HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

Standing Committee on Health

HESA • NUMBER 031 • 1st SESSION • 41st PARLIAMENT

EVIDENCE

Thursday, March 1, 2012

Chair

Mrs. Joy Smith

Standing Committee on Health

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● (0845)

[*English*]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): We can begin now. We have a reduced quorum, but people will be coming in. Because of the weather, things are a little iffy with the traffic and everything.

I would like to welcome from the Public Health Agency of Canada, Ms. Elmslie, the director general for chronic disease prevention and control. I'd also like to welcome Dr. Beaudet.

We will be going from 8:45 to 9:45 on the presentations here. Who would like to begin?

Ms. Elmslie.

Ms. Kim Elmslie (Director General, Centre for Chronic Disease Prevention and Control, Health Promotion and Chronic Disease Prevention Branch, Public Health Agency of Canada): Thank you, Madam Chair. It's always a pleasure to appear before this committee.

[*Translation*]

Madam Chair, honourable members, I am very pleased to be here today to speak to the issue of neurological diseases.

I would like to take a few moments to summarize some of the important considerations related to neurological diseases. As you know, neurological diseases affect the brain or the nervous system.

[*English*]

Multiple sclerosis, Alzheimer's disease, Parkinson's disease, cerebral palsy, and epilepsy are but a few of the myriad of neurological conditions. These conditions are a leading cause of disability in Canada. Very few are curable and most worsen over time. Neurological diseases can be devastating for all those affected by them. They often take away so many of the things we take for granted—the ability to move, to communicate, and to remember.

We estimate that at least one million Canadians are affected by neurological diseases and suffer from the challenges of long-term disability and reduced function as a result of their neurological conditions. Whether the person affected is a grandparent, a parent, a child, or a neighbour, neurological diseases can inhibit Canadians of any age from participating in society. They can be present at birth, or they may develop in young adults, and they are often associated with aging.

This will be particularly important as the baby-boom generation begins to reach their senior years. Neurological diseases such as Alzheimer's disease and Parkinson's will affect more and more older adults. We estimate that these diseases cost the economy about $9 billion a year. There are other important costs for which it is difficult to attach a dollar figure—the human costs of neurological diseases. However, there have been, and continue to be, important developments in research, care, and treatment for these diseases. For the most part, there is no cure.

We do not have a full and accurate picture of the number of people affected by neurological diseases, the causes of the diseases, and their impacts on Canadians, families, and caregivers. Our existing surveys are dated, and are only available for a very limited number of conditions, such as epilepsy, MS, and Parkinson's disease.

[*Translation*]

Data gaps mean that we don't know which programs and policies will best serve Canadians affected by these conditions. That is why it is so important that we learn as much as we can about how prevalent neurological diseases are across Canada and understand the impact they have on the lives of individuals, their families and caregivers.

● (0850)

[*English*]

We also need to understand much better the implications for health care in our country. We know there are major data gaps for people residing in long-term care facilities who live with neurological conditions. To give you a sense of the extent of neurological diseases in Canada, I offer these facts.

Canada has among the highest rates of MS in the world, striking young adults, with women three times more likely to be diagnosed than men. Nearly 160,000 Canadians are living with epilepsy, a number that grows by almost 15,000 every year. Epilepsy affects both children and adults, with almost 25% of new cases occurring after the age of 60. Today, we estimate that approximately 500,000 Canadians are living with Alzheimer's disease and other dementias. An estimated 100,000 Canadians have Parkinson's disease. Approximately 200,000 are living with an autism spectrum disorder.

Taken together, it's very clear that a significant number of Canadians live every day with a neurological condition. Although there is no cure for many of these conditions, prevention and treatment can slow or delay their progression. By collaborating with provincial and territorial governments, health charities, other stakeholders, and researchers, we begin to address these knowledge gaps.

I don't have to tell you that good information is needed to make informed decisions, which is why investing in research is so vital. We can solve the real-world problems faced by individuals, families, and communities through research now and into the future.

[*Translation*]

The Government of Canada is advancing the knowledge of neurological diseases by funding the National Population Study on Neurological Conditions—a $15 million investment over four years. Working in partnership with the Government of Canada, Canadian neurological charities have come together under the umbrella of the Neurological Health Charities Canada, or NHCC.

[*English*]

Through this coalition of organizations, such as Alzheimer Society Canada, Parkinson Society Canada, and the Multiple Sclerosis Society of Canada, to name a few, Neurological Health Charities Canada represents people with chronic and often progressive neurological diseases. This coalition of health charities provides leadership on brain health by evaluating and advancing new opportunities for collaboration specific to advocacy, education, and research projects.

The study on neurological diseases that we are undertaking in collaboration with Neurological Health Charities Canada will help to fill knowledge gaps and will forecast the impact of neurological diseases over the next 20 years. It will provide a clearer picture of the state of neurological diseases in Canada, and very importantly, give Canadians living with neurological diseases, as well as their caregivers, a chance to tell their stories.

The study results will aid governments and stakeholders in planning programs and providing health services for Canadians with neurological conditions. It will provide us with key information to improve our knowledge about the extent of neurological disease, risk factors, use of health services, economic costs, and the impact of these conditions. It is the most comprehensive study of neurological conditions ever to be conducted in this country.

Better understanding the impact of neurological conditions on individuals in their homes, in their communities, and on their families and caregivers will help improve the quality of care and overall quality of life.

In the final year of the study, a comprehensive report will be published, and very importantly, a consensus conference will be held so policy-makers across Canada can discuss the findings and discuss what they mean for our approach to neurological diseases going forward.

Being able to forecast the impact of neurological diseases over the next few decades is of particular importance in the context of an aging population. Parkinson's, Alzheimer's and other dementias, although not a normal part of aging, are more prevalent in older adults. Having this kind of information can help prepare us for these future needs.

● (0855)

[*Translation*]

Another federal initiative that addresses neurological diseases, more specifically multiple sclerosis, is the Canadian MS Monitoring System, which was announced in March 2011.

The development and implementation of the MS Monitoring System is being led by the Canadian Institute for Health Information, or CIHI, in close collaboration with the provinces and territories, the Canadian Network of MS Clinics and the MS Society of Canada.

[*English*]

The new monitoring system will help make good information available on the treatment of MS for Canadians who live with this devastating disease. It will compile data from multiple independent data systems across the country. It will provide a standardized way of collecting those data, and will create a national data system on MS, its treatment, and information on the quality of life of those living with this disease. Over the longer term, this system will monitor patient outcomes and help identify the most effective therapies in the treatment of MS.

The information gathered and distributed through the monitoring system will help health professionals identify future needs and plan resources to ensure that those diagnosed with MS have access to the care they need. More research on neurological diseases will provide Canadians with the best possible information for the treatment and management of their condition. We have some knowledge about how neurological diseases affect the body, and some effective treatments, but we also need to know more so that Canadians affected by these conditions can participate fully in society.

This can only be achieved with research on neurological diseases —research done in collaboration with the provinces and territories, health charities and organizations, and importantly with input from patients who live day to day with the challenges of their particular neurological condition.

[*Translation*]

My colleague Dr. Beaudet, from the Canadian Institutes of Health Research—

[*English*]

The Chair: I'm sorry you've gone over your time, Ms. Elmslie.

Ms. Kim Elmslie: I was just going to hand it over to Dr. Beaudet. Perfect timing.

The Chair: I notice we don't have your handout. Do you have a presentation, or a handout that we can take home with us?

Dr. Alain Beaudet (President, Canadian Institutes of Health Research): We can send you the presentation.

The Chair: Okay. Great. I just wanted to double-check. Thank you.

Dr. Alain Beaudet: Thank you, Madam Chair.

I would first like to thank your committee for inviting me to speak to you about research activities dealing with neurological diseases in Canada and to provide you with an update on recent activity related to multiple sclerosis.

Today I would like to highlight some of CIHR's strategic initiatives that will help us better understand, prevent, or provide better treatments for neurological diseases. First, I'd like to give a few examples of how CIHR-funded research has already had a major impact on health outcomes for Canadians living with neurological diseases.

Since its inception in 2000, CIHR has invested $1.1 billion in the field of neuroscience, and this investment has been fruitful. A sizeable proportion of these investments have been in the area of neurodegenerative diseases, notably in studies on the pathophysiology and treatment of Parkinson's disease. As you may know, this chronic and progressive brain disorder can give rise to major motor impairments, which include rigidity and tremors.

Clinical studies carried out by Andres Lozano of the University of Toronto have confirmed a beneficial effect of deep brain stimulation surgery for the treatment of the cardinal motor features of Parkinson's disease. While the likelihood of improvement varied from symptom to symptom and from patient to patient, the surgery was found to be very effective in reducing motor fluctuations and involuntary movements—the primary reasons for patients' intolerance of medical therapy.

As another example, Dr. Bin Hu, a CIHR-funded professor from the University of Calgary, has developed an innovative tool called a “gait reminder” to help people living with Parkinson's disease have better walking movements. This new device computes leg movements and reminds individuals to take large steps to remain stable. Such a device prevents falls and helps prolong the functional mobility of individuals living with Parkinson's disease.

Important progress has also been made to better understand and treat traumatic brain injuries, including concussions and post-traumatic stress disorder, or PTSD. As you know, PTSD occurs after exposure to a terrifying ordeal, such as military combat, and treating this disease has proven a challenge. However, CIHR-funded research programs have shown promising results in the treatment of this disorder. For instance, Dr. Gordon Asmundson from the University of Regina found that exposure therapy, where patients are exposed to prolonged and repeated images of trauma until the images no longer cause anxiety, can be very effective in treating this disorder.

CIHR also supports innovative research aimed at improving the lives of paralyzed people. For example, CIHR has contributed to the work of Dr. Popovic from the University of Toronto on the development of neuroprosthesis to improve grasping function in spinal cord injured and hemiplegic individuals. By being able to grasp and hold objects with this prosthesis, paralyzed individuals can significantly improve their independence in activities of daily living.

● (0900)

[*Translation*]

As you heard earlier, as a result of population aging, we are facing a worrisome increase in neurodegenerative diseases, especially Alzheimer's and other forms of dementia. That is why the Canadian Institutes of Health Research and their charity partners have launched the International Collaborative Research Strategy for Alzheimer's Disease. Some of the strategy's goals are to prevent and delay the development of the disease, stop or slow down its progression and enable the health care system to face the challenges of long-term care for patients suffering from the disease. It is important to point out that this initiative is based on the development of many international partners, including the United States, France, the United Kingdom, Germany, Belgium, Ireland, Italy and China. We have prioritized an international cooperative approach in other areas of neurological sciences and especially in traumatic brain injury research.

In 2011 in Brussels, Canadian Institutes of Health Research and their European Union counterparts implemented an international initiative of over $50 million to address traumatic brain injury. In addition to that initiative, efforts are being invested nationally to advance research in this area. As part of those efforts, the Ontario Neurotrauma Foundation and the Hotchkiss Brain Institute recently joined CIHR in order to develop a Canadian national initiative on traumatic brain injury.

In addition to those initiatives on specific neurological diseases, some more general initiatives have been implemented by Canadian Institutes of Health Research in order to understand the origin and cause of certain diseases and provide—thanks to the latest technology—more specific and more effective diagnoses and treatments.

[*English*]

For instance, to better understand the interaction between genetic and environmental factors in the development of neurological diseases, CIHR has recently launched a Canadian epigenetics, environment, and health research consortium. We hope this initiative will help us develop better prevention and treatment programs, and rapidly translate epigenetic discoveries into new diagnostic procedures.

In the same vein, to better understand the genetic prevalence and signatures of diseases, and hence to be able to offer more targeted treatments, we have recently launched, in partnership with Genome Canada, a large-scale initiative on personalized medicine. This initiative represents a federal investment of $67.5 million, to be matched one to one by private and provincial partners, for a total investment of $135 million in personalized medicine. We're confident that this major investment will help us offer new diagnostic and therapeutic approaches for a variety of disorders, including neurodegenerative diseases.

I would like to conclude by providing you with an update on the actions undertaken by CIHR in the field of multiple sclerosis. As you know, in 2009, Italian physician Paolo Zamboni proposed that the blockage of veins in the neck and chest, a condition he referred to as chronic cerebrospinal venous insufficiency, or CCSVI, was the cause of MS, and he suggested that opening these veins would relieve the patients' MS symptoms.

It is important to realize that this proposed venous angioplasty procedure is not a routine procedure. As stated by the Alberta Health Services, and I quote:

> ...there are *no* situations where venous angioplasty is an accepted and satisfactory treatment....Therefore, the claims that venous angioplasty is a “routinely done procedure” are *not* true.

Researchers around the world are still questioning the safety and the efficacy of the procedure. Important initiatives have been undertaken around the world to better understand the CCSVI condition and its potential impact on the health of MS patients.

As part of this effort, CIHR has launched a call for proposals for a phase one and two therapeutic clinical trial to determine whether the proposed procedure is safe and efficient. The application deadline for this funding opportunity was yesterday. An international peer review committee has been established to review the applications received and a research team will be selected by the end of the month.

I am pleased to say that CIHR is working in close collaboration with the provinces and territories, and the MS Society on this important initiative, and that our approach to move cautiously has been endorsed by key health organizations, such as the Canadian Medical Association, the Association of Faculties of Medicine of Canada, the Collège des médecins du Québec, and the Canadian Society for Vascular Surgery, as well as other international health research organizations.

I will gladly provide this committee with future updates on MS as they become available.

Thank you.

● (0905)

The Chair: Thank you very much, Dr. Beaudet.

We will continue, beginning with our first round of questions and answers. I just want to say that at the end of the meeting we'll have a 10-minute business meeting, so we'll adjourn with 10 minutes to go to have that business meeting about a couple of small things.

Now we'll begin with Madame Quach.

[*Translation*]

Ms. Anne Minh-Thu Quach (Beauharnois—Salaberry, NDP): Thank you, Madam Chair.

I want to thank our two witnesses for joining us today. My question is for Mr. Beaudet, but both witnesses may answer.

Both of you conduct a lot of research. Yesterday and the day before, I met with representatives of the Canadian Organization for Rare Disorders. At a conference held yesterday, we learned that Canada was the only developed country without any policies on medication for rare diseases, given our small population. Internationally, a number of countries work together in order to establish a patient pool that is large enough to make information sharing possible, to make available medication that may be more appropriate or at least to suggest medication that may hopefully be used to treat those patients.

Some advancement was apparently made in the area two years ago, but things have stagnated since, and we do not know what Health Canada has done in this regard. What do you think? Why has no progress been made? Why are we not joining forces with other developed countries?

[*English*]

The Chair: I'm sorry, but our topic is neurological diseases. This is another topic.

But if you can answer...?

[*Translation*]

Ms. Anne Minh-Thu Quach: Yes, but some rare diseases are related to neurological diseases.

[*English*]

The Chair: Thank you—

Dr. Alain Beaudet: Obviously, I cannot comment on the policy aspects of things, that would be for Health Canada.

The Chair: Yes.

Dr. Alain Beaudet: I'm sure they will be happy to provide you with an answer when they meet with you.

What I can tell you, however, is that we have been very sensitive and sensitized to this very important project for many years. You are absolutely right that the nature of these diseases is such that very often the pharmas are not all that interested in engaging in research because the potential markets are extremely small. It's really for us to support research in this area, which we have done. We've done it at the level of understanding what diseases are, so that we can target proper therapeutics for them. In particular, we've had a very successful collaborative initiative on rare diseases with Genome Canada, which has led, I must say, to the discovery of several new genes for rare disorders. I think there is quite a bit of hope there for patients with these disorders.

We've also been involved with the provinces in a major clinical trial for enzyme replacement therapy in Fabry disease. We are clearly aware of the problem, and we've been ramping up our research efforts in that area. We are not involved in regulating, as I'm sure you understand.

● (0910)

[*Translation*]

I apologize for answering your question in English. I should have answered in French, but you seem to have understood what I said.

Ms. Anne Minh-Thu Quach: Yes, it's okay. Our interpreters are excellent.

Mr. Beaudet, you also talked about personalized medicine, and about therapies and treatments. Could you give us more details about that and tell us which area is the most developed?

Dr. Alain Beaudet: There is no doubt that personalized medicine is a major hope for all countries. Progress has been made in research in the U. S. and in Europe. Asia is also beginning to see some advancement. I think that Canada was lagging a bit behind in this area. That is why a major strategy on personalized medicine was launched a few weeks ago and was announced jointly by ministers Aglukkaq and Goodyear.

Personalized medicine could completely change the way diagnoses are made. I hope we will one day be able to use it to treat patients. Currently, a large number of patients being treated with medication are not responding to it. In many cases, that is due to the fact that the patients simply do not have the genetic elements that encode the targets the medication has an effect on. Therefore, medication is usually given to much more people than would be likely to respond to it.

The advantage of personalized medicine is that it will enable us to stratify patients and thereby focus specifically on the people whose genetic makeup predisposes them to respond to that medication. That will help us target treatments much better. As you know, that method is already being used to treat cancer in cases where it must be determined whether certain types of cancer cells will respond to a specific chemotherapy treatment, for instance. If it is known that, in terms of genetics, cells can respond to a chemotherapy treatment, we can subject patients to chemotherapy—which, as you know, is no trivial matter—and ensure they respond to it. On the other hand, that same treatment will not be administered to patients whose cancer cells do not have the required receptors for the medication and who, consequently, would not respond to it at all. So it is really a matter of specifying who is at risk, what the signature of the disease is and how we can ensure that the therapy is actually in line with a given treatment.

Personalized medicine is also very useful in the drug industry. Once randomized treatment trials are carried out, we will be able to ensure that we target specifically those groups of people that can respond to the treatments being tested. We hope that this will enable us to conduct randomized treatment trials on fewer patients and that we will not have to submit patients to treatments they are unlikely to respond to. In the case of neurological diseases, it is often not a matter of specific diseases, but syndromes that, presumably, cover various genetic identities. Therefore, we would be able to administer treatments that are more appropriate for stratified patients we refer to as responders.

[*English*]

The Chair: Thank you so much.

Thank you, Ms. Quach.

We'll now go to Dr. Carrie.

Mr. Colin Carrie (Oshawa, CPC): Thank you very much, Madame Chair.

I want to thank the witnesses for being here again to update us on this very important study.

I did want to touch base with you, Dr. Beaudet. Could you give the committee a rundown of the progress made in the last year on CCSVI? I know you mentioned that it was just a couple of years ago, in 2009, that Dr. Zamboni hypothesized that this was a cause for MS.

I know there are many organizations around the world, including the Canadian Medical Association, that still consider it a recently proposed condition. Are there any definitive tests out there that doctors could use to diagnose CCSVI?

Dr. Alain Beaudet: That's an excellent question, Dr. Carrie. As you know, one of the numerous difficulties, to start with, has been in establishing protocols of research to even demonstrate whether or not there was a higher prevalence of an association of CCSVI with patients with MS than with patients without MS. As you know, when you look at the literature on the subject, there's a huge variation and it is widely believed that the reason for that is the difficulty of diagnosing the CCSVI condition.

It is an ultrasound diagnosis, to start with, and several of the seven studies that the MS Society is currently supporting are actually comparing various diagnostic methods. What's interesting is that they all compare the various methods—for instance, intravenous angiography or NMR spectroscopy—with the Zamboni standard, which is ultrasound. So the idea is whether or not we see the same thing as with an ultrasound, and in some cases, an ultrasound performed using exactly the same machine as Zamboni used. There are some groups in Canada that actually went to the trouble of purchasing the same machine as Zamboni's and sending their technicians in the trial to Zamboni's lab, so that they would really learn to do it exactly as he did, and then they compared this with a variety of other approaches of looking at venous pathology, which are the current imaging approaches to look at venous pathology.

As you will see if you go on our website and look at the protocol for the therapeutic trial that we launched several months ago now, we've been extraordinarily specific—actually, I would say more specific than CIHR usually is in its call for proposals—in how to establish a proper diagnostic procedure, and preferably several diagnostic procedures, to make sure that we wouldn't start putting balloons in the veins of patients where the existence of CCSVI could be questionable. But if you read the recent review articles on this topic, you will see that this question of the difficulty of diagnosis is a recurrent one.

● (0915)

Mr. Colin Carrie: I do see it as a difficult diagnosis, and that's why I was wondering. I want to thank you for that update because it seems to me there's been some questioning around whether it exists and whether people without MS can have CCSVI, and I'm glad that you were able to—

Dr. Alain Beaudet: It has been one of the problems, actually, because some of the people who really don't believe in the association of CCSVI have put forth exactly this observation: Why is it that so many patients have the same abnormalities in their vein system and don't show the MS symptoms?

We could discuss at length the various reasons for that. Let's just say that right now there's enough evidence, as you know, for the possibility of an association, or an increased prevalence, for the working group to recommend to us that we go with a trial. And if we're moving on a trial, it's because we believe there are scientific reasons for it. Otherwise we'd know there would be no chance for the ethics review boards to approve such a trial. So if we launched it, it's because we feel at this point there are enough question marks of importance to really further investigate this.

Mr. Colin Carrie: I do want to commend CIHR for helping to coordinate this research, because so many people are counting on it.

You brought up trials. We recently heard that the Italian MS society's scientific community was mandated to review Dr. Zamboni's clinical trial, but did not approve his large-scale clinical trial. Why was that decision made, do you know?

Dr. Alain Beaudet: Very simply, they recommended to Zamboni that he should do things the way they're normally done—that is, go first to a phase one and two trial before moving to a large number of patients, as we always do with clinical trials. It's the normal prudent process. You first demonstrate that it is safe, you demonstrate therapeutic efficacy on a small number of patients, and then if there are no problems and if things are positive, you ramp it up to a large number of patients.

Basically, what the committee of the Italian MS society told Dr. Zamboni is, well, to do as Canada does. They didn't really say that, but they recommended that he take an approach that is exactly the same as the one we've chosen to take.

Mr. Colin Carrie: Is there anywhere in the world, that you know of, that has attempted to legislate the research process? I was wondering what you thought of that as a precedent. What would it do to researchers?

Dr. Alain Beaudet: I am not aware of any precedent. Irrespective of MS now—and I think I've been very clear on this topic, publicly—I think it would be a dangerous precedent to legislate the type and the object of research that we carry out and that the federal government would be supporting in this country. The federal government—I'm sure you're aware, after a number of very serious issues that arose with the use of some drugs like thalidomide and laetrile, where there were major complications, when trials were not as tightly regulated as they are now—set up some very stringent regulatory mechanisms to ensure that trials carried out on patients are scientifically based and ethically approved.

They have set up principles to do that. That have set up organizations such as ours to do that. I would think it would not be a good idea to bypass the process you've already set up to protect the safety of the population and to start legislating on very specific objects of research. I understand very well, on humane grounds, how tempting this may be.

● (0920)

The Chair: Dr. Beaudet, I'm just going to say we're over time now. We need to go on. Thank you so much.

Dr. Duncan, go ahead.

Ms. Kirsty Duncan (Etobicoke North, Lib.): I have seven minutes?

The Chair: You have seven minutes. Welcome to the health committee.

Ms. Kirsty Duncan: Thank you. Thank you to the witnesses.

Dr. Beaudet, you and I have known each other a long time. You know we don't agree on this. I'm going to point out that this has been done in 60 countries. There have been 30,000 procedures and three major safety studies involving over 1,000 patients. We just heard a discussion about how we don't know how to do the imaging. I was at the International Society for Neurovascular Disease conference a week ago, where I gave two talks. You will see the positive and negative studies linking CCSVI in my rebuttal to the Health Minister of her letter of February 17 and her reminder of February 23. I show who, in those studies, did multimodal, non-invasive imaging, and who did non-invasive and invasive imaging. The studies that involve many modes are the studies that, of course, have the better results. I think the consensus is that we need to do multimodal, non-invasive and invasive imaging. On the ISNVD, there has been a consensus statement about how imaging should be done.

I think it's important for people to understand that this is not a new theory. This goes back to 1839. There was a division between the vascular surgeons and the neurologists back in the 1980s. We're having this debate again. I should also point out there are three FDA phase two studies approved in the United States, which are being undertaken right now.

One of the first questions I'll ask is, will the CIHR roster all the Canadian patients who have been treated for CCSVI to date? Yes or no? I'm just looking for a yes or a no.

Ms. Kim Elmslie: As you know, the government is supporting the development of a monitoring system for all MS patients.

Ms. Kirsty Duncan: Ms. Elmslie, I know this. Yes or no; are we going to track those we have—

The Chair: Dr. Duncan, can we please give—

Ms. Kirsty Duncan: I'm not getting an answer, Madam Chair. I have a right to—

The Chair: She's going to give you an answer. Can you give her one minute, please? You interrupted her.

Ms. Kim Elmslie: I want to say this. The Canadian Institute for Health Information, our premier health information agency in Canada, is developing a monitoring system that will, over time, include all MS patients in Canada, provided that those patients and the clinics they are attending agree to be part of that monitoring system.

The Chair: So the answer is yes, right?

Ms. Kim Elmslie: The answer—

The Chair: Give her a chance—

Ms. Kim Elmslie: —is yes, provided that—

A voice: They agree.

Ms. Kim Elmslie: —they agree.

Ms. Kirsty Duncan: We will have lost 33 months by the time we start collecting data this September from the time that patients went overseas. We have lost the opportunity to track them at one, three, six, 12, and 24 months.

Will the follow-up include an MS quality of life-54 score, yes or no?

● (0925)

Ms. Kim Elmslie: The process to determine exactly what the monitoring system will include is under way now. We're in the developmental phase of the system. We have the country's experts involved in that. The question of exactly what the monitoring system will collect will be known in the next few months.

Ms. Kirsty Duncan: Thank you.

Dr. Beaudet, this is a hard question. You know I'm not a combative person; this is difficult. In light of there being an absolutely robust anti-CCSVI campaign, how is CIHR going to guarantee a non-biased study? That's of real concern to the patients.

Dr. Alain Beaudet: Actually, that's a very good question. The way we're going to do this is by ensuring that all—and that's really rare for us—all the members of the scientific evaluation panel will be from outside Canada.

Ms. Kirsty Duncan: Thank you. I appreciate that.

Dr. Beaudet, have you personally read all the positive studies, as well as all the negative studies, that I mentioned in my rebuttal to the health minister's letter of February 17?

Dr. Alain Beaudet: Actually, I have. I've seen your letter and I've read the articles.

In fact, I'd like to quote perhaps just one sentence from the latest one I've read, which was published in February 2012 in a reputable peer-reviewed journal, by Diaconu and colleagues:

> Beyond the limited published reports on CCSVI intervention, much of the support for endovascular interventions in CCSVI currently comes from anecdotal patient self-reports posted on web sites, blogs, and chat rooms. Prospective randomized control trials will be necessary to fully understand the impact of endovascular treatment of CCSVI due to significant potential placebo effects, blinding will be of major importance in the randomized trials.

This is what we're doing.

Ms. Kirsty Duncan: And I can say that we absolutely agree on the need for evidence-based medicine; you know that.

I'll point out three FDA phase two trials currently being undertaken in the U.S. I'm now going to quote Michael Shannon, former deputy surgeon general for Canada and director general of the laboratory for disease control:

> It would seem that we have learned nothing from The Krever Commission which very clearly placed the blame for both the HIV and Hepatitis C misadventures of the 80's on the shoulders of the Red Cross and Health Canada. Their inability and unwillingness to protect the Canadian public was at least in part driven by financial considerations and tragically cost thousands of Canadian lives and ultimately the Canadian taxpayer billions in health care costs and law suits.
>
> Is CCSVI any different? Having lived through the restructuring of the Canadian Blood System in the late 90's—

He helped to enhance both the regulatory and public health concepts. He continues:

> —I consider the lack of definitive action on the part of Governments, Government agencies such as the CIHR and NGO's such as the Canadian MS Society extremely disappointing.

How do you respond to that?

Dr. Alain Beaudet: I think I've already responded to that.

I believe we are doing the right thing. We're doing it as fast as we possibly can, and I realize that research is a slow process, and you know that as well as I do. We're doing that under the advice of experts in the field, from Canada, the U.S., and from other countries, and I certainly, like you, do hope that the results of the trial will prove positive for patients in this country.

Mr. Colin Carrie: Madam Chair, I have a point of order. I wanted to correct the record, when my colleague started her statement, she did say that I asked about diagnostic imaging. I just wanted to clarify that I didn't ask Dr. Beaudet that question specifically. I asked him if there was any definitive test to diagnose CCSVI. I just want to make that clarification.

The Chair: Yes?

Ms. Kirsty Duncan: I want to ask that this group review the latest information from the ISNVD, which is the group that looks at CCSVI. There is a consensus statement on the best way to image.

The Chair: And I know we have to go on—

A voice: It's not diagnosis.

The Chair: Excuse me—

Ms. Kirsty Duncan: Well, diagnosis is based on imaging—

The Chair: Order.

Dr. Duncan, we just need to go on and keep order. I know how passionate you are, but these are medical doctors here, and we need to listen very carefully to what they say.

We'll go to Mrs. Block now.

● (0930)

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

I too want to welcome you here. It's always a pleasure to have you appear before the committee. I think your briefings to us are always full of excellent information.

I want to go back to a comment my colleague made about the anti-CCSVI campaign that's taken place, in her estimation. Certainly I would take some umbrage to a comment like that, because I think those of us who are questioning this therapy are doing it because we haven't precluded the outcome. We are willing to allow the researchers to do the work they need to do in order to ensure that this is evidence-based.

The Canadian Medical Association wrote a letter supporting the position that the majority of our members took yesterday on this issue. Could you explain why the CMA supports our position? Have you had that conversation?

Dr. Alain Beaudet: Actually, I was cc'd on their letter, as you probably noticed, so I did see it.

I would summarize this in two points. We've already alluded to the first thing—

The Chair: Excuse me. I'm sorry, Dr. Beaudet, but there's a point of order from Kirsty Duncan.

Ms. Kirsty Duncan: I'm sorry to interrupt, but I have to address my colleague.

The implication there was that I'm not ready to...that I have made a foregone conclusion. I'm a former health professor, research—

The Chair: Excuse me, Ms. Duncan, these are not points of order, these are debates.

Dr. Beaudet, would you go on, please.

Dr. Alain Beaudet: Certainly.

Basically two points are made in this letter. The first thing is that, as was mentioned before, it would create a dangerous precedent to legislate on the type and object of research when we have mechanisms that have been set up by Parliament to do this on behalf of the Canadian public and the Canadian government. That's the first thing.

The second thing concerns more specifically CCSVI, which is that we must abide by the principle of clinical research, and get the information, as we're actually proceeding to get it, in a phased fashion.

Mrs. Kelly Block: Thank you.

I also want to go back to the MS monitoring system, which Ms. Elmslie spoke about, that was announced in March 2011.

I know my colleague asked whether or not we will be tracking all Canadians who have received the CCSVI treatment. I want to know if you can expand on why it is important to do this—first of all, to have the monitoring system, and second, why it may be important to ensure that we capture those individuals who have received the CCSVI.

Ms. Kim Elmslie: Thank you very much.

I'll start by saying that, as you know, the monitoring system is for all MS patients, including those who have chosen to have the CCSVI procedure, but not exclusive to those patients.

The reason it's important to have this monitoring system is that right now people with MS are going to a variety of clinics across the country for their care and treatment. Each of those clinics have different ways of collecting information on their patients, on the quality of life of their patients, on the types of treatment, and on their functions.

So we don't have, at this point, a national data system that allows us to understand what is happening to MS patients in this country in terms of improved function, disability, and quality of life. We also don't have a national data system, then, that allows for good information for doctors and for those who are responsible for planning services for these patients.

That's why this monitoring system is so important. It will unify, in a standard way, those data systems so that we have a large data system that we can use for a variety of different purposes—for research purposes, for understanding care, for looking at treatment patterns over time, and for looking at outcomes in these patients.

The CCSVI, of course, is very important to this dimension of the monitoring system, because it is one of the types of interventions that Canadian patients at this point in time are choosing to receive. We want to know more about what's happening to these patients, side effects as well as potential benefits.

● (0935)

Mrs. Kelly Block: Can I just make one comment in response? I don't know how much time I have, but I commend you for putting in place or developing this monitoring system, certainly with Canada being one of the countries, if not *the* country, with the highest incidence of MS. It's very important for us to do this.

Can you speak to the fact that this is going to be voluntary and to the implications it is going to have on our being able to have a robust data system?

Ms. Kim Elmslie: Yes. It will be a voluntary system, which means that at the clinic level, there will be a choice made by MS clinics about whether they will participate. At the patient level, there will also be a decision about whether they would want their anonymous information—so no personal identifiers—included in the national system. Of course, that is the way we operate in this country. We provide free consent to individuals as to whether they wish to participate in these types of ventures or not.

There's a huge interest when we look around the world and in Canada among people living with various neurological conditions, not just with MS, about being part of these types of monitoring systems, because they understand the benefit not only to themselves but also to Canadians at large. So we're quite confident that once patients with MS understand what this is, understand their right not to participate or their right to stop their participation at any time, they will be very receptive to participation in the monitoring system.

If I have just two more seconds, I'll say that when I talked about the national population health study of neurological conditions, one of the major parts of that study is talking to patients. One of the major advantages of this study will be that it's the first time we're learning directly from talking to patients about their experiences with neurological conditions, and they love participating in that part of the study.

The Chair: Thank you, Ms. Elmslie.

We're now going to our five-minute round, five-minute questions and answers.

I want to welcome Mr. Harris. Welcome to our committee. It's nice to have you here.

Mr. Jack Harris (St. John's East, NDP): Thank you, Chair, and I'm happy to be here.

I was very interested in the presentations, and thank you for them.

I'm going to change the topic a little, although we've been talking about MS for quite a bit.

I note in your presentation something that seems startling to me, Ms. Elmslie, that there are 160,000 people in Canada living with epilepsy, which is 3 times the number of MS patients—not that it matters. I don't know whether that's high or low, frankly, but what startles me is that your evidence was that the number of people with epilepsy is growing by almost 15,000 per year, which is a rate of 10% and strikes me as somewhat alarming.

Can you offer any more information on that fact, that statistic? Does anyone know why this is happening, what it means, or whether we're just getting better information?

Ms. Kim Elmslie: Well, it's a very good question and comment.

In fact, that's precisely why we are working with Neurological Health Charities Canada to undertake the Canadian study. We need to understand whether we are seeing better reporting of neurological conditions and that's driving up the numbers, or whether there are other underlying factors that we don't know about right now that are influencing rates of neurological conditions.

Unfortunately, we do not have good data in this country yet on many of these conditions. Therefore it's hard to answer the question you're asking, but we do need to answer it. We will know. We will have the answer to that question as the study finishes in 2013.

Mr. Jack Harris: That even gives rise to other questions. I don't hear any alarm bells going off about that. Should I? How is it that we're only now figuring these sorts of things out? Call me naive, but I know the Canadian Institute for Health Information has been around for a while. Is that who's doing this study, or is someone else doing it? Do we have a problem in coordination of health information throughout the country, in part because of our system? Is there something we need to do as a federal government to enhance the availability of this data? After all, it's extremely crucial to population health, if you want to use that term. How is it that CIHI is not doing this? Have we got cross-purposes going on?

● (0940)

Ms. Kim Elmslie: No, we don't. There is a great deal of data collection that's being coordinated through the Canadian Institute for Health Information, largely around health services data and population health data—but largely health services data. That tends to be a focus of their work, as they're informing the health system writ large on ways to improve the organization and the care that is provided.

Mr. Jack Harris: They've also built services.

Ms. Kim Elmslie: Yes. But there are gaps in information, and these are the gaps we're now starting to fill through other types of studies. The neurological health study is not just looking at one source of data. It's looking at data on surveys that are being conducted by Statistics Canada. It's doing new studies that interview patients, in particular. It's reaching out into communities to understand neurological conditions more effectively and comprehensively. What we're doing is creating a whole suite of different types of studies and surveys that allow us to fill in the pieces of the puzzle around these conditions.

Yes, we're concerned about rising rates of neurological conditions in the country. We know that the aging of the population has an impact. We're trying to learn more about autism, which is another new dimension of our work. We're putting in place the ability—again for the first time—to track cases of autism in the country, and not only from the health perspective. As you know, oftentimes it's the education or social service system that's picking up cases of autism before they're ever known in the health system.

These are complex ventures. They take time because you have to standardize the way you are collecting data so everybody is doing it in the same way. Otherwise, we get a mishmash of information about rates and prevalence and we don't know what to do with it because people are collecting it in different ways and it doesn't mean the same thing.

Mr. Jack Harris: My time is up, but it seems rather primitive for us to be dealing with these very basic questions in the 21st century. I'm new to this committee, and of course I'm not an expert on health, but as a lay person I find it startling that we're at such a basic place when it comes to these issues.

The Chair: Thank you, Mr. Harris.

We're going to suspend now. I want to thank the witnesses so much for being here. I want to thank you for your time today.

We have another round of witnesses coming forward, so we will suspend for two minutes to allow the other witnesses to step forward and then we'll begin immediately.

Thank you.

●

(Pause)

●

The Chair: We're now going into our second round.

I want to welcome, for our second panel, from the Brain Canada Foundation, Ms. Inez Jabalpurwala—what a beautiful name—and Dr. David Kaplan. Welcome back.

From Neurological Health Charities Canada, we have Ms. Vanessa Foran, director of policy, partnerships and government relations; and Ms. Celina Rayonne-Chavannes, director of research initiatives. Welcome.

We'll begin, first of all, with your presentation for 10 minutes.

Inez, are you splitting your time with Dr. Kaplan? You have 10 minutes between the two of you.

Who is going to begin?

● (0945)

Ms. Inez Jabalpurwala (President and CEO, Brain Canada Foundation): I'll begin.

Thank you very much, Madam Chair, and thank you to the committee for receiving us today.

The brain is the most vital and complex organ in the human body, and it is the source of all human experience and understanding. There are more than 1,000 brain disorders, including Alzheimer's disease, Parkinson's, multiple sclerosis, brain tumours, chronic pain, depression, stroke, addiction, and spinal cord injuries. It is important to remember that there are more than 1,000 conditions, and so while we hear about certain conditions because they're more prevalent, there are in fact a range of disorders. We also hear about these disorders as separate entities, and it's further important to recognize that brain disorders encompass both neurological and psychiatric conditions.

Some brain diseases respond to treatment, but of course, there are no cures at the present time. People with a brain disorder may live for a long time with their condition. With some conditions, a person may slowly degenerate and lose function before dying.

Brain Canada is a national charitable organization. Our goal is to fund research aimed at unlocking the mystery of the brain and developing diagnostics, treatments, and ultimately, cures for brain disorders. We seek to maximize current investments in research, and to make future investments more efficient and more focused on outcomes that will benefit patients.

On March 15, 2006, Brain Canada's predecessor, NeuroScience Canada, published “The Case for Canada's Increased Investment in Neuroscience Research”. NeuroScience Canada made the case that there are commonalities across brain disorders, and that, therefore, brain disorders should be considered as a group.

We further argued that there has not been a comprehensive study on the burden of this disease grouping, which would take into account both the range of disorders and the disability costs associated with brain disorders. Previous data collected focused on individual diseases, and on mortality and hospitalization rates. It did not include suffering or disability that does not result in death or hospitalization, nor lost productivity and psychosocial costs to patients, families, and their caregivers.

When direct costs and costs linked to disability are combined, the economic and human burden is estimated at $60 billion, or about 38% of the total burden of disease. This is a greater burden than that of cancer and cardiovascular disease combined. NeuroScience Canada argued that we need to better understand the true burden of brain disease. We need to raise awareness about these disorders in order to stimulate private and public investments in brain research, and we need to increase investments in research in a focused, strategic manner, and at a ratio that is proportionate to the burden of disease.

I'm very pleased to be able to say that since “The Case” was published, we have made progress in all three areas. First, NeuroScience Canada provided the impetus and rationale for the founding of Neurological Health Charities Canada. The concept of health charities coming together was aligned with “The Case” document, which said that if we can bring diseases together around commonalities, so too should disease-based organizations seek a common purpose in working together.

“The Case” and the efforts of NHCC led the government, on October 9, 2009, to commit a total of $15 million to a major study on neurological diseases. It is important to recognize that this study focuses on certain conditions and does not address mental health conditions.

The Mental Health Commission of Canada, and the Global Business and Economic Roundtable on Addiction and Mental Health have contributed to our understanding of mental illness, but we still need to consolidate both neurological and mental illness in our understanding of the total impact of brain disorders.

Second, NeuroScience Canada piloted a team grant model called the brain repair program, which demonstrated that funding collaborative research projects involving the best researchers across diverse disciplines can produce breakthrough thinking, which has an immediate application to how we diagnose, treat, and cure brain disorders. The NeuroScience Canada model drew on the “one system” approach to the brain, and focused on commonalities and underlying mechanisms across a range of disorders.

Five teams were funded from 2004 to 2010. Each team received $1.5 million over three years, and each team had a breakthrough discovery every year of their grant.

Finally, in March and June of 2011, the Government of Canada committed to matching up to $100 million raised by Brain Canada from non-governmental sources to establish the Canada brain research fund.

● (0950)

This will be the largest single investment in brain research ever made in Canada. The fund will be started by Brain Canada, and we will support a three-prong research program, which was developed with the Canadian Association for Neuroscience. The fund will compose team grants modelled after the brain repair program, training fellowships, and operating support for national technology platforms. Brain Canada encourages the Government of Canada as it fulfills this commitment.

The fund will maximize the return on investments in infrastructure and salaries already made by government and private donors by increasing operating funding. The fund will focus our research investment on the brain as one complex system and not just a collection of diseases, and invest in commonalities where a single breakthrough has the potential to create therapies for multiple conditions.

The fund will better coordinate existing efforts to spur discovery, and create resources and a toolkit for all neuroscientists to use.

Finally, the fund will excite the public around one unifying vision for the brain, and encourage all the key players to work together—scientists, business and philanthropic leadership, and the voluntary sector. The result will be more efficient, effective use of public funding, and a leverage effect to stimulate private investment in brain research.

Thank you.

The Chair: Dr. Kaplan.

Dr. David Kaplan (Vice-Chair, Science, Brain Canada Foundation): Thank you, Madam Chair and committee.

I am the chair of research for Brain Canada, but I am also a laboratory researcher working on neurological and psychiatric diseases. As a scientist, I can say the reality is that there are no cures for neurological diseases. My feeling is that Brain Canada has one of the best opportunities to help address that.

So how are we doing that through our research program? As an American who moved to Canada 15 years ago, I'll just describe briefly why I feel Canadians are best poised to create breakthroughs in terms of neurological diseases, cures, and therapies. Also, I'll give you a few brief examples of the successes of our different research teams in our pilot brain research program.

When we set up our brain repair program, our first goal was to try to accelerate research findings into the clinic, but another major goal was to encourage the best Canadian scientists to come up with ideas that would result in breakthroughs and shift the paradigms of the field. If we have no cures for neurological diseases, we need new ideas.

What are Canadians known for? We're known for being innovative, new ideas, but also for working together. We work together and play together much better than Americans—coming from the U.S., I can say so. We also do this with what we call “bang for the buck”. Canadian researchers are funded to study brain diseases at about one-third of the level per capita of our American colleagues. Yet our research is known to be the equal to research in the U.S. We're known for bang for the buck. I've always said, “Imagine what would happen if you funded Canadian brain researchers at the same level as the U.S. What would we then be able to accomplish?”

Our teams are not meant to focus on a particular disease, but to find the underlying causes of multiple neurological diseases and conditions. So when a discovery is made by a team working on Parkinson's models, that will also be applicable, for example, to multiple sclerosis, Alzheimer's, and epilepsy.

We also encourage a team and multidisciplinary approach. We want physicists working with biologists. We want Parkinson's researchers to work with Alzheimer's researchers. We fund those teams at ample levels—a half million a year—which is much more than our CIHR levels. We also want our ideas, when they're proposed to us, to be internationally validated, so Americans, Europeans, and Canadians look at those ideas and say that's the best idea they've ever heard for trying to cure or approach a neurological or psychiatric disease problem.

I don't know if I have enough time. I wanted to briefly tell you the outcomes of some of our teams. We have funded five teams thus far, out of about 30 or 40 ideas that were proposed to our international review committee. I'll just give you brief examples.

One is a chronic pain team where researchers at the Université Laval in Quebec City and at SickKids hospital in Toronto found one of the causes of chronic pain, and what they think is a major cause. Right now, over half the elderly and many people with diabetes, viral infections, cancer, and neurological problems have chronic pain, and only very strong narcotics will even begin to approach it. What they've found is that a cell in the immune system that normally fights infections is sending signals to our nerve cells to make those nerve cells hypersensitive so that acute signals, such a pinprick, become chronic signals. They now have generated a company as a result of those results to try to bring that to patients.

● (0955)

The Chair: Thank you.

Dr. David Kaplan: Thank you.

The Chair: Now, we'll go to Ms. Foran, please.

Ms. Vanessa Foran (Director, Policy, Partnerships and Government Relations, Neurological Health Charities Canada): Thank you, Madam Chair and committee members.

On behalf of Neurological Health Charities Canada, I'd like to thank you for the opportunity to appear before you today.

Neurological Health Charities Canada, as you've heard, is a coalition of 25 health organizations established in 2008 to represent people with chronic, and often progressive, brain diseases, disorders, and injuries. Its role is to provide leadership by evaluating and advancing new opportunities for collaboration specific to advocacy, education, and research projects related to brain health. It is a conduit for federal, provincial, and territorial governments to reach 25 organizations through one NGO.

Collectively, our members represent and advocate on behalf of more than five and a half million Canadians living with neurological conditions and their families, and invest approximately $50 million per year to fund basic clinical and psychosocial research.

The Chair: Ms. Foran, you're covering a lot of territory in a real hurry and the poor translators are—

Ms. Vanessa Foran: Am I reading too quickly?

The Chair: Yes, you are. If you could slow down, we might have it in both languages, and that would be a good thing.

Thank you.

Ms. Vanessa Foran: Thank you, Madam Chair.

I would like to begin today by expressing NHCC's gratitude to Parliament for its $15 million contribution to brain health through the establishment of the national population health study on neurological conditions, which is addressing the gaps in knowledge about the prevalence and incidence of brain diseases in Canada.

As many of you know, the study is the first of its kind in Canada, managed by both NHCC and the Public Health Agency of Canada. It is expected to provide information about the current impact of neurological diseases now and over the next 20 years.

With 127 Canadian researchers at more than 30 institutions across the country, this study will ensure that systematic approaches are used to define brain conditions, help decision-makers identify the resources needed to meet the requirements of this expanding population, illuminate the economic impact of neurological conditions on the health care system, and provide much-needed data related to Canadian incidence, prevalence, risk, and health service utilization.

NHCC asks that the results of this study be used by this government to develop a national brain strategy to address the needs of the growing numbers of Canadians living with brain conditions. To support this strategy, we ask the government to take a leadership role in the following areas.

The first area is in education. As with mental health problems, too few Canadians have sufficient understanding of the problems they are experiencing to seek the help they need. Too few Canadians get the kind of diagnostic treatment and support they are seeking because front-line providers have an inadequate understanding of the brain's central nervous system and the conditions to which they are prone. Stigma and misunderstanding create huge barriers to effective treatment for both the people with neurological conditions and their caregivers.

To address this issue, we ask the federal government to provide education to the public and front-line health care professionals to increase their understanding of brain health and improve direct care for all those with neurological conditions.

In the area of caregiver support, the role of caregivers changes throughout the course of most neurological conditions. Initially, when the person with the condition is still living at home, the focus of the informal caregiver may be on helping with transportation, household finances, or personal care. While the individual is receiving care from home care providers, the scope of the caregiving role broadens to include management and supervision to ensure that services are delivered safely and as scheduled. Once an individual is in a nursing home, the needs change again. While support for the activities of daily living is provided by the care facility, the caregiver continues to be engaged as a member of the care team.

We ask the Canadian government to provide meaningful support for caregivers in the form of a comprehensive package of education, respite, and mandated workplace accommodation with regard to the episodic needs of caregivers.

Next is the area of income security. Whether the condition is diagnosed in childhood, such as with cerebral palsy, Tourette Syndrome, or epilepsy; in early adulthood, such as with multiple sclerosis; or later, as with Parkinson's or Alzheimer's disease, where most people are diagnosed after the age of 50; as the disease progresses, it takes a toll on a person's productivity. This includes no longer being able to work—perhaps because of the disease, but all too often because of a lack of accommodation in the workplace—or a family member having to work part time or to stop work for long periods to care for a loved one.

People affected by neurological conditions need a new plan. The NHCC would appreciate the opportunity to work with the Canadian government to develop an approach to income security for people affected by neurological conditions. Development of this strategy would involve provincial governments, people with neurological conditions, and the organizations that represent them.

However, we also suggest that there are some relatively easy actions that could be taken right now. This includes making employment insurance benefits more flexible to allow people who have episodic conditions to work part time and receive partial benefits. We also ask the Canadian government to apply EI benefits to caregivers for caregiver leave in provinces where this kind of leave is available through provincial legislation.

In the area of integrated care, there is a considerable body of literature on the subject of integrated models of care. Anyone who has experienced a neurological condition in their family knows that it entails many visits to many different settings. One of the most significant concerns voiced by people who are frequent users of the health services, as patients and as caregivers, is that their care is uncoordinated. It's very hard to tell who's running the show. In short, the system is very difficult to navigate.

NHCC recommends that the Canadian government take a leadership role to provide integrated care and support both for individuals with chronic disabling conditions and those with acute illnesses. This would include case management; team-based care with defined roles for primary care physicians, nurses, medical specialists, and other care team members; and care delivery system redesign, integrating mechanisms among primary care, institutional care, and community providers.

● (1000)

In the area of prevention, access to treatment to prevent the progression of brain diseases and associated disabilities is the most pressing need of those who live with neurological conditions. To address this issue we ask the Canadian government for accelerated and targeted investment in neuroscience, as it is essential to find both causes and cures for brain diseases, and best practices to prevent and manage these chronic conditions.

For conditions such as stroke and acquired brain injuries where primary prevention is achievable, we ask the federal government to establish public education programs to help integrate brain health into the broader context of healthy living and prevention awareness.

Finally, in the area of genetic fairness, you may already know that many neurological conditions have a genetic basis, but did you know that Canada is the only G-8 country that does not have a genetic fairness policy in place, whether through legislation or a voluntary moratorium by the insurance industry? It is a well-established principle that individuals not be discriminated against based on disability, yet outdated laws allow insurance companies to discriminate based on perceived or potential disabilities.

Insurance laws permit insurers to require health information and use it without transparency to determine eligibility, set premiums, and manage the risks. Insurers ask applicants to divulge personal health information, including genetic data and family histories, and consent to have this information verified. This unfairly puts Canadians under duress, because they're denied needed coverage if they fail to do so. Canadians must also agree to have their personal health information, including genetic data, shared with other insurers through a medical information bureau, effectively closing off an individual's insurance options and threatening privacy rights.

As you know—and mentioned earlier today—this government recently announced that it is investing $67.5 million into a personalized medicine health care strategy that will factor in a patient's genetics and the specific characteristics of their illness before customizing a treatment plan. NHCC applauds both Genome Canada and CIHR for their leadership in supporting research in this area, which will lead to predictive, preventive, and precision care. However, if we do not protect Canadian citizens against discrimination with regard to their DNA, who will step forward to participate in this research? We will not get maximum benefit from our investment into personalized medicine if we do not remove the barrier of genetic discrimination. Canada has an opportunity to make this right, like all other G-8 countries have. It is time for Canada to act now to establish measures to protect all citizens from discrimination.

To conclude, NHCC recommends that the Canadian government develop a national brain strategy, based on the results of the national population health study on neurological conditions, to address caregiver support, neuroscience research, integrated care, prevention, genetic discrimination, income security, and public education and awareness. With an established network of stakeholders, a demonstrated track record of effectively engaging the neurological community, and an excellent working relationship across the federal health portfolio, NHCC is best positioned to undertake this work in collaboration with the Canadian government.

We thank you for your consideration.

● (1005)

The Chair: Thank you so very much.

We'll now go into our seven-minute rounds of Q and A's.

We'll begin with Dr. Morin.

[*Translation*]

Mr. Dany Morin (Chicoutimi—Le Fjord, NDP): Ms. Foran, I would like to begin by thanking you for the work you are doing. I also want to thank you for describing the lives of the people who care for those living with this type of disease.

My grandfather had Alzheimer's. So I was able to see just how much impact the management of that disease can have on a family. Fortunately, my grandfather had many children and all of them provided him with support until his death. Obviously, since families are having fewer and fewer children, caring for ailing parents is becoming a burden.

My first question is for the Brain Canada Foundation representative.

In the 2011 budget, the Government of Canada announced that $100 million would be injected into the fund. I would like to know how that money will be distributed and what resources it will go towards.

[*English*]

Ms. Inez Jabalpurwala: The $100 million is a match-funding program, so it is a public-private partnership with one component being to stimulate private investment in brain research. So a potential envelope of $200 million over the next five years will be allocated to the three research programs I described: the team grants, the training fellowships, and the operational support to national technology platforms. We will do this through an open-competition model, and then national and international peer review, which, as Dr. Kaplan described, was our practice with the brain repair program.

For us, what is most critical is that we are supporting excellent and innovative research that is benchmarked against international standards. We work with the CIHR to ensure that the peer review process matches the gold standard, and we work with other organizations that match that standard.

I think there are two features that set us apart. One is that we have a little bit more latitude to fund riskier research. We don't have to fund just incremental research, because as Dr. Kaplan described, we're looking for the best ideas, no matter where they come from. If it means bringing a chemist together with a physicist and an engineer to do spinal cord repair, we're willing to look at it, if it's peer reviewed. It's a very important feature.

The second feature is that we work closely with the Canadian Association for Neuroscience, and we work with and invite as partners all voluntary health organizations, provincial agencies, institutions, and research centres, so that there's an exchange of understanding about key priorities and the key areas of promise. It is not a top-down approach. We have predetermined certain strategic priorities. It is very much a living, bottom-up approach where there's flexibility to pursue the best research as it emerges.

[*Translation*]

Mr. Dany Morin: You talked about priorities. Does the Brain Canada Foundation prioritize certain disease or certain problems?

[*English*]

Ms. Inez Jabalpurwala: No, this is partly because of the commonalities approach. I can't emphasize this enough. I've been involved in this field for over 10 years, and my sense is that some conditions will receive more attention, in many cases because of the number of people affected. But there are many conditions that don't necessarily have a group to speak on their behalf, and I think that when we're setting research priorities solely based on diseases that have a strong voice, we may neglect conditions that equally merit attention. In addition, with a commonalities approach, when you're looking at multiple impact, we may be looking at something like repair in the white matter of the brain that has impact not just on major diseases, but also on other conditions.

There are really only three things that are the big problems with brain disease: one, cells die in a particular region; two, they don't connect well; and three, there are chemical and molecular imbalances. So looking at some of these underlying causes gives us clues to a much broader range of conditions. I think that is the right way to set strategy.

● (1010)

[*Translation*]

Mr. Dany Morin: Thank you very much.

Madam Chair, I will let Ms. Mathyssen have my remaining few minutes.

Ms. Irene Mathyssen (London—Fanshawe, NDP): Thank you very much, Mr. Morin.

[*English*]

Thank you very much for being here.

Madam Foran, I was quite taken by your concern with regard to the use of personalized medicine and genetic research. I have to confess that I was concerned by it when I heard it reported on the news. One of the things that really bothers me is that there has been no planning made for the 9.8 million seniors who will be here in Canada by 2036. Part of that planning, obviously, has to be what you were addressing.

You talked about legislative changes at the federal level. Should they also occur at the provincial level? Could you provide the committee with examples of genetic discrimination that's currently being experienced with regard to neurological diseases.

Ms. Vanessa Foran: Yes, indeed, there should be legislation, both at the provincial and at the federal levels. They should mirror each other to protect Canadian citizens.

In the 1990s, there was an insurance claim where the individual passed away and the family was not able to get their claim because of the genetic mutation found in this individual, which had nothing to do with his death. More anecdotally, for Huntington's disease, where there's a direct genetic link, I've heard of cases where a grandfather is diagnosed with Huntington's, and because there's such a strong genetic component to that particular disease, the children and the grandchildren couldn't get insurance for their house. That is very limiting to Canadians, and very unjust.

The Chair: Thank you.

And thank you for the question, Ms. Mathyssen.

We'll now go to Mr. Brown.

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

I remember in June 2009, I went down to the MaRS centre with a constituent of mine, Derek Walton, who had been suffering with ALS for seven years. He spoke at the announcement for the population study with Neurological Health Charities Canada. I thought that was a great initiative.

I was hoping to ask CIHR today for an update on ALS research, but I didn't have a chance. I thought maybe you could provide some information on where we are and if there are any new initiatives we could be hopeful about.

Ms. Celina Rayonne-Chavannes (Director, Research Initiatives, Neurological Health Charities Canada): With respect to the national population health study, there has been some progress made in terms of the work that's being done. The national study is a suite of 17 research projects—three surveys and 13 projects across the country, as well as one micro-simulation.

To speak to ALS specifically, we are starting to find some numbers with respect to incidence and prevalence. This study is actually looking at the epidemiology of neurological conditions, impacts as well as risk factors and health service utilization. In terms of the literature reviews that have been completed and the work that's starting to be done, which includes a lot of Canadian data, there are some numbers with respect to incidence and prevalence of ALS and other neurological conditions. But to say we have any specifics in terms of treatment and others, that's not within the confines of the study.

● (1015)

Mr. Patrick Brown: I realize you have until 2013 to complete that study.

Ms. Celina Rayonne-Chavannes: Yes, we do.

Mr. Patrick Brown: Do you get updates on research from your member associations, or is Neurological Health Charities primarily focused on this study, and fundraising and advocacy? Do you have any information you could share with the committee specifically on ALS research, or is that beyond your scope?

Ms. Celina Rayonne-Chavannes: That would be beyond my scope.

Mr. Patrick Brown: In terms of Brain Canada, will you be doing any work with the Alzheimer Society? When I went to our annual walk and skate last month for Alzheimer's month, I was asked about this initiative. There was hope about the $100 million and the potential matching funds.

What type of work do you think we'll be doing in the area of Alzheimer's?

Ms. Inez Jabalpurwala: We have made an outreach to all organizations to say we would like to partner with them. Having that kind of partnership and input is something that we strongly feel will make a huge difference in the quality of the study.

Our approach is an open model. We can't predetermine how many projects we will receive in the Alzheimer's area. What we can say is that there is strong Alzheimer's research happening across Canada. We have every expectation that when we launch our first open competition there will be a number of quality applications. That will enable us to form partnerships with the Alzheimer Society around research programs, around joint projects that we can fund together, and also around ensuring that there is that dialogue, because having the input of the groups that work with patients, families, and caregivers is an ongoing challenge for us that will continue through the course of this fund.

Mr. Patrick Brown: How will the brain research fund complement the work that's being done in other neurological research with the CIHR? Will there be a synergy between efforts?

Ms. Inez Jabalpurwala: Yes.

Do you want to cover the part about CIHR?

Dr. David Kaplan: I have funding from CIHR and I've also had funding from Brain Canada. I do work on Alzheimer's disease, and I've had major findings in the field. Our approach is quite different from CIHR's in that we don't target a particular disease. We have chosen not to target. If we're targeting, we want to target underlying causes of multiple neurological diseases.

For example, in ALS, nerve cells die, and in Alzheimer's, nerve cells die. So what we want to do is encourage teams to come forward with the best ideas to ask how we can keep all nerve cells from dying in multiple conditions. We believe that a drug or therapy that will then address one particular condition will address multiple conditions. This complements both what CIHR is doing and the individual NHCC members are doing in targeting conditions, because our goal really is to bring the research community together—the different disciplines and the different disease groups—to ask what the underlying problem really is and whether we can approach it. It's a complementary approach. Both are needed—CIHR's and NHCC individual member's, as well as ours.

Mr. Patrick Brown: I realize there are always more research proposals that have merit than there are dollars to fund them, so I guess it's very important that you have that coordinated effort. The danger would be if you ever had any overlapping research. I'm sure that wouldn't be the case.

I know Canada is also doing some partnerships internationally on Alzheimer's research. With that partnership with the U.K., France, and I think, Germany, will the findings and the work that's being done with the international partnerships be coordinated as well with your efforts?

Dr. David Kaplan: Sure. We have another model that will fund Canadian teams to work with international teams, and the member countries will fund their scientists to work with our scientists. This is a model that we're developing and that we think will be very valuable—to not just have a made-in-Canada solution but a worldwide solution to these conditions.

Also, because the team members that we fund are really renowned researchers in their particular fields, we do have cost and input from what's happening in the different fields to make sure that what we're doing is something new, and not just the same projects that are being done internationally.

Ms. Inez Jabalpurwala: We talk about the CIHR, but we should also mention the National Research Council of Canada because it is quite focused on the commercial aspect of research discovery, and it's also looking internationally to find the countries where there's complementarity.

We're not just forming partnerships for the sake of being present in the international scene. We're saying there's real value, because there are some countries that possess the knowledge or expertise that we don't have and vice versa, and we can share.

In addition to that, for Brain Canada, our focus is not the commercial part. It's everything up to that point. So partnering with NRC, for example, would be a very positive synergy.

● (1020)

Mr. Patrick Brown: Perfect.

With the neurological charities, I note that previously we had Shannon MacDonald before our subcommittee. Obviously, the contributions that you have made before this committee have been very helpful. I know when we did our study on neurological disorders with Kirsty Duncan and Judy Wasylycia-Leis, who was here before, Shannon was a tremendous help to us. I know that a lot of her work is being incorporated into our final report on neurological disorders.

Given that we have you here today, is there anything additional that you think we should be looking at when we finally do a final report in a few weeks from now?

Ms. Vanessa Foran: I think what we'd really like to see from the study—

The Chair: You just have a minute.

Ms. Vanessa Foran: Okay. We'd like to see, from the study and from the collective work of the NHCC, the members develop a national brain strategy. In May there's going to be a mental illness strategy launched. NHCC is already in contact with the Mental Health Commission of Canada.

The Chair: Thank you, Ms. Foran. I'm sorry. I know Dr. Duncan will probably pick up on that.

You're next, Dr. Duncan.

Ms. Kirsty Duncan: How much time do I have, Madam Chair?

The Chair: You have seven minutes.

Ms. Kirsty Duncan: Okay, great.

Thank you all for coming. Thank you for the work you do each and every day. It's wonderful to hear all the presentations. I think we absolutely need a national brain strategy in this country.

Europe is calling for 2014 to be the year of the brain. I would love to see that happen in Canada. I think it's important to increase the public profile of the importance of optimizing brain health and reducing the burden of brain disease on individuals and their families. I think we have to seize the vital opportunity to maintain brain health, and decrease the stigma associated with neurological and psychiatric conditions through nationwide education.

I think we have to support those with brain disorders by enhancing the pace of scientific discovery, and by the availability of compassionate, coordinated, and effective care. We have to draw political attention to the human and economic costs of brain disease now and in the future.

We need to build these international collaborations in education and science to enhance brain health across the world. We have to leave a lasting legacy in Canada of increased awareness and better understanding of brain health and disease, and improved diagnoses and treatment.

I'm wondering if Ms. Foran and Ms. Jabalpurwala can both comment on whether we need a year of the brain in Canada.

Ms. Vanessa Foran: Yes, I think that we do need a year of the brain. We need it for awareness.

It's actually interesting that it's going to be 2014, because that is the year we will have all the information from the national population health study. Celina is working very hard on a knowledge transfer piece. That piece will be available in the year 2014 so that it's available for researchers and the public, as well as health charity organizations and government, and in a language that they can understand and can relate to. I think that the culmination of the international year of the brain with the KT piece of the population health study is a perfect fit.

Ms. Inez Jabalpurwala: As you know, the U.S. had declared the 1990s the decade of the brain. What followed was an explosion of research, which is why 90% of what we know about the brain was discovered in the last 15 to 20 years.

I would overwhelmingly support declaring 2014 the year of the brain. I think that there is a value in raising attention and profile. I think the timing is right. There is a lot of interest about the brain and brain disease now. There is so much more understanding about the impact. This would be a perfect opportunity to see a convergence of all of that, so I would absolutely support that.

Ms. Kirsty Duncan: I appreciate that. I'll ask you both, and Dr. Kaplan as well. Should we make a recommendation in the report to be done here that year 2014 should be the year of the brain? I'll ask each of you to respond to that.

Dr. David Kaplan: I would absolutely agree. I think it's necessary. You've made a very astute observation and comment. There are a thousand neurological and psychiatric conditions, but there's one healthy brain. You mentioned the healthy brain a lot. What we have to be concerned about, and I think what we can appeal to the public for, is to find out ways to keep the brain healthy. That's as important as treating neurological and psychiatric conditions, but the public will understand that. I think that the observation and statement you made is right on.

● (1025)

Ms. Inez Jabalpurwala: Of course, yes, as supporting my previous comments, I would fully endorse putting that forward.

Ms. Vanessa Foran: NHCC would fully support 2014 as the year of the brain.

Ms. Kirsty Duncan: I'm very cognizant of the time because I have to leave.

I'll ask Dr. Fry if she could join me up here. I have to go. I'll ask the question, if you could come here—

The Chair: Just ask the question and then you may leave.

Ms. Kirsty Duncan: If there's a recommendation you could make to this committee regarding the need for a national brain strategy, could you be very clear in what that would entail? Should this be a recommendation that we need a national brain strategy?

Ms. Vanessa Foran: Yes, thank you.

We definitely need a national brain strategy. We really need it to include all the areas I mentioned, including integrated care, genetic fairness, caregiver support, research, prevention, and education. I think that's essential.

Ms. Kirsty Duncan: Should this be a recommendation in the report—that we need a national brain strategy?

Ms. Vanessa Foran: Absolutely.

Thank you for your question.

The Chair: Did you have another comment?

Ms. Celina Rayonne-Chavannes: I just wanted to add that within the national brain strategy and in putting together the year of the brain in 2014—just to pull together both of your questions—the national population health study on neurological conditions will be presenting a very robust report looking at....

I know that Mr. Harris in the last session spoke about the numbers and why we didn't have numbers related to neurological conditions. A lot of our studies or a good third of our studies are looking at the incidence and prevalence, looking at numbers for various neurological conditions. We need to understand the impact of neurological conditions in order to be able to move forward.

Once that information comes out in 2013-2014, that will be an excellent opportunity to build on current knowledge, to look at the gaps in the study, and to build on the research that will then have to go forward after that point.

The Chair: Thank you for your very astute answers.

I've asked Mr. Gill if he'd allow me to have a question, but I'll let him go first.

Mr. Parm Gill (Brampton—Springdale, CPC): Go ahead with your question first.

The Chair: Thank you. Mr. Gill is such a gentleman.

We haven't said much about essential tremors today, and I know from the studies I've seen that there are a lot of essential tremors that are emerging, much more. I don't have the stats in front of me right now, but I was astounded to see the amount of misdiagnosis between Parkinson's and essential tremors. I was talking to a neurosurgeon the other day who deals with Parkinson's patients, and he says that some tremors can be very pronounced and be mistaken for Parkinson's, but that it doesn't progress. Parkinson's progresses, but the tremors stay.

Could you give some input on any possible solutions for people who have tremors? At the beginning of your presentation, you were saying earlier, our witness was saying, that there's no cure for these neurological diseases. We've studied these diseases at length. Everyone around the table is very passionate about them and wants to do the right thing to help these patients.

Have you any research on or any cures for pronounced essential tremors? Dr. Beaudet mentioned brain surgery but that was the only thing I heard this morning. Is there anything else?

Dr. David Kaplan: The only things that have been proposed are brain surgery and deep-brain stimulation, as two possibilities. As we're learning more about Parkinson's, we now have to start learning more about essential tremors. With Parkinson's, we felt, in the research community, that there was greater need because it is progressing. But I agree with you; we now have to turn our attention to essential tremors, because so many people are being diagnosed with it.

For us, then, what is the cause? Is there a cause? What's a possible treatment? Is it similar to that of Parkinson's or not? We're still right at the beginning, really, of a non-surgical intervention possibility.

● (1030)

The Chair: And what is that beginning?

Dr. David Kaplan: The beginning is to look at what are the causes, and how they are different from or similar to Parkinson's.

The Chair: Mr. Gill, can I ask another quick question?

Mr. Parm Gill: Absolutely. Take your time.

The Chair: I'm watching the time. I'm not cheating.

There are also some studies that are indicating, and they're not solid research....

My background is science and solid research, so I like to see the solid research. But these studies are suggesting that farmers and people working around herbicides are developing a large amount of Parkinson's cases and essential tremors.

Do you have any information about that? I found that extremely interesting, and the research keeps coming up. I wish I had time to do the research myself. It's mind-boggling to see the farmers who are sitting in front of neurosurgeons trying to deal with either Parkinson's or essential tremors.

Is there any connection there that you know of, or any new research?

Dr. David Kaplan: The research is on what the toxic compounds in the environment are that cause Parkinson's. Some of them that we use in Parkinson's models are ones that are traditionally used by farmers, for example, to clear fishing ponds. We have had hints all along that it could be very toxic to the brain among vulnerable populations, resulting in Parkinson's.

For us, then, how do we protect those populations from all the insults in our environment? And it's not just what farmers see, but what we see every day.

Ms. Celina Rayonne-Chavannes: I would just like to add that Dr. Krewski's team at the University of Ottawa is part of the national population group of studies. His work is looking at risk of onset and prognostic factors, and as Dr. Kaplan has said, has looked at environmental factors that influence diseases, looking at international literature reviews and at some newer studies related to that as well.

To go back to your previous question just briefly, with regard to misdiagnosis of Parkinson's versus essential tremors, three of our teams within the national study are looking at validating algorithms for case definitions for neurological conditions, looking at the ICD-9 and ICD-10 codes, and looking at the feasibility of having neurological conditions added to the Canadian chronic disease surveillance system.

So they're really looking at each of these codes and finding a good way to have these codes used by doctors correctly. They're finding that they're used a lot better at hospitals than they are within physicians' offices.

These studies are trying to find a good common way of making sure that those misdiagnoses don't happen and inflate incidence numbers.

The Chair: Thank you.

I'm feeling guilty, because Mr. Gill has been so generous.

Mr. Gill, go ahead.

Mr. Parm Gill: Thank you, Madam Chair.

I want to thank the witnesses for being with us.

I have a question for Brain Canada. As announced in budget 2011, the Government of Canada has formed a partnership with Brain Canada to establish a $100 million Canadian brain research fund that will be matched by other resources, I guess raised from Brain Canada's other partners.

How significant is this, and how will it help people who have neurological disorders on the ground?

Ms. Celina Rayonne-Chavannes: I'm sorry, I missed the last part of your question.

Mr. Parm Gill: How will this help people on the ground?

Dr. David Kaplan: In terms of impact, the Canadian Institutes of Health Research spend about $120 million a year on brain research. The charities spend another $20 million to $25 million.

The investment here, including the investment from the government as well as our partners, is potentially $40 million a year, so that really increases by 20% to 25% our research capacity in studying the brain and studying neurological and psychiatric conditions. So this, in our community, is a huge increase and a huge commitment from the government.

How will it help people on the ground? In our case, one of our major missions is to accelerate discoveries in the laboratory to the patient. One of the ways to do that is by an increased investment. CIHR often can only afford to fund a project at, say, $100,000 a year. If we do half a million a year, we feel we'll be able to accelerate the best ideas and the best discoveries very rapidly to the patient.

● (1035)

Mr. Parm Gill: Thank you.

The Chair: Mr. Gill, I'm sorry. Our time is done because I took it.

Mr. Parm Gill: No problem.

The Chair: My apologies. I'm paying penance.

You have so many interesting comments, and we've appreciated them so much. We could have you here for a week. I'm sure we will be discussing neurological disorders at other times, so we'd love to have you.

We'll dismiss now. I'm going to ask our guests to leave the room, and we're going to go in camera for business.

[*Proceedings continue in camera*]

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