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Chair

Mrs. Joy Smith

Standing Committee on Health

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● (0850)

[*English*]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): Good morning, ladies and gentlemen. Welcome to the Standing Committee on Health today.

Pursuant to Standing Order 108(2), we're doing a study of neurological disorders. As the committee knows, there has been a lot of work done on this particular file. We had a very active subcommittee on this, and we are very pleased to have our witnesses here today.

There are a couple of witnesses who aren't here yet. I waited a couple of minutes just to see if they would arrive, but we're going to start and continue with them as we do it.

As you know, it's ten minutes of presentation.

Dr. Hu, if you could start with the presentation, I would be very grateful. Thank you.

Dr. Bin Hu (Professor, Department of Clinical Neurosciences, University of Calgary, As an Individual): Thank you very much, Madame Chair. I am very happy to be here.

I'm Sutter professor at the University of Calgary, which is a unique position. It is jointly supported by the Parkinson's Society of Alberta, the university, and Alberta Health Services. I do both translational research in patients as well as basic research in the laboratory.

My interest in Parkinson's disease is about how sensory cues, particularly music, can be used to help Parkinson's patients recover their motor function. The interest originated from a phenomenon we know as paradoxical movement. Patients with Parkinson's can't move, but some of them can dance, and they dance well.

I assembled a team five years ago, and this is the only study funded by the Canadian Institutes of Health Research to study how music can be used to help Parkinson's patients regain their function. The scientific basis of Parkinson's disease—how and why they respond to music—was not very well understood five or six years ago. But now we have a pretty good idea about where the brain circuitry is that is possibly responsible for these actions.

One thing I want to highlight here is that Parkinson's disease is a chronic disease. However, if you look at the patient populations, there are patients who are extremely resilient: they walk in the room, they're 80 years old, and they don't look like they have Parkinson's. And there are the patients on the other extreme: they're extremely worse. The question is why some patients are doing extremely well and others are not. The second question is how can you prevent disease progression to a state where they've lost their functional independence?

In experimental research we have noticed, and many other people have noticed, that when you make animals Parkinsonian by injecting them with toxins, some of these animals spontaneously recover. They actually become symptom-free after a few months. When you look at their brain, there's a functional compensation. So you lose some parts of the brain, particularly the so-called dorsal striatum. The dopamine is depleted. But just beside this structure there is overgrowth. There is a part of the brain that is compensating. This is the part of the brain that responds to music.

The challenge has been if you want to use music and in what way you want to do it. I have worked with two Canadian start-up companies who have developed an app for the iPod Touch. This device came about eight months ago with very precise sensors that can measure step size. What happened with this device was that we had a long list of music, a play list, and a patient would put the device on his or her thigh so that when they walk they have to walk with larger steps in order to get the music to play.

I can give you a brief demonstration. If you push one button, you will see on the screen it will read directly the step size. When it's rotated it measures your step size and you will play the music. But if your step size becomes small, the music will stop. It reminds the patients to re-engage.

When this device was put on the patients, some of them did not walk at all. Now they walk about two kilometres a day. The 20 patients I have now have, as a group, accumulated 1,000 kilometres walking, 300 hours listening to music.

Does it work? This is a small population. What we have found is that actually some patients have some unique symptoms. For example, they were afraid of going on escalators, and now they can go up and down without any hesitation or freezing. They couldn't swing their arms, and now they swing very easily.

So I am very optimistic about the new technology and the new science behind its design. If we can help patients to engage self-care and make them more resilient, I think many patients can benefit not only from music but also from exercise. The exercise itself actually is the single most mentioned intervention, and it has been shown to reduce the mortality rate by 50% for an average person who walks half an hour a day.

So how do we make these people comply? Parkinson's disease is a good example. Parkinson's patients have a mobility problem. They are older. If we can mobilize this population to walk more, for the general population as a whole, I think this could work even better.

I will stop here and take your questions.

● (0855)

The Chair: Thank you.

We hear all the presentations and then we have a designated time for the questions.

Mr. Strahl has kindly asked me if I want to ask some questions, so I will put my name down for later. Thank you, Mr. Strahl.

We'll now go on to our next presenter, from the Parkinson's Society of Canada.

David Simmonds, you're on. We usually have the presentation for ten minutes, but you're saving it, so we'll put you on for five more minutes.

Dr. Simmonds, go ahead.

Mr. David Simmonds (As an Individual): Thank you.

My name is David Simmonds. I'm a former national chair of Parkinson's Society of Canada, but I'm here on my own behalf, as an individual who's lived with Parkinson's for the last 20 years. You said Dr. Simmonds, and I just want to make sure there is no misunderstanding.

Parkinson's disease is a disease of deterioration of the brain. Traditionally everybody has thought of Parkinson's disease as being expressed and needing to be treated by motor functioning, but it's actually a disease that affects executive functioning in the brain. It affects the personality, and therefore it affects relationships.

Although I've had Parkinson's for 20 years, I'm very fortunate that last year I had what's called deep brain stimulation surgery. This is basically having a brain pacemaker implanted: electrodes in your head, batteries in your chest, and a remote control device, which my wife would like to use more often than I do. Before I had that surgery, every day was a bit of an adventure.

Parkinson's patients have what they call on periods and off periods, when the medication ceases to function well. My off periods were about two hours a day. For example, I couldn't turn in bed; I couldn't get up in the morning until my drugs had kicked in. Going for a glass of water in the kitchen was an adventure. You have to get the pill, the glass, the water, and you have to walk between all the points. That was very difficult.

My symptoms have diminished and my neurologist tells me that I now present like a person with either no Parkinson's or first-year Parkinson's. But that's with only two of my motor functions. My executive functioning, vis-à-vis my vocabulary and IQ, has significantly deteriorated. My complex reasoning skills have diminished.

The surgery has been great, but it came ten years after I had to retire because of Parkinson's. It's been a marvellous boon to my movement, but it hasn't been a cure, and it's by no means a cure.

People like me who have Parkinson's worry about a number of things. One is the timeliness and quality of diagnosis. By the time you see a neurologist, you've probably had Parkinson's for many years. The question is, do we have enough primary care physicians and para-physicians in the field who will know the symptoms early enough to spot them so intervention can be more successful?

Second, we worry about the cost of Parkinson's disease, in terms of lost income, disability income—is it going to be there? Are the drugs going to be too costly? Is the hands-on paid care going to be there?

The Parkinson's patient tends to withdraw, become more private, less communicative, quite inexpressive in their emotions, so their sociability suffers a great deal. More seriously, the burden falls on the family tremendously. I'm sure you've heard before about caregiver burdens, but the sacrifices that are made by family members are very true.

I said it's a disease that affects the personality. I certainly feel that my personality has changed, and my wife would say—this is hearsay evidence, I guess, but as a lawyer I would say that—she's been lonely and I'm not the person she married. My personality has evolved through the Parkinson's, to her detriment, I think.

If I had anything to say about the impact and the need to act with respect to Parkinson's, it would be that any illness has a dead weight of social cost that has no real economic value. The disability insurance industry evaluates an illness and asks how sick you are. Are you sick enough to get disability insurance? Are you sick enough to get a full disability credit? That has no economic value-added.

● (0900)

Parkinson's, like other neurological illnesses, is a disease that wastes the opportunity for intellectual capital to be developed in Canada. I mean, you can argue that our oil and gas are our biggest natural resources, but our second-biggest natural resource is our intellectual capacity. These diseases rob us of our intellectual capacity. To me, that's the tragedy of it, the lost opportunity to Canada.

Canada is a leader in both pure research and bedside research. At the Toronto Western Hospital, where I had my surgery, there were doctors and post-docs from literally all over the world—China, South America, Asia, Europe—coming to study at that facility to see the latest in surgical and intervention techniques.

I encourage Canadians to continue to support that bench and bedside research.

If there's any plea I would make, it's that the Swedish studies that are under way under the supervision of the Public Health Agency of Canada not simply be dropped on the table. They should be followed up with action across the front of the illness, and a national strategy should be developed.

If any one person perhaps symbolizes the tragedy of the lost opportunity for the development and employment of intellectual capital by Canadian society, it's one of your colleagues, my friend and the honorary national chair of Parkinson Society Canada, Senator Michael Pitfield, who I'm sure you all know.

Those are my remarks. Thank you.

The Chair: Thank you so very much. You had some very profound remarks, and from a personal side it gives us a picture. Thank you so much, Mr. Simmonds.

We'll now go to the Parkinson Society, with Joyce Gordon, please.

Ms. Joyce Gordon (President and Chief Executive Officer, Parkinson Society Canada): Thank you, Madam Chair and members of the health committee, for the opportunity to speak to you today about three key points. The first is integrated care, which includes specialist and primary care access for people with Parkinson's. The second is caregiver support. And the third is public and professional awareness.

Parkinson Society Canada has ten regional partners, covering every province and territory, and 235 community-based support groups from coast to coast. We are the leading voice for people living with Parkinson's in this country. We provide innovative leadership, information, and resources to Canadians, policy-makers, industry, health care professionals, and the media.

Today, as you know, 100,000 Canadians live with Parkinson's disease, and this number is forecast to double by 2030. It is the second most common neuro-degenerative disease, and its prevalence continues to grow as the population ages. Parkinson's is a progressive, chronic disease. The cause remains unknown, and there is no cure. It affects all aspects of daily life.

The average age of onset is 60, although more than one in 10 people are diagnosed before the age of 50. Parkinson's is more prevalent in men than in women and affects people of all ethnicities.

Parkinson's is not just a disease of the elderly, and it is not a natural part of aging. It affects adults across a wide range of ages when they are busy building careers and raising families, as you've just heard from David. Thousands of Canadians have been forced into unplanned early retirement, and many face the harsh reality of poverty as an added consequence of this disease.

Most people think of Parkinson's as a movement disorder. As David mentioned, it's a complex brain disorder that includes non-motor symptoms, such as depression and cognitive impairment. Unfortunately, the non-motor aspects of Parkinson's disease are often under-recognized and poorly treated.

Studies have shown that over 50% of people with Parkinson's will experience some form of cognitive decline. The motor symptoms that most people associate with Parkinson's include shaking, slowness of movement, impaired balance, and rigidity, but it's much more than that.

As you've heard from David, and you would hear from most people who have Parkinson's, the disease affects every system in their bodies and every aspect of their lives. For example, soft speech becomes a challenge in day-to-day communication, and reduced facial expression impacts how other people view a person with Parkinson's. Both motor and non-motor symptoms of the disease bring on hospitalization, which results in an increase in health care utilization and the escalation of economic burden.

Many people who require such care are not being referred to the relevant specialist, and our primary care professionals need more information on how best to handle appropriate treatment options as they work together with a specialist.

We need health care policies at early diagnosis, and cost-effective treatments that slow the progression of Parkinson's disease and reduce the symptoms. This could result in improvements in productivity of the working-age population, decrease the need for caregiving, improve the quality of life for people living with Parkinson's, and reduce the economic burden on our health care system.

We must also ensure that caregivers are supported. Caregivers, as you know and have heard from David, are often spouses or family members who contribute many unpaid hours of support, saving the health care system millions of dollars. Policies such as respite, tax credits, and employment insurance benefits for caregiver leave must be put in place to ensure that caregivers receive the support they need to continue their efforts. This would be very helpful in alleviating their financial burden, particularly as many must leave their employment for short periods of time. Some are eventually forced to become full-time caregivers and often provide support to the detriment of their own personal health and financial well-being. More must be done to prioritize and address the needs of this invaluable volunteer workforce.

There is also an incredible need for sustainable public awareness and education programs to reduce societal stigma and build better understanding of the brain and neurological conditions among both the Canadian public and health care professionals.

Several studies have demonstrated that depression and anxiety, key Parkinson's non-motor symptoms, are associated with stigma. For people with Parkinson's, stigma and discrimination often result from a lack of public and professional awareness of the disease. Canadians with Parkinson's tell us that their lives would be significantly improved if people in their communities understood more about Parkinson's and brain disease overall.

To conclude my portion of our presentation, because Dr. Fon will speak next, Parkinson's Society Canada gratefully acknowledges the work of this committee and the individual interest and dedication each of you has shown to this cause.

● (0905)

We believe the brain must be positioned as one of Canada's social, economic, and health priorities. We sincerely hope that, through this committee, work will begin to develop a national brain strategy—it has begun with this work—that will address the need for income security measures, genetic fairness, prevention, investment in neuroscience research, integrated care, and public education to reduce the social and economic burdens of neurological conditions in Canada.

We would also like to thank the Government of Canada for its investment in and commitment to the national population health study of neurological conditions. This study will provide crucial information on the incidence, prevalence, risk, health service utilization, and impact of Parkinson's disease, as well as many other neurological conditions in Canada. We ask the members of this committee to continue supporting this important work and also ask that neurological conditions be added to the Canadian chronic disease surveillance system.

We have a tremendous opportunity to work together in a collaborative way to develop plans to address the needs of millions of Canadians with neurological conditions, including Parkinson's. It is exactly this thinking that brought 25 charities together to form Neurological Health Charities Canada, and it is this thinking that we need our elected representatives and public servants to employ when developing policy and making investments. We must do a better job of supporting people living with neurological conditions at every age and every stage of life.

Dr. Fon will now provide an overview in terms of what the Parkinson program is doing in research.

● (0910)

Dr. Edward Fon (Director, McGill Parkinson Program and National Parkinson Foundation Center of Excellence, Montreal Neurological Institute, McGill University; Parkinson Society Canada): Thank you, Madam Chair.

[*Translation*]

Esteemed members of the committee, thank you very much for giving me this opportunity to meet with you.

[*English*]

As director of the McGill Parkinson program and as a practising neurologist, I am confronted daily with the progressive disability and suffering of patients afflicted with this devastating chronic illness, as people like Mr. Simmonds know much better than I do.

[*Translation*]

Parkinson's disease affects approximately 1% of the population above 65 years of age. It thus represents an enormous burden not only on patients and their caregivers but also on our society as a whole, and this burden will only increase as our population ages. In the next 25 years, neurodegenerative diseases, of which Parkinson's accounts for a major proportion, are likely to represent the single most important health-related challenge facing our society.

[*English*]

In addition to caring for patients with Parkinson's, I also run a very active research program focused on trying to uncover what goes wrong in the brains of patients with Parkinson's disease. My laboratory uses molecular and cellular approaches to investigate how defects in Parkinson's disease genes lead to degeneration in neurons in patients with PD. Thus, as both a clinician and a scientist, I have a strong conviction that the only way to get to the cure for PD and other neuro-degenerative diseases is basic research.

The primary focus of Parkinson Society Canada's national research program is to continue building on our strong PD research community by supporting basic science. It is basic science that is translated into breakthroughs in therapy, and it is this kind of investigator-driven research that encourages curiosity. It allows scientists the freedom to explore and make groundbreaking discoveries.

Parkinson Society Canada recognizes the importance of basic research. Since 1981 PSC has been the leader in non-government-funded research, contributing more than $20 million to support studies that might not otherwise have been funded through government or private industry. This approach is fundamentally different from other PD foundations, such as those in the U.S., which either don't fund basic research or adopt a very top-down approach.

PSC has also been a major driving force in establishing Neurological Health Charities Canada, which also strives to emphasize the commonalities and shared mechanisms of various brain diseases and fosters cooperation among the different stakeholders. This is something that Canada does very well.

In addition to being chair of the PSC scientific advisory board, I've participated in scientific review committees for the Canadian Institutes of Health Research and

[*Translation*]

for the Fonds de recherche du Québec — Santé,

[*English*]

as well as for international organizations such as the National Parkinson's Foundation in the U.S. and the Michael J. Fox Foundation, so I feel that I am particularly well positioned to evaluate the quality of Parkinson's research being carried out in Canada, and the major contribution of PSC. I can say without any hesitation that the quality of research funded year after year by PSC is second to none and is cutting edge by any standards worldwide.

[*Translation*]

Indeed, Parkinson's research in Canada builds on a long tradition of breakthroughs that have shaped the field around the world. I am referring to discoveries such as those made by Dr. André Parent and Dr. André Barbeau in Quebec. They were among the first to understand the functioning of the dopaminergic system and to use levodopa, which has now become the most frequently used and most effective therapy to treat Parkinson's disease. In Saskatchewan, Dr. Ali Rajput was among the pioneers who discovered the environmental factors involved in Parkinson's. Others, such as Dr. Lang and Dr. Lozano in Toronto, were pioneers in deep brain stimulation, which we have heard about before.

[*English*]

One reason we've been so successful thus far is that we've taken a highly collaborative approach and share resources and knowledge very openly. Again, this is something Canadian scientists are renowned for. However, our concept of Parkinson's is changing rapidly.

It's now clear that PD is not limited to the loss of dopamine neurons. The disease probably starts decades before the typical motor manifestations. When they become apparent, they may spread insidiously from one neuron to another in the brain. This is being increasingly recognized in the many non-motor manifestations we heard about just a few minutes ago, such as sleep disorders, cognitive disorders, personality changes, which had previously gone unnoticed. This turns out to be a big challenge for investigators and clinicians. Because it's apparent many decades before, it's a great opportunity to identify patients before the typical manifestations and potentially offer them groundbreaking therapies before it's too late.

It is also apparent that there is a shift in our basic understanding of the molecular mechanisms of neuro-degeneration in PD. PD was once thought to be a typical "non-genetic" disorder, but it's turning out to be one of the most complex multi-genetic diseases of the brain. The challenge for researchers now is to try to understand and sort out how the different genes interact with environmental factors in common cellular pathways such as protein misfolding and mitochondrial dysfunction.

Finally, our treatments for PD have also become much more sophisticated than just a decade ago. New strategies like deep-brain stimulation are becoming mainstream and pose serious financial challenges to our health care systems. Innovative approaches, such as virtual reality, as we heard of a little earlier, are also beginning to surface, with several Canadian scientists leading the field.

● (0915)

The Chair: I'm sorry, your time is up, Doctor. Thank you so much.

Dr. Hu, could you get us a copy of your presentation today? Do you have it in written form?

Dr. Bin Hu: I can e-mail it.

The Chair: It's very important to e-mail it to the clerk. I guess we can pick it off Hansard as well, but if you could e-mail it today to me —

Dr. Bin Hu: Sure.

The Chair: —that would be great.

Dr. Bin Hu: I will.

The Chair: When do we get Hansard, in a couple of days? We do have it on Hansard, but it's nice to have your written copy as well, in case there's something else in there that you didn't get a chance to cover verbally. I'm sure it's slightly different. We have your verbal presentation. I'd like to see your written one as well, if we could.

Now we'll go to Dr. Krewski. Welcome. I'm glad you're here today. Would you like to give us your presentation? You have ten minutes.

Prof. Daniel Krewski (Professor and Director, R. Samuel McLaughlin Centre for Population Health Risk Assessment, Institute of Population Health, University of Ottawa): Thank you.

[*Translation*]

I am happy to have this opportunity to present our research on the causes of neurological diseases.

[*English*]

What I'm going to talk about for the next ten minutes is our work in the area of what causes neurological disease in general. I'll refer to the slides I have, of which you have copies.

We're actually doing a systematic review of 14 different neurological conditions as part of the national population health survey of neurological conditions that the Public Health Agency is sponsoring. There are five institutions across the country, and we are the lead institution doing this work. You'll see in slide two a list of the institutions and in slide three some of the research team members, which includes a number of graduate students at different universities in Canada.

The next slide explains that the purpose of this project is to understand what we know about the causes of different neurological conditions. There are 14 in total.

Shown on the next slide is “Neurological Conditions of Interest”. One of the conditions you're particularly interested in is Parkinson's disease.

What I'd like to do is show you how we're doing this study. On the next slide you'll see a flow chart where step one is defining the disease terms for the condition. I'm going to talk about brain cancer briefly and I'll finish with what we've found so far on Parkinson's disease.

As you can see, we go through a very systematic approach. We identify where, which databases we're going to search—PubMED and others—and what search terms, so the review should be totally reproducible and done according to objective criteria. We quality-score all of the studies we look at to make sure we have relevant data.

The next slide gives you more information on how we search the data, which data base is used, which search terms.

The next slide begins with primary brain tumours. That's one of the three conditions we're doing at the University of Ottawa. So when we identify a relevant paper, we go through six levels of screening, extracting key information out of that paper.

The next slide points out that we actually have two people extracting the critical information and confirming that they're both getting the same results, so there's a little bit of quality control built in.

You'll see the next slide, called “Data Extraction Table for SR/MA”, is for brain tumours. This is the sort of information that we produce in summary form. We're literally looking at thousands of papers on brain cancer. We're looking at tens of thousands of papers on Alzheimer's disease. So you really need to be disciplined and structured about how you search through this literature.

The next little case study is Alzheimer's disease, for which, as I said, the literature is particularly voluminous, so I'll skip through the details. You can see some of the results we're finding in the slide that begins with “Data Extraction Table”.

There is a third condition we're studying at the University of Ottawa, which is ALS.

A lot of these neurological conditions have similar ideologies or share some ideologic factors. Through PrioNet Canada we've been pursuing for the last few years the hypothesis that protein misfolding may play a role in many of these conditions. I think we have some really great opportunities, if we pursue that scientific hypothesis in the future, to help address the burden of several neurological diseases, including Parkinson's.

I'll skip over the medical analysis, which we do when we have enough data to try to get a quantitative estimate of different risk factors, what agricultural chemicals, what risk they might propose for ALS. We're actually going to try to quantify that by combining the data from multiple research studies, and the same for heavy metals.

What I should tell you a little bit about, what you're most interested in, is what we are doing with Parkinson's disease. That condition is being led by the University of Toronto, and the team there was kind enough to give me some hints as to what they're finding initially. This is all not final yet, so we're looking at a whole series of dietary factors, fruits, vegetables, dairy products, alcohol, coffee, tea, junk food. We're looking at macro nutrients, micro nutrients, lifestyle factors such as coffee drinking, cigarette smoking, physical activity, family history of Parkinson's, personality characteristics, environmental factors, agricultural chemicals, farming, well-water drinking, living in a rural environment. We're looking at comorbidities, such as melanoma and diabetes, a whole series of genetic risk factors, target genes as well as polymorphisms, and a number of drugs that are used to treat Parkinson's disease, whether they have any, and a number of drugs that people may be taking, such as anti-hypertensives, and their role in the onset of Parkinson's.

When we have finished this very ambitious study we will have covered the world's literature through to the present time on what we know at this point in time about the causes of all these neurological conditions. Parkinson's is the one you're interested in, but we're going to do 13 others for the Public Health Agency of Canada.

We have a second question: what factors influence the progression of the disease once the disease has been initiated? We're targeting finishing this by about January of 2013 and presenting the final results at a national conference that the Public Health Agency will host in March of 2013. That's when I'll be able to tell you everything you want to know about what we know about what causes Parkinson's.

● (0920)

Thank you.

The Chair: That was very interesting. Thank you for your presentation.

We'll begin with our first seven-minute round of questions and answers and we'll begin with Ms. Davies, please.

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

Thank you so much to the witnesses for being here today. You've provided us with an incredible wealth of information, from research to new advances, to living with Parkinson's, and to new therapies.

Dr. Hu, your information about your music program is quite incredible to hear. It seems so simple, but I know we don't know the complexities that are behind it...and trying to figure it out.

Certainly to Mr. Simmonds, thank you so much for being really frank in sharing very personal information about what it's like to live with Parkinson's. I'm sure it must be a bit daunting to come before a parliamentary committee and open up about your life. We really appreciate that you were so open and frank with us, because it does help us to understand. My father died of Parkinson's, so I have some knowledge of what the disease is like and what it means for families and caregivers. We very much appreciate the information you've provided.

I wanted to make one general comment and then I have a couple of questions.

Ms. Gordon, I think what you identified—in fact a number of you did—is the impact on families and caregivers and how serious this is. We have heard this repeatedly, and it's something that I think many of us have personal experience with as well. It's such an important question and we're not doing nearly enough to support caregivers financially in terms of respite care, whether it's through the taxation system or supports at home. I want you to know that I don't think we're doing nearly enough. We've been doing another study on chronic diseases and of course that issue surfaced there.

The questions I have, though, and you mentioned it very briefly, Ms. Gordon, when you talked about genetic discrimination.... I met with the Coalition for Genetic Fairness iseveral months ago, and it was a subject I was not familiar with. I know it's an issue for the Parkinson Society of Canada too. I wonder if you could speak a little bit more about that, especially as we get into this age of electronic health records and information sharing, databases and all of that. From what I understand, this is a huge issue where people are feeling very vulnerable about information that can be used against them by insurance companies and by workplaces. I hope you could share a little bit more about what we need to do about that. That's one question.

The other question I have is on the cost of drugs, and I would throw that out to the panel for anyone who would like to respond. In our research background we are told that a typical patient may have $1,000 in drug costs a month. We know in the health accords there was a commitment made to have at least catastrophic drug coverage. Nothing has been done. Presumably all of the folks you work with are still facing these horrendous situations of massive costs in drugs. I think it would be helpful for you to provide a little more information about that.

If we have time I'll sneak in one other question. The surgery you had, Mr. Simmonds, how common is that? Is it now widely available? Is it one of these problems where if you're lucky enough to be in the right city and get in at the right time...? I have not heard of the surgery before. I'm curious to know how available or accessible it is in Canada.

● (0925)

The Chair: Mr. Simmonds, would you like to start, please?

Mr. David Simmonds: Sure.

In terms of drug costs, the suite of drugs that I was taking prior to my surgery, which is now reduced by virtue of the surgery, had an aggregate cost of about $20,000 to $25,000 a year. I was fortunate to have a medical plan that covered a good chunk of it, but nevertheless somebody was paying that cost.

In terms of the surgery, the surgery is not high-risk surgery. It's relatively routine surgery. But in terms of the selection of patients, I think there's much more demand than there are surgical places available. Therefore, they tend to pick candidates who are good, solid risks for successful surgery. I wouldn't like to hazard a guess as to what the proportion is, but certainly many more people could benefit from the surgery than have had it.

Ms. Libby Davies: Thank you.

On genetic fairness, if you don't mind responding....

Ms. Joyce Gordon: Thank you for the question.

There is a coalition that has come together called the Canadian Coalition for Genetic Fairness, which you may have heard from. It is led by the Huntington Society. We are a member of that coalition. On how this arose, across Canada and all over the world there has been promotion of opportunities for people to have their DNA tested and have a report back about what they might be at risk for. I don't know if you've seen it in the papers. Full-page ads have been taken out. There's 23andMe, where you send them $25 and they send you back your whole genetic profile.

A number of issues arise from that. One of them is that when people receive the information, what are they supposed to do with it? It's advised that people have genetic counselling. If they may be at risk for certain conditions and have full genetic testing done, they should have the appropriate support to determine how best to use the information. That's one issue.

The second issue is I don't think people in Canada are aware that we do not have legislation to protect people once they receive that information. If you fill out an insurance form that asks you if you have had genetic testing and you answer yes, there is no legislation that protects you from not providing that information to them. They have every right to ask you what it said and to ask for the results. That can result in discrimination around insurance applications. Some professional individuals whose ancestors have had a history of Huntington's have been denied professional insurance because it's viewed as a high-risk genetic factor, for example. With Parkinson's, about 10% to 15% of people with Parkinson's—maybe more, given the information we've just heard—are affected by genetic.... Ted could speak more to this than I can.

So there is no legislation to protect people once they receive this information. Generally, companies doing this are private ventures to provide people with information that is supposed to identify if they're at risk for certain conditions. If you've seen the advertisement, it lists most of the neurological conditions, which is kind of surprising. On the other hand, when you get that information, what are you going to do with it? Secondly, once you have it you are at risk for having to declare it when you're asked. That implies employment situations. If an employer asks, you do not have the right to say no. You do not have the right to say you're not going to give it to them, and they have the right to not hire you. So it has enormous implications.

This coalition has come together and has been looking at amendments to the charter of human rights. They have put together a whole portfolio to make changes so individuals would be protected from having to declare that they've had genetic testing. They would then be protected from some of these issues around insurance, employment, or other opportunities.

● (0930)

Ms. Libby Davies: Do I have any more time?

The Chair: You have one minute.

Ms. Libby Davies: Okay. I have just a quick follow-up.

The Chair: I'm sorry, you don't have any more time. I was involved in what she was saying.

In fact, you've gone over time, Ms. Gordon. I'm breaking my record. This is bad.

Ms. Joyce Gordon: I'm sorry.

The Chair: Now we will go to Mr. Brown.

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

It's great to have you all here today. We've all taken a great interest in the topic of neurological disorders from our previous study on them.

Joyce, I know you've been here a few times, with both the Parkinson Society and the neurological charities. We certainly appreciate that.

Some of the comments have certainly been interesting. One area that I've always found particularly fascinating is the collaboration with other neurological disorders. Mr. Fon and Mr. Hu both talked about that.

When you talked about Parkinson's you said you discovered that the neural breakdowns can potentially happen decades before. I know with Alzheimer's they're now doing a population study over a much longer period to try to examine how this happens and what causes it.

Will you be doing any similar large population studies over an extended period on Parkinson's? It's a general question to the panel.

Dr. Edward Fon: Thank you very much for that question.

I think you're absolutely right, and it's really been a shift in the way we think about Parkinson's disease. Literally 15 years ago people were completely focused on the motor components—the tremor, the slowness in movement. As we've gotten better at treating those parts of the disease, it's become very clear that patients have many other features. Maybe more interestingly, and I think this is what you're getting at, some of these features appear years if not decades before the motor manifestation.

I think this is really an opportunity to identify these people. I won't call them “patients”, because they're not really patients yet, necessarily. There are certain features...for example, a loss of smell. Almost all patients with Parkinson's lose smell. This is something that you could easily identify, possibly on a population level, as you were hinting at. Other things include sleep abnormalities, which occur sometimes a decade before.

One study led by a Canadian group—Ron Postuma at McGill—showed that there's a certain kind of sleep disorder, called REM sleep behaviour disorder, a very distinctive sleep disorder, and about half of the people who have that disorder, which is a huge amount, go on in the next decade to develop Parkinson's or Parkinson's-like disorders. You can imagine that if we had a way of identifying this subset in the population, it would be tremendous. You could not only potentially help them symptomatically, but if there were new breakthroughs in neuro-protective therapies, these would be the ideal patients to try to target.

I don't know if we this mentioned earlier, but by the time someone presents in your office with Parkinson's disease, about 70% of their dopamine neurons are gone. It's very late in the game by the time you see the patients. So if you could identify these people 10 or 15 years earlier, that would be tremendous.

I think Canada is ideally positioned to do those kinds of studies you're hinting at, because there's a very good cooperative, collegial atmosphere among the different research centres, among the different Parkinson's clinics. I think we're really poised to do those kinds of studies.

● (0935)

Mr. Patrick Brown: Does anyone want to add to that?

Prof. Daniel Krewski: Just very briefly, I'm really excited about your question of what we can do to better understand the etiology of Parkinson's treatment and progression. We're currently just about to start a two-year study, which will be led by one of my doctoral students. We're going to look at Parkinson's patients throughout the province of Ontario—what medications they take, how effective those medications are, and whether there are any adverse reactions to those medications.

With a population of 12 million people we have retrospective data on going back some 15 years, we'll be able to get a really good handle on the factors affecting the onset, the progression of the disease in a large population, and particularly looking at the effectiveness of the medications the patients are taking.

A second part of the same study will be a parallel analysis of a similar data set from the United States. That is actually larger. We have data from 500 U.S. health care institutions, representing over 35 million patients' electronic health records. We'll do two analyses, one based on a large Canadian data set from Ontario and one based on nationally representative U.S. data sets. When those results are in, I think they'll be tremendously useful to answer some of the questions you're posing this morning.

Mr. Patrick Brown: Mr. Hu, do you have a comment?

Dr. Bin Hu: Yes, I have a brief comment.

As I think my colleagues have indicated, it is extremely important to find the cause for any disease. For Parkinson's, for example, substantial evidence links Parkinson's with pesticides, metals, and other things.

The challenge is can you remove all the pollution, and at what cost? I think the solution would be to find the highest-risk population and intervene a little earlier, but not on a large scale that causes unnecessary economic burden. When it's something where we know the cost.... Take pesticides, for example. You can't ban pesticides. Some of the farmers use certain things, and they don't want to grow less food.

So you really need to support research in that area: how to prevent disease, on the one hand, and on the other, how to balance the other costs to society.

Mr. Patrick Brown: Joyce, I'm glad you mentioned the stigma associated with some of these neurological disorders in communities. I remember we had Greg McGinnis testify. He's a constituent of mine from Barrie. I remember Kirsty was there for that. It breaks your heart when he talks about the tribulations he's had to go through. I am sure that's common with many Parkinson's patients. I think that's something we should certainly note.

I realize I only have one minute left. I guess if there's an opportunity very quickly.... I understand we spend $9 million a year from the federal government on Parkinson's research. Are we spending in the right areas? Are there things that aren't being researched that should be researched? Is there anything you would like us to get in our report?

The Chair: Ten seconds, Dr. Fon. I'm watching now.

Dr. Edward Fon: You want the ten-second answer? It's not enough.

The Chair: No. Time is up. Of course that's a very profound question.

We will go now to Dr. Duncan.

Ms. Kirsty Duncan (Etobicoke North, Lib.): Thank you, Madam Chair, and thank you to you all for coming.

Mr. Simmonds, thank you for sharing your story. You touched us all. And thank you for saying that our brain power is our greatest strength and we must do everything to protect it and promote brain health in this country.

To our researchers, thank you for the extraordinary work you do. It was really exciting to hear about your work.

To the Parkinson's and neurological health charities, thank you for supporting Canadians.

We've heard from other witnesses. I just want to check in with you all. We heard this should be a recommendation in our report that we should make 2014 the year of the brain, in coordination with what's happening in Europe, and that we need a pan-Canadian brain strategy. Would you agree? Just yes or no.

Dr. Bin Hu: Yes.

Ms. Kirsty Duncan: Everybody's nodding. Terrific.

For our researchers, should it be a recommendation in our report that the government should provide transformative multi-investigative grants to accelerate research from discovery to the development of new treatments and therapies for neurological and psychiatric diseases? Should that be a recommendation in the report?

● (0940)

Prof. Daniel Krewski: Absolutely, but I don't know if you have thought about how to best do that, because there are a number of different venues for stimulating that kind of activity.

Ms. Kirsty Duncan: Would you like to briefly...?

Prof. Daniel Krewski: I'll mention one that both Ted and I have participated in for the last seven years. It's the concept of a network of centres of excellence where you get a series of centres collaborating. It promotes new research collaborations that hadn't existed. You get this tremendous intellectual synergism by bringing new ideas, new people, and new disciplines together. We had some terrific successes with prion diseases, which we think include Parkinson's and many of the other neuro-degenerative diseases.

So if I had to shoot from the hip, I think the NCE model or some version of it has a lot to be said for it.

Ms. Kirsty Duncan: Dr. Krewski and Dr. Fon, should a network of centres of excellence for neurological and perhaps psychiatric disease be a recommendation in this report then?

Dr. Edward Fon: Yes. I can add that my good friend and colleague Dr. John Stoessl also appeared before this committee, and I want to second his comments. I think they were in response to a request from you, Ms. Duncan.

I think the time is right to establish a consortium of networks of excellence for neurological disease and ideally for neuro-degenerative diseases. I think Parkinson's and other neuro-degenerative diseases are really going to be the major number one health issue in the next decades as the population ages.

Ms. Kirsty Duncan: Absolutely, so should that be a recommendation?

Dr. Edward Fon: I think that should be a strong recommendation.

Ms. Kirsty Duncan: Thank you.

I'm going to ask if this should be a recommendation. Should the government develop a coordinated pan-Canadian program to develop technology platforms in neuro-genomics, neuro-imaging, neuro-proteomics, and disease models?

Dr. Edward Fon: Absolutely.

Ms. Kirsty Duncan: Absolutely? Okay. So that should be a recommendation in our report.

Should it be a recommendation that the level of support will need to be increased until such time as brain diseases are being successfully overcome therapeutically?

Dr. Edward Fon: Certainly.

Ms. Joyce Gordon: Yes.

Ms. Kirsty Duncan: I need to hear it, folks. Thank you.

Prof. Daniel Krewski: I could be even more specific and give you some examples of funding levels for NCEs that have sort of a similar level of complexity.

PrioNet, which Dr. Fon and I both are a part of, was $35 million for the first seven years, so $5 million a year. We had a plan for a larger program that would run to $55 million. I'm also part of another NCE on carbon capture and storage that is $50 million over five years.

These are the sorts of levels of investment that tend to give a big payoff. If you underfund it, you'll make little incremental advances, but this level of investment offers the potential for significant breakthroughs.

If you could structure the research initiative so that it covers all facets—the basic biology by which neuro-degenerative disease is occurring—you have to understand that before you can think about treatment and cure.

We had some notions about possible therapeutic and prothotic vaccines for certain neuro-degenerative conditions that I think are within a decade of coming to fruition. This could be part of the treatment aspect.

Ms. Kirsty Duncan: Sorry, Dr. Krewski, I'm going to move this on, because I want to get some more recommendations in here.

What value of investment are we looking at to get some real change?

Prof. Daniel Krewski: I would say more is always better, but I think an investment of an additional $5 million a year for at least five to seven years would be the minimum.

Ms. Kirsty Duncan: Thank you.

Dr. Bin Hu: May I make a comment here?

Ms. Kirsty Duncan: I'd like to move on, if you don't mind, Dr. Hu.

Should it be a recommendation that government fund a pan-Canadian training program to nurture the next generation of neuroscientists with stable funding for a period of four years?

Dr. Bin Hu: Yes, absolutely.

Ms. Kirsty Duncan: Yes? That's terrific.

Should it be a recommendation that the government recognize that in a globalized, competitive world it is Canadian brain power that will determine Canada's success economically?

Dr. Edward Fon: It certainly is.

Ms. Kirsty Duncan: Okay, I have one more for you, which is that the government should strengthen research in critical neurological and psychiatric disorders, promote innovation and knowledge transfer, and ensure innovative ideas are turned into new products and services that create growth and quality jobs and assess neurological and psychiatric disease and disorders. Should that be a specific recommendation?

● (0945)

Ms. Joyce Gordon: Can I ask a question? What does “critical” mean? Sorry, it's a great recommendation, but I wasn't sure if that was limited to a group....

Ms. Kirsty Duncan: No, it's not limited, Joyce.

Ms. Joyce Gordon: Okay, yes.

Ms. Kirsty Duncan: So that should be a recommendation.

I'm going to ask one more. We have focused on neuro-degenerative issues. As you know, in the future this committee might consider that there are some neurological diseases that would be environmental, such as FASD; developmental, such as perhaps autism; or a combination of environmental and developmental, such as CP. Should this be something we look at, going forward?

Dr. Bin Hu: Yes, but there's limited scope.

Ms. Kirsty Duncan: Just as a study—

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

Ms. Kirsty Duncan: Thank you, Madam Chair.

The Chair: We'll now go to Dr. Carrie.

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

I want to thank our colleague from the Liberal Party for being here. Normally we wait for recommendations from witnesses, we usually don't plant them ahead of time, because the committee talks together and comes up with recommendations. But there were certainly some good points put out there, some of them within provincial jurisdiction, though, and we do have to be careful of that.

I am very pleased to hear your testimony today, and the good news that Canada is a leader in the world. I do have to ask, though, Dr. Krewski, because you come from the R.S. McLaughlin Centre.... As you know, I'm the MP for Oshawa, and he's our most famous citizen, so it's nice to see that the wonderful things that he brought, not only to my community, have been spread out across our great country.

I know you've received funding from the government to lead this study, a team of researchers from across Canada conducting the systematic review of factors influencing the onset and progression of 14 neurological diseases, and you did go over a review of that, or a little synopsis of it. But it's such a big project, it's so important, not only for Canada but for the world, and I was wondering if you could expand a little bit on how the project is going.

Also, after you get all this data together, how is it going to be applied by clinicians on the ground, and how is it going to help with the management of these conditions over the next few years, which are so important with the demographic changes?

Prof. Daniel Krewski: Thank you for the chance to speak to that.

The project we're doing on a systematic review of these 14 conditions is one of about 15 projects that are part of the PHAC national population health study of neurological conditions. We're looking at what we know at this point in time about factors that cause neurological disease, the 14 in particular that we're studying, and factors that influence their progression. We have a very structured approach to doing that. The bottom line is that at the end of the day I will be able to tell you, in about six to nine months' time, everything that's known by mankind about onset and progression of 14 conditions, including Parkinson's.

That's one of about 15 projects. There are other projects within the PHAC initiative that look at health services delivery, community initiatives, and we have annual meetings among all of the investigators in that $15 million three-year initiative that PHAC has funded to exchange ideas, see how we can help each other move forward to the development, ultimately, of a strategy to address neurological disease in Canada. We will be having a wrap-up meeting in March 2013 to look at everything we found scientifically, advice that might be helpful to practitioners, and we then want to see if we can use that as a basis for helping to create a national neurological disease strategy for Canada under the auspices of the Public Health Agency.

On just one last point, we will be planning knowledge translation activities, which will make sure all of this information gets in the hands of government officials, public health authorities, and practitioners to the best of our ability.

Mr. Colin Carrie: Has anybody ever done this before?

Prof. Daniel Krewski: Not at this scale. Systematic review is the standard now in trying to distill what we know about an issue, but to do 14 times two, because it's onset and progression systematic reviews, is really, I think, a first.

Mr. Colin Carrie: I know Ms. Gordon would like to comment on this, but I was wondering if you could also comment on another aspect, because I have an important question I'd like you to answer.

The Chair: Just one minute, Ms. Gordon. We haven't ignored you. It's just that Dr. Carrie wants to add one.

Mr. Colin Carrie: I would add one to your comment, if you don't mind, because in budget 2011 our government invested more than $60 million to support research in the area of personalized medicine. Given that it enables medical practitioners and researchers to determine which medical treatments are safe and effective for particular patients, and we know about different genetic factors that contribute to the development of Parkinson's disease and other neurological diseases, I was wondering if you could comment on what role personalized medicine could play in the treatment of these diseases as well.

I'll let you finish up with those comments, Madam Gordon.

● (0950)

Ms. Joyce Gordon: I was just going to add comments. Was your question to me?

Mr. Colin Carrie: If you could do that, but then answer the question I just posed.

Ms. Joyce Gordon: I just wanted to make a comment about the Public Health Agency study. It's a really unique collaboration between Neurological Health Charities Canada and the Public Health Agency of Canada. It's a really unique partnership. It has been an equal, equitable, hard-working project that has 18 studies in it. It actually came out of the fact that none of us had data to make our case for neurological diseases in Canada.

So I just wanted to say that I applaud the work that is being done in this particular project, but the other projects cover the whole range of everything we've talked about today, and we're actually evaluating the work together. The reason I'm making this point is that it is about collaboration and it is about partnership and it is about exploring common ground, to be able to benefit the entire neurological community. As you may be aware, that was a $15-million project for which we will have the results in 2013. So it's a very exciting venture forward around not-for-profits showing together that we can make a difference together. But with government, we can actually have a collaboration that will have meaningful results for the Canadian population.

Prof. Daniel Krewski: Could I just apologize in five seconds to Joyce for not acknowledging the critical role of the NHCC in initiating this initiative and coordinating it with the Public Health Agency? Sorry.

Ms. Joyce Gordon: Well accepted, but you didn't need to say it.

Mr. Colin Carrie: Would you be able to comment on the personalized medicine question that I asked?

Ms. Joyce Gordon: I don't know a great deal about the details of it. I can tell you that we have been involved and we have been asked to put forward our position as Neurological Health Charities Canada on personalized medicine in terms of how that issue will affect our constituents.

So we have been asked to come to various fora by the Canadian Medical Association, for example, and by other partners. Actually there's a meeting today dealing with this in Toronto, which our staff are attending. We believe in the principles that have been espoused, in general, by the CMA. I would use the words “patient-centred medicine” or “individual-centred medicine”. We actually don't use the word “patient” in our organization. We're about empowerment and about talking about individuals taking control for themselves, but the whole issue of personalized medicine and of individuals being able to manage their own condition in dialogue with primary care and with specialists is absolutely key.

There were points I was making with you about public awareness, public education. I didn't share with you, but Parkinson Society Canada will be publishing clinical guidelines in June.

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

We'll now go into our second round of five minutes.

Dr. Sellah, would you like to pick up with five minutes of questioning? You'll be first, Dr. Sellah. I don't know if you want to pick up on that—or whatever you have. Go ahead.

[*Translation*]

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

I thank the witnesses for having come here to enlighten us further on Parkinson's disease.

A study was conducted by Health Canada and Parkinson Society Canada on the social and economic impacts of Parkinson's disease. The study showed that more information was needed on the disease in various areas, epidemiological data being one.

There are two types of Parkinson's, i.e. the one that presents with tremors and occurs more frequently among young people, and the type which involves gait difficulties and occurs among persons of 70 or older. Unfortunately the medical information does not allow us to diagnose Parkinson's disease early, because there are no blood tests to do so. So, we proceed by a process of elimination.

I would also like to know more about the burden on individuals and families. Mr. David Simmonds just mentioned that aspect.

Will the quadrennial study of the Public Health Agency of Canada, on Canadians living with neurological diseases, examine these gaps?

Do new studies have to be done in order to increase investment in these sectors?

● (0955)

[*English*]

The Chair: Who would like to take that question?

Ms. Joyce Gordon: Maybe I could answer that.

There are a number of studies that are looking at the everyday lived experience of Parkinson's. For example, the LINC study out of Dalhousie, which is a cross-collaborative study, will be looking at what happens day to day with care partners, with family members, with individuals. When you look at the whole study, it's around all the things you named—incidence, prevalence, risk factors, health systems. There should be suggestions or key findings coming forward that will be helpful to determine how best to move forward. We tried to make the study as broad as possible, to touch major areas around the impact of neurological diseases on the Canadian population and on the Canadian economy.

David Simmonds was part of a micro-simulation study, which, I have to say, was very powerful and very moving. He and his wife came and talked about that experience over the lifespan, and it was going to be used to project out what happens over the life course of various diseases.

So I think the answer is yes, it's broad enough to cover many of the topics you've asked about.

[*Translation*]

Mrs. Djaouida Sellah: Do I have any time left, Madam Chair?

The Chair: You have two minutes left.

Mrs. Djaouida Sellah: You referred to the deep brain stimulation Mr. Davidson benefited from, and I am curious to know at what stage of the disease it can be determined that a patient should receive that treatment. As we know, Parkinson's disease has many stages, and it evolves. This evolution may last 10 or even 20 years.

Dr. Edward Fon: Indeed, the disease has several stages. Generally, the patients who are good candidates for that procedure are those whose disease is relatively advanced, but not too much so. Good candidates are those in whom we observe a lot of fluctuations. As you know, most patients are treated with medications and experience fluctuations. When they take the medication, they feel well, but the effect does not last long enough.

The stimulation allows us to reduce the doses and to even out the symptoms. But you cannot wait too long. The problem is that the number of patients who could benefit from this treatment is disproportionate compared to the availability of the treatment. At the Neurological Institute, we treat approximately 100 patients a year, but there are 400 or 500 patients who would be good candidates. Unfortunately, access to that treatment is insufficient.

[*English*]

The Chair: You have about 15 seconds.

[*Translation*]

Mrs. Djaouida Sellah: Why can a larger number of patients not benefit from this treatment?

Dr. Edward Fon: There is no doubt that lack of funding is a large part of the problem. I can talk about our own experience. We were forced to create a special budget for the stimulators, which can cost up to $25,000 each. They are expensive, but Mr. Simmonds said that medication costs $25,000. Which is to say that over the long term, this equipment may not be a bad investment.

[*English*]

The Chair: Thank you so much, Dr. Fon. We always get very good questions. Dr. Sellah is actually a medical doctor, and she asks extremely good questions.

Mrs. Block.

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

Thank you as well to all of our witnesses today.

I think my colleague Ms. Davies framed it very well when she said we received this very broad picture across the spectrum of the issues surrounding neurological diseases and their different stages.

I want to comment, Mr. Simmonds, on the sharing of your personal story. That always is a profound way for us to get a better understanding of what individuals are living with. When we're doing this study and we're talking about research, often we don't make that connection. So I really do appreciate your coming in.

You made a statement in your remarks that these diseases are robbing our country of intellectual capital. I think that if we can get that understanding, it will compel us to continue in our efforts towards some prevention and potentially a cure for something like Parkinson's or many other neurological diseases.

I just want to focus on another statement you made. You said timeliness and diagnosis are the issue and that diagnosis often comes too late, so then we find ourselves in that pressure of focusing on prevention but also having to ensure that individuals living with Parkinson's have the quality of life they deserve.

Actually, some of my questions are for Mr. Hu around the therapy he described for us today. You may have mentioned this in your opening remarks, but I just want to go back and ask, what provoked you to do this study in the first place?

● (1000)

Dr. Bin Hu: It was curiosity. I didn't set out to cure Parkinson's at all.

Dr. Fon mentioned that curiosity-driven research is the start of any innovation and discovery. So my research field deals with how the brain processes auditory information that matters to you. We hear a lot of sounds in the environment, and we ignore them by focusing on speech. There's a particular brain network devoted to that part of auditory processing.

If you think about a pianist, one outstanding performer, they play music not by reading individual notes but by processing large chunks of music and transforming them almost immediately, automatically, into movement. That is the part of the brain mechanism I'm interested in.

So I studied the basic mechanism—molecular, cellular, neurophysiology—but it wasn't enough. My personal opinion is that we have done a tremendous amount of research, but if people are caught up in these mountains of knowledge they have to step aside to see how much they can apply. I took that initiative.

Because this intervention is non-invasive, I can do it. That's how it has evolved. We couldn't do it until a couple of years ago because of technology. Now there's the technology. With fourth-generation iPods we can link the music very precisely with the step size, almost in real time.

Dr. Edward Fon: I will be asking Dr. Hu to buy a copy of my new CD now.

Dr. Bin Hu: We're a committee on health, not on music.

Dr. Edward Fon: I'd like to underscore what Dr. Hu said. I think that in Canada we're very good at discovery research. We do a lot of basic outstanding research. But the next step is to turn research discoveries into innovation. Innovation involves a lot more than just finding things; it involves transforming things into what will help patients.

I think we have to shift a little bit and try to support that kind of thing. Dr. Hu's example is a good one, but there are many others.

Mrs. Kelly Block: Okay. That's a great segue into the next question I have for you.

What other innovations are occurring in the treatment of Parkinson's disease that relate to therapeutic brain stimulation?

Dr. Bin Hu: We do a fair bit of basic research on deep brain stimulation.

One of the remarkable advances in research related to this issue is using light to stimulate the brain. You have an electric pacemaker. Now you can transform the cells by introducing a particular gene that builds ion channels, and you shed light on those cells. You can selectively stimulate only one type of cell and not the other. It's very selective. It has been used in animal models to replace deep brain stimulation. So there's hope to do it.

The Chair: Thank you, Dr. Hu.

We'll now go to Dr. Morin.

[*Translation*]

Mr. Dany Morin (Chicoutimi—Le Fjord, NDP): I want to thank you very much for all of the research you do in order to improve conditions for Canadians living with Parkinson's disease, as well as the lives of their family.

My question is for Ms. Gordon.

Ms. Gordon, you said in your presentation that by 2030, the number of Canadians with Parkinson's will double, and will be close to 200,000 people. That figure tells me that there will be a lot of pressure on caregivers, on families. My question is about that, especially since you mentioned that when the disease progresses, these families become increasingly impoverished. In your presentation, you even talked about tax credits for caregivers, and other tax measures which the government offers these families to help them.

Are the federal tax measures sufficiently generous for low-income or middle-income families? In your opinion, are the eligibility criteria flexible enough for those families?

● (1005)

[*English*]

Ms. Joyce Gordon: In answer to your question, I don't think the support is adequate, and I can give you a couple of current examples if that would be helpful.

With the population doubling, as you pointed out, that's going to be a challenge to manage. We have a number of individuals who contintue to tell me how difficult it is, from a federal perspective, to get CPP, disability, or access and to be able to apply the means to justify staying on the CPP. As we mentioned, Parkinson's is a chronic, progressive, debilitating condition. When you have it sometimes you can appear to be well, and other times it's going to progress and get worse.

I think it has to be made easier for people to gain access to it and stay on it. There is obviously the question of incremental value so people can maybe look at other supports through caregiver respite or EI opportunities. I think there's a need for families to be able to have some relief from care, because it is very stressful for individuals who are doing it around the clock and who don't have the means. They may not even have enough food.

I know some of these are provincial issues, but I think at the federal level it is about the basic income that individuals can receive monthly to help them live at a certain standard of living, to pay their rent, to pay for those basic things that will provide....

The other part—and I know this is also a provincial issue—is around the balance of medications across the country. It becomes federal, in relation to caregivers, when you consider whether people across this country can get access to the best medications through the common drug review process to ensure that they can have the best quality of living while they have Parkinson's. Managing their Parkinson's well can actually allay and offset some of the caregiver issues.

That is also related to what therapeutics are available federally and provincially. I think there has to be a balance between good therapy and good primary care support. As well, caregivers need to get basic income not only to pay basic needs but also to have a quality of life that will allow them to on one hand get support and on the other to live life fully each day.

[*Translation*]

Mr. Dany Morin: Thank you for your answer.

I might like to obtain more information on the current tax credit for caregivers. A lot of families whose income is very low cannot benefit from that tax credit. Would you agree that this should instead be a benefit paid to caregivers?

[*English*]

Ms. Joyce Gordon: I would agree with that, and I think we need to do more work on that.

We work with the MS Society looking at income security for people with neurological conditions, so we'll come forward. In our last presentation we actually recommended six financial considerations. I can forward those to you if that would be helpful.

Mr. Dany Morin: Can you send them to the clerk?

Ms. Joyce Gordon: I'll forward them to the chair.

Mr. Dany Morin: Good.

Lastly, you talked about the national brain strategy. What would be the next steps to implementing that in Canada?

Ms. Joyce Gordon: First we need the results of the study Dr. Krewski talked about. That information will provide the pathway to what we need for funding. The next step would be to take that report and to be able to look at what's required across this country to support the key findings. I'm hoping that will be the case in 2013-14.

Mr. Dany Morin: Thank you very much.

The Chair: Thank you, Dr. Morin.

Thank you, Mr. Strahl, for allowing me to ask a couple of questions. I really appreciate it, and I will time myself very carefully.

That being said, this has been a most insightful morning.

I'm really looking forward to that study in March 2013, Dr. Krewski. I do hope the findings will be readily available.

Also, very practically speaking, I'm going to pick up on what Ms. Block was talking about. We learn a great deal from the experience of someone who has gone through the disease. You were talking about that brain surgery, and I was astounded to hear you say that it's relatively run-of-the-mill surgery, because a lot of people are afraid of it. Could you comment on that, Mr. Simmonds?

● (1010)

Mr. David Simmonds: Without meaning to be melodramatic, it's a six-hour-long surgery while you're fully conscious. I think the notion of the brain being drilled and sawed into is kind of a frightening one, especially when you have a steel frame attached to your head, and there are holes drilled into your skull to keep your head in place.

That being said, the surgery has been done at many institutions for over ten years now, and I don't think the surgeons who do the surgery would say that it's particularly high risk. I think it's more a question of the patient's willingness to swallow the image.

The follow-up to the surgery is almost as important as or more important than the surgery. The surgery really just gives you the key to the door. The setting of the equipment to give the right mixture of electrical impulses in the right direction in the body is very sensitive. It took me six to twelve months before I felt the surgery had actually benefited me directly because of the fineness of the adjustment of the machinery, the electrodes that go into your....

The Chair: You speak and move extremely well and you're a bright person, so what you say is very credible. Thank you for sharing that.

The other question I have is for Dr. Fon. You said that sleep patterns change drastically and that if this were examined scientifically there might be some red flags, causing you to test whether that person has potential to have Parkinson's. What do you mean by sleep patterns? How are they different? What happens?

Dr. Edward Fon: I was alluding to a specific kind of sleep disorder. Normally, when we're sleeping there's a part of our sleep where we have these vivid dreams; it's called REM sleep. We've all had these dreams where we're running away from people, or falling —

The Chair: I have them frequently, Dr. Fon; they're called nightmares.

Dr. Edward Fon: The body has a way to protect you when you have dreams; it paralyzes you. Otherwise, what happens in these patients is that the system fails. So when they're dreaming they're running away, they're moving around, thrashing around. Sometimes they injure themselves and fall out of bed, sometimes they injure their partners. This is called REM sleep behaviour disorder. It's not that common, but what's amazing about this discovery is that half the people who have this disorder turn out to develop Parkinson's disease in the next ten years or so. That's an enormous percentage. This is something we've learned only in the last few years.

What this tells you is two important things. First, it's not only the part of the brain we thought that's affected in Parkinson's disease—it's probably much more widespread. There are other centres in the brain that are affected, and they are affected earlier than the movement centres. Second, it gives you the potential to identify these people early. They could be candidates, if there are new treatments that come along, to get at the disease before 70% or 80% of the neurons have degenerated.

The Chair: That is profound. I was talking to a Parkinson's patient who said that early on she had dreams that felt like she was right there, like it wasn't a dream. Is that what you're talking about?

Dr. Edward Fon: That could be part of it, but it's mostly the failure to be paralyzed during these vivid dreams. It's like living out your dreams literally.

The Chair: Yes, so they get caught when they run away.

Dr. Edward Fon: That's right.

The Chair: I see.

Dr. Krewski, does that encompass some of the possible prevention of Parkinson's? As Dr. Fon said, if we knew about this before everything was damaged in the brain, we could do a lot of good things so people wouldn't have to go through what Mr. Simmonds went through. Does your study encompass that?

● (1015)

Prof. Daniel Krewski: We'll be able to tell you what is known about the causes of Parkinson's, about early symptoms that may not be classical Parkinson's symptoms, about the factors of active aggression. All of those pieces of knowledge are going to be key to designing proper treatments and therapies.

I wonder if I could take ten seconds to make one comment on personalized medicine.

The Chair: Yes.

Prof. Daniel Krewski: One of our big interests in the McLaughlin Centre—and I want to thank R. Samuel McLaughlin for the generous donation that created our centre 12 years ago—is drug safety, efficacy, use, and communication. We're looking at drugs, their effectiveness, adverse health outcomes, and whether people follow the dosing regimes.

Looking at these large population-based databases, I mentioned this cohort of 35 million patients we're working with in the U.S. We can look at what factors affect outcomes that may determine whether a drug is effective for an individual patient. These would include factors like pre-existing health conditions. Renal disease, for example, might affect treatment of certain conditions, so might genetic characteristics or lifestyle factors. So we end up being able to define which patient will respond to which treatment, and which treatment may actually be risky. I was interviewed by a British clinical journal a month ago about our work in this area, and I think this is really going to be a way of the future. We will be looking at large databases where you understand everything about the patient's health profile, lifestyle, polypharmacy, comorbidity, and you work towards using that information to define more effective personalized medicine.

The Chair: We're very excited about this study and March 2013 is indelibly printed on my brain. So thank you.

We'll now go to Madame Papillon. Welcome to our committee.

[*Translation*]

Ms. Annick Papillon (Québec, NDP): Thank you very much.

[*English*]

How much time do I have?

The Chair: You have five minutes.

Ms. Annick Papillon: Thank you very much.

[*Translation*]

Thank you very much to all of you for having come here. Your presentations on various aspects were really very interesting.

I am a member from Quebec, and I met with some Parkinson Society representatives less than two weeks ago, and they explained some of the issues you have been discussing. It will be my pleasure to talk about them again.

There are various things that need to be improved. There will be a conference in two weeks on the topic of being physically active in order to have a better life, and its purpose will be to explain all of the benefits of physical exercise for those who suffer from this disease. There is the story of a Quebec man who has Parkinson's disease; he is a teacher in a CEGEP. When he is having a crisis, he finds a partner and starts to dance, because if he dances for five minutes, this allows him to keep his mobility and stay in shape. That is interesting.

One of the problems the organization said it had is that it only manages to reach some 500 of the 3,000 or so people who are living with the disease. Do you have any recommendations to make to us that might help to dispel the stigma around this disease, allow people who are living with it to access services more easily, and also allow them to talk about it?

Dr. Edward Fon: In our clinic, when we see patients, we always give them all of the necessary information to communicate with Parkinson Society Canada and the one in Quebec. And so the information exists, but as you say, a lot of people prefer to keep things to themselves. And so there is a gap between what is offered and the way in which people deal with the disease.

For a lot of people, there is the stigmatization aspect you referred to. People feel stigmatized and prefer to isolate themselves. And so we regularly organize events such as the ones you have described, at least twice a year, to which we invite patients and their caregivers. I agree that the caregivers are absolutely crucial for the people suffering from this disease. A large part of the burden is taken on by the family caregiver. And I agree with you entirely—we have to find a way of destigmatizing the disease.

Moreover, one of the strategies we adopt, as do many other centres, is a very multidisciplinary approach. When patients come to see us, they are not only seen by a doctor, but also by a nurse, an occupational therapist and a social worker. This raises awareness and allows people to find out what the milieu offers to patients.

● (1020)

Ms. Annick Papillon: That is interesting.

You also talked about basic research, and you got my attention there, since there is often a debate around basic research and applied research. It is true that both types of research have different objectives, but they both have their raison d'être, in my opinion. I know that at this time basic research is being called into question a great deal. For your part, you stated that an important part of your successes was related to that type of research. I would like you to take the few minutes we have left to tell us why this basic research, with the success it has led to, deserves sustained funding.

Dr. Edward Fon: That division between basic research and applied research in clinical settings is very artificial, and I believe that both types of research go hand in hand. This is something we do quite well in Canada, and so I do not think that there is a real conflict or debate.

Certain physicians are more interested in doing clinical or applied research, but my personal conviction is that ultimately, especially given the explosion of these neurodegenerative diseases, if we really want to see the end of these problems, the answers will come from basic research. That said, I would not agree that we have to devote all of the resources to it. Dr. Hu's case is a perfect example: by carrying out very fundamental research, he comes up with some very practical results. And there are many other such examples. Often—

[*English*]

The Chair: Thank you, Dr. Fon, and thank you, Madame Papillon.

We'll now go to Mr. Gill.

Mr. Parm Gill (Brampton—Springdale, CPC): Thank you, Madam Chair.

I'd also like to thank the witnesses for being here with us today on this very important topic. I want to thank you for your wonderful presentations.

I'm actually very interested in the study Dr. Hu has been conducting on music and how it's going to help patients. Would you be able to share with us what you've discovered from this study so far?

Dr. Bin Hu: This study is not built on just my own research. It is built on very broad research.

You have exercise. You're walking. You have music. And you have Parkinson's pathology. It turns out that Canadians are leaders in this field. The music aspect of the study I gained from the Montreal Neurological Institute. Dr. Zatorre's group has shown that music, especially with vocals, actually stimulates the motor pathways, because when you hear a singer sing a song, you visualize, not even consciously, the person's face and facial movements. I think this is the aspect of music we have found most effective. When the patient walks with these highly salient vocal songs, the person's motor circuitries are activated. There's a synergy between auditory stimulation and walking. They converge on these neural networks, causing long-term plasticity change.

What we have found out so far is that patients start forming a habit. Some patients have told me that if they don't walk, they feel that they've missed something. It's very fundamental. With Parkinson's there is this problem of forming new motor habits.

Second, Parkinson's disease is characterized by very specific deficits. People have the will to do something, but they can't transform that will into action. Dopamine is considered something like a lubricant. It helps you very smoothly make that transformation. After this walking, the patients tell that they can automatically increase their stride length, while they couldn't do it before.

Last, and I think most important, is what we heard from the other witnesses about non-motor symptoms, such as fear of falling, anxiety, and depression. These are the most important benefits patients will gain from this aspect. I gave you the example of the person who was afraid to step on the escalator. This patient is essentially symptom-free, so she doesn't need music any more. For twenty years she couldn't get on the escalator.

● (1025)

Mr. Parm Gill: At what stage is the launch of a larger trial of 700 people?

Dr. Bin Hu: How did you get that number, 700? You're quite close. Statistically, we need 800 patients. We're proposing a study that starts with 200. Alberta has a new program called the collaborative research program. They are very interested in funding this type of research. My plan is to have a pan-Canadian network of trials with 2,000 patients in the next four years. I already have a link with people in Edmonton and Vancouver. So yes, we're going to do larger trials.

Mr. Parm Gill: How does the music compare with the use of medication when it comes to increasing mobility among people with Parkinson's?

Dr. Bin Hu: It won't replace medication. Medication is always the front line. But the medications lose their effectiveness after ten years. There's a honeymoon. The main problem is loss of mobility and then avoiding activities. There is general physical deconditioning. So mental health and depression is very high. It's 40%. These patients will not move. They can't move, and they get into a vicious cycle. Their condition gets worse and worse. The medications will not cure that aspect of the disease.

This therapy will probably help patients delay that process. Second, if you look at the brain network activated when you're walking and listening to music, the activation in terms of the spatial and the intensity is probably five times greater than it is with medications. The brain receives a very strong stimulus.

Mr. Parm Gill: How much time do I have, Madam Chair?

The Chair: Your time is up. Thank you, Mr. Gill. Those were really good questions.

Now we'll go to Mr. Lizon.

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

Good morning, and thank you, witnesses, for coming here this morning.

I have a few questions that will follow up on the questions that were asked.

My first question is for Dr. Krewski. In the study you are conducting currently, you're doing several other diseases, not only Parkinson's. You and Dr. Hu stated that there are several causes of neurological disorders: pesticides, food, etc. Is there a geographical aspect of those diseases or of Parkinson's in particular? As far as I know, and I might be incorrect, there are places, for example, where people do not get MS. Is this the case with Parkinson's or other diseases that are part of your study? If that's the case, do we have any idea why it is so?

Prof. Daniel Krewski: A second study is being done. This is one of the 18 studies under the PHAC initiative, which is looking at incidence and prevalence by geographic location. We're not involved in that. It's being led, I think, by the University of Calgary. That will directly answer your question if there are hot spots or areas where we don't see the disease occurring, and then we can ask what is unique about those areas that may contribute to those differences.

Mr. Wladyslaw Lizon: In the general public, generally we all consume the same things. We are exposed to pesticides, fertilizers, because they all go into the food chain. Why does a particular group develop the disease in their lifespan and the larger group doesn't? Is there an explanation for that? What triggers the disease?

I would assume, not knowing enough about medical science, as I'm not a medical professional, that we can all develop Parkinson's or other diseases, but maybe we don't live long enough and therefore we don't get it in our lifespan.

Can anybody respond to that?

● (1030)

Dr. Edward Fon: Maybe I can have a crack at that one. That's a fantastic question. That's a question that's at the centre of a lot of the research that's going on.

Clearly, as you've heard today, there are almost certainly environmental factors, maybe pesticides, maybe other factors, and hopefully we'll have some answers about those, but you're absolutely right: people living in the same house who are doing the same work, one gets Parkinson's and the next person doesn't. It's almost certainly a combination of the environment and genetic susceptibility. These are the two big factors that come into play about exactly who develops Parkinson's.

You may have someone who has a certain combination of genes whereby no matter how much pesticide he may see in his lifetime, he would never develop Parkinson's, whereas someone else may be extremely susceptible, even though they are very mildly exposed to it.

This also plays into the question of personalized medicine. Probably certain genetic and environmental factors will make people more responsive to certain treatments. Now we treat almost everyone with Parkinson's in a similar way, whereas we think that in the future, with personalized medicine, which is a field that's just in its infancy, if we can say a person is much more likely to respond to one medication than another, or someone might be more responsive to music than to tai chi.... There is another study showing that patients with Parkinson's who do tai chi have fewer falls when they practise tai chi. This is the kind of thing where we'll see a big shift in the future.

Prof. Daniel Krewski: Could I answer the question in a similar way but with a different perspective? All day long I work in a research centre that focuses on what determines the health of populations. In most cases it's a combination of a number of factors, so we have to look at biological factors such as the status of your immune system, genetic susceptibility, the environment within which you live, your occupation, social behaviour, what access you have to health services. Lifestyles serve as factors. All these factors typically interact to determine whether you might demonstrate an adverse health outcome, and trying to disentangle them and understand those interactions is my job, not just for Parkinson's but for a whole host of diseases.

That's the general answer, I think, to why we don't see the same thing everywhere. It's because of these complex interactions among a wide range of health determinants.

Did we say the same thing, Ted?

Dr. Edward Fon: Sort of. You said it much better.

Prof. Daniel Krewski: I thought you said it better.

The Chair: Your time is up. Thank you, Mr. Lizon.

Now we'll go to Dr. Duncan.

Ms. Kirsty Duncan: I get to go again?

The Chair: You do. Now be good and stay in the federal jurisdiction.

Ms. Kirsty Duncan: I'm always good, and it's okay to bring ideas to committee after you've talked—

The Chair: Do you have a question, Dr. Duncan?

Ms. Kirsty Duncan: I do. I'm just saying it's okay to bring ideas to committee after talking to researchers across the country.

We have an aging population. We're talking about Parkinson's today, and another concern is dementia. One person is diagnosed with dementia every five minutes. The cost is $15 billion a year. The human costs are horrific, but in 30 years that's going to be once every two minutes and the cost will be $153 billion.

The World Health Organization has called for countries to produce a national dementia strategy. Five of the G-7 nations have done so, and Canada is lagging behind.

What are the Parkinson's impacts? We've talked about the human impacts. Can we talk about the economics?

The Chair: Who would like to take that?

Dr. Bin Hu: I can talk about the costs to patients and their family members. Sometimes you can't measure the economic and emotional burdens just by numbers. For example, many patients' spouses told us it drained them every day to take care of their husband or their wife.

In addition, I think what you look at is the cost to the entire family in extra worry. Children are constantly worrying about their parents and disrupting their work and their lives. The quality of life declines. And then there are the falls. Actually, these are the biggest costs to society. I think the cost of falls by itself is around $3 billion a year, taking into account the cost of fractures and hospitalizations.

● (1035)

Ms. Kirsty Duncan: Thank you, Dr. Hu, for bringing out the human costs, which are what profoundly matters.

Dr. Krewski, you wanted to pick up on that?

Prof. Daniel Krewski: I liked your characterization of the magnitude of the problem that's facing us now and a decade or two from now.

If we're spending $15 billion a year to treat neurological disorders in the broad sense, and $5 billion of that is due to Alzheimer's alone, and if that multiplies by a factor of ten over the next two decades, can we afford it?

Ms. Kirsty Duncan: You're absolutely right, and worldwide this is a major concern. Governments around the world are preparing for this. The *Rising Tide* report came out a year ago, but the WHO released a report at the end of March saying we can't afford it.

Prof. Daniel Krewski: It's the same story everywhere. Everybody is coming to the same conclusion. What we have here is a disaster in slow motion. Imagine if you were to invest $10 million a year for five or ten years, $50 million to $100 million, and you could reduce a significant chunk of this neurological public health burden. What a huge success. What a huge return on investment. What a huge trade-off in benefit and risk.

Ms. Kirsty Duncan: Dr. Krewski, I agree wholeheartedly.

What would be your recommendation to the committee? What would you like to see in the report?

Prof. Daniel Krewski: I like your suggestion of trying to stimulate the research community to help find new ways to address this public health problem. You had asked us for some ballpark figures. I threw out a figure of $5 million. I'd rather see that at $10 million a year for five to ten years.

Ms. Kirsty Duncan: On the centre of excellence, is it $200 million or $300 million that we need in research? If we're looking at costs of $15 billion now, then $153 billion, what is the amount that we need to invest?

Prof. Daniel Krewski: Probably anybody who's an active researcher will say more is better, but we have to be practical and compare it with other major crises that we're facing.

Ted, would $10 million a year for five to ten years help you make a difference?

Dr. Edward Fon: I think that would be a start. If you look at funding in Canada for basic research, we're really lagging. Per researcher, per capita, the National Institutes of Health spends about five times more for basic research than the equivalent in Canada, than the CIHR.

We make up for it by having these different streams, for instance these networks of centres of excellence. Given what you've just said, which is that—

The Chair: Thank you, Dr. Fon.

We have time for one more now. Do you have one, Ms. Davies?

Ms. Libby Davies: Just very quickly, in terms of this massive study that's being undertaken looking at all the different research—I think you said globally, Dr. Krewski, and I think you said it would be completed in March 2013, and I don't know how long your funding goes—what is anticipated after that, in terms of follow-through, particularly from a funding point of view? How does that keep up to date?

I have the sense that things are moving quickly, that there are new developments, although I don't know that because I don't have it relative to any other either neurological or other diseases. You gave the impression that things are moving quickly.

How do we actually keep up that data? Maybe by next year there will be a whole bunch of things, and by the time you've caught up there will be new things happening. So could you tell us what the follow-through is?

● (1040)

Prof. Daniel Krewski: I'm going to say something very brief, and then I'd like Joyce to maybe expand on that.

This is part of a very well thought through initiative started jointly by the NHCC and the Public Health Agency of Canada. We had three years of funding for 18 projects. Mine is just one. Another was how the incidence and prevalence of these diseases vary by geographic area. Others focus on the delivery of health services.

The idea was that at the end of that period to collectively take stock of what we've learned and then take some steps towards trying to develop an evidence-based strategy to deal with neurological disease in Canada.

That is where I would like to pass the ball to you, Joyce.

Ms. Joyce Gordon: I just wanted to clarify some of the timeframe. The reports will all be completed by March 13, 2013, but there will be a synthesis event where we will bring together all the researchers to share their findings and to look at commonalities, and what key findings may be.

Then there will be a consensus conference, which will engage stakeholders. The anticipation is that the report will be tabled with the minister in March 2014. That will be the final report.

That in itself will be extremely helpful. I just want to confirm what you've said, that the intent then would be.... Well, not then; we need to have that planning now. We need a strategy in place that would be based upon the evidence and facts presented in that report, and should have some very clear directions about where the best investments could be.

The challenge with it is that if we wait until then, it may be too late and we may have a report that may sit and not have implementation. We would like to see a concept around a national brain strategy being thought about now, and plans starting to be put in place on what would be the legacy. The second part would be to ensure that neurological diseases are included in the surveillance system within the Public Health Agency. It's started on that path, but that would ensure the continuity of gathering some of this information on an ongoing basis. That would be one legacy that would be quite incredible, if we could ensure that would happen.

Ms. Libby Davies: Is there more time?

The Chair: You have one minute.

Ms. Libby Davies: That's really useful for us to know. As a layperson, I guess I feel surprised. You often think that these things are being done, that globally there is already this collaboration and you have these conferences.

The fact that we're having to do all this work to even get to a point of developing an effective Canadian strategy and practice, it's kind of surprising. I don't know. That's just my impression based on what you've said today.

Dr. Edward Fon: I think you're absolutely right that these things are done, but not systematically. They're done and people in their fields know about things, but what's really remarkable here is that it's being done very systematically.

Ms. Libby Davies: Do you then expect the knowledge base to jump 25% or some huge amount? Is there an enormous—

The Chair: Our time is up, Ms. Davies.

Can someone just quickly answer her question?

Ms. Joyce Gordon: Yes, there's a knowledge translation and transfer plan in place, and that will happen.

The Chair: Okay.

We want to thank you very much. As you know, in the health committee we get your enthusiasm for this particular topic, and that's really good.

I was very happy to hear that Canada is on the cutting edge and really moving forward on this issue. I'm very pleased that this study is going on and that we will have some very hard, concrete, scientific data in the end.

Thank you so much for joining us.

The meeting is adjourned.

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