility. I'm wondering if Alzheimer's stands out as a bit different among the kinds of neurological disorders we're talking about today, and whether it can lend itself to the same type of health care model that Dr. Kleiner-Fisman referred to for the movement disorders.

Dr. Ian McDowell: I think as you work backwards from the very end stages of all of these diseases, there are so many similarities, more commonalities as people approach the end of their condition. As has been already said, as you move upstream the disabling effects are broadly similar, so we have to have comparable programs for supporting caregivers, no matter what the diagnosis.

As you then move back upstream toward the clinical type of research, of course the differences become very considerable. When you move even further back upstream within one condition, we suddenly discover the thing we had been calling Alzheimer's disease suddenly starts to get much more complicated and there are many sub-categories. When you start to look at the etiology, as Mr. Walton already commented with a couple of illustrations for ALS, there can be lots of different causes that lead to the very same disease process.

So the further upstream you go in trying to design a strategy ultimately to manage, prevent, treat, and so on, the more diverse the strategy has to be at the upstream end. We have to pay attention to the fertilizers that we do or don't put on our gardens that our children play in and may absorb, and so on. That is of course being done. It's all part of a brain strategy. But that only affects a tiny fraction of the eventual cases that may develop ALS, or Alzheimer's, or whichever disease. So we have to have multiple upstream strategies to protect health. It's very much like a public health type of approach. The more we learn, the more we understand, the more we can point the finger at these various hazards.

Of course there is a tremendous political balance, then, between protecting a tiny fraction of the people who are susceptible to those agents versus the convenience of being able to keep our lawns nice and green and so on and so forth. That's evidently in your domain. I think our domain as researchers is obviously to supply the information that would allow us to model—just to continue with the pesticide example—if we were to ban pesticides, this is the likely number of cases we might be able to prevent and suggest what would be the net cost-benefit of all that sort of a strategy.

It gets very fascinating. I think that ideally a brain strategy should have a clear model of how we think about this entire nationwide process of approaching neurological disorders, that in some ways they're very comparable and in some ways they're hugely different.

The last comment is that when you get right upstream, in fact the same etiological agents are hazards for multiple conditions. Pesticides may well be damaging for ALS; they're sure bad for your Alzheimer's; they're bad for your brain in general.

● (1040)

The Vice-Chair (Ms. Libby Davies): You have just about 30 seconds left for a question and response, so make it short.

Mr. Matthew Kellway: Let me just take those 30 seconds to thank you all for coming, and particularly Marie and Derek for having the courage to bring your personal stories before us.

To you, Derek, I thought you were absolutely courageous to come and talk to us today, even before I found out you leapt from planes every summer, so I appreciate that very much.

Thank you.

The Vice-Chair (Ms. Libby Davies): Thank you, Mr. Kellway.

We'll now move to Mr. Strahl.

Mr. Mark Strahl: Thank you very much to my colleagues for allowing me to pick up again.

I wanted to go back to the MS Society. Unlike some who expressed concern about the provinces taking a lead, having a different approach in their jurisdictions, I personally think that could be of great benefit to Canadians. I'm wondering if the MS Society is gathering the information that is being collected by the various approaches on CCSVI that the provinces are taking and whether that information is being shared between jurisdictions as it comes out. Or are we really in the preliminary stages and therefore there is nothing really to share yet?

Mrs. Deanna Groetzinger: I did mention that a Canadian MS monitoring system has been established. CIHI, the Canadian Institute for Health Information, has the lead on that, with funding from the Public Health Agency of Canada, and the MS Society is part of that monitoring system. Through that system there will be opportunity to pull in information from these other systems, the observational study in Alberta and the B.C. registry. There was actually a very small observational study as well in Newfoundland. So you're right: the provinces have taken different approaches.

The monitoring system is in early days, but I think it is the mechanism by which we'll be able to actually put this information in a usable way, as opposed to just people collecting lists of people. It has to be done appropriately, so you can actually pull data out of it once you put it in.

Mr. Mark Strahl: You mentioned that the minister announced phases one and two of clinical trials, and that the MS Society was involved with that. We talked about the funding. Is that the limit of your involvement? Do you only provide funds, or is there another role you're playing in these clinical trials?

Mrs. Deanna Groetzinger: At the moment, because we're still in a review period, we're waiting for a successful conclusion. After that, we will be in a position to help obtain the people who want to take part in these clinical trials. We have a big network of members from coast to coast, and we will be able to reach out to them and encourage their participation.

● (1045)

Mr. Mark Strahl: Dr. Kleiner-Fisman, the minister recently announced a pilot project on personalized medicine. I'm wondering what your thoughts are on that, given your whole-of-person approach to treating these sorts of neurological diseases. I'm also wondering whether there are any other centres like yours in other parts of Canada, or whether you are the flagship for the country.

Dr. Galit Kleiner-Fisman: On the personalized medicine question, I think it is absolutely critical. I can comment specifically on Parkinson's, and I think it's true of MS and other conditions, that everybody manifests symptoms and reacts to treatment in a different way.

I think the reason our clinic works so well is that we address every person as an individual and target needs according to individual priorities, not my priorities. I think this is really optimizing. There are no cures, but there are some treatments, and we are maximizing what we can do with the treatments that are currently available. It doesn't cost extra money; it's just using what we already know. Even though that sounds intuitive, you'd be amazed how rare it actually is.

Treatments of chronic neurological diseases can't be perceived like infectious diseases: you get an antibiotic, you take it for ten days, and then it's over and done. It's an ongoing entity and it affects every aspect of a person's life. In order to do what we can for people and use the resources that we have, we have to address what their needs really are.

Now, in relation to other clinics in the country—

The Vice-Chair (Ms. Libby Davies): Dr. Kleiner-Fisman, could you wrap up, please? We're just about at the end of the meeting.

Dr. Galit Kleiner-Fisman: There aren't any other clinics in the country that are doing it in the way we're doing it. There are other places that are working on a much smaller level, but not with this comprehensive approach.

The Vice-Chair (Ms. Libby Davies): Thank you.

We've just come to the end of our time for the committee. I'd like to thank all of the witnesses for coming. You gave us an enormous amount of information. Thank you for your commitment and time today. We'll be continuing this work.

I would like to let the committee members know that the clerk received some information from the Parkinson Society. She has a couple of packages of information, one in English and one in French. If anybody wants to look at this material, please contact the clerk.

The meeting is adjourned.

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