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Chair

Mrs. Joy Smith

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● (0850)

[*English*]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): Good morning, and welcome to the Subcommittee on Neurological Disease of the Standing Committee on Health. We're so pleased to have you here this morning.

We meet from 8:45 to 10:45 on Tuesdays. This subcommittee has become an extremely important committee. Neurological disorders or diseases are something that this subcommittee has taken a great deal of interest in and done a great deal of study on.

Pursuant to Standing Order 108(2), we are continuing our study on neurological diseases. We have a number of witnesses today.

From Parkinson Society Canada, we have Joyce Gordon, president and chief executive officer. Welcome, Joyce.

From the Ottawa Hospital Research Institute, we have Michael Schlossmacher, a scientist in neuroscience.

From the University of British Columbia, we have Jon Stoessl, professor, head of neurology, director of the Pacific Parkinson's Research Centre, and Canada research chair in Parkinson's disease.

We are also so pleased to have Mr. Greg McGinnis, here as an individual.

Each of you has five to seven minutes to present, and then we go into our round of Q and A.

We're going to begin with Ms. Joyce Gordon.

Ms. Joyce Gordon (President and Chief Executive Officer, Parkinson Society Canada): Thank you, Madam Chair and members of the subcommittee. I appreciate the opportunity to speak with you on behalf of more than 100,000 Canadians who live with Parkinson's today, and their families, and on behalf of the thousands of volunteers and donors who support the work of Parkinson Society Canada.

Parkinson Society Canada was founded in 1965 by a small group of people with Parkinson's in Toronto. Today the organization stretches across Canada with regional partners in every province and with 235 community-based support groups from coast to coast. Our collective work is about making connections, ensuring that individuals living with Parkinson's are connected to the information and support they need throughout their disease; investing $1.2 million each year to fund Canadian investigators to make connections through basic clinical and psychosocial research; connecting researchers across Canada to ensure that knowledge is being shared and translated into best practice; and connecting people living with Parkinson's to policy-makers such as yourselves to ensure that the impact of the Parkinson's experience is understood and the needs of our community are met. Parkinson Society Canada is the only national organization in Canada doing this work.

I am delighted to share the panel today with Greg McGinnis, who will educate all of us about the realities of young-onset Parkinson's, and with two of Canada's best minds in Parkinson's clinical practice and research, Dr. Stoessl and Dr. Schlossmacher.

I'd like to use this opportunity to highlight some important issues and needs facing Canadians with Parkinson's and their families that are often overlooked.

There is no known cause of Parkinson's and there is no cure. The number of people with Parkinson's is expected to double in the next 20 years. Parkinson's is not a disease of the elderly and it is not a natural part of aging. Parkinson's affects adults across a wide range of ages, all too often in their thirties, forties, and fifties, when they are busy building careers and raising families. Most are forced to leave the workforce only a few short years after their diagnosis, facing unplanned early retirement and the harsh reality of poverty as an added consequence of Parkinson's disease.

Parkinson Society Canada has developed six recommendations about how the Government of Canada might adjust existing finance policy to help individuals and families living with Parkinson's experience greater financial stability and security. We would be happy to provide the documents to the subcommittee.

Caregivers, often spouses or family members, play a vital role for people with Parkinson's. They are an integral part of the care team. Remembering that Parkinson's is a degenerative disorder that cannot be slowed or halted, the reality is that people with Parkinson's experience an ever-increasing need for care and support from those around them. Very often caregivers provide the 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, without whom governments at all levels would be overwhelmed. Understanding the delivery of health care is a provincial and territorial mandate. It is important to note that the best care for Parkinson's disease is delivered by a multi-disciplinary team with expertise in Parkinson's.

I'm sure Dr. Stoessl will touch on the role of the movement disorders clinic. However, I'd like to emphasize that in many provinces, wait-lists are long, as much as 18 months. As one might expect, these centres of excellence are located in urban centres, meaning that rural residents must travel some distance to access care.

Canadians with Parkinson's tell us that their lives would be significantly improved if people within their communities understood more about Parkinson's and brain disease overall. As Parkinson's progresses, the outward symptoms mask the person inside. People often feel misunderstood and minimized. Frustration, embarrassment, and communication challenges build as they become more and more isolated from their families and their communities. The general lack of awareness and understanding results in continuing stigma and makes way for many types of discrimination.

One of the areas of concern to the Parkinson's community is discrimination on the basis of genetics. Legislation is urgently needed to protect the privacy of individuals' genetic information and to protect Canadians from unfair treatment on the basis of often-misguided perceptions about the role that genetics can play in developing brain disease.

● (0855)

Parkinson Society Canada is an active member of the Canadian Coalition for Genetic Fairness, and again, we would be happy to share detailed information on this issue with the subcommittee.

Parkinson Society Canada has been raising these issues with policy-makers and parliamentarians for many years. Unfortunately, due to the relatively small size of the Canadian Parkinson's community, these issues have been overshadowed by other conditions with perceived greater impact than Parkinson's.

It was for this reason that Parkinson Society Canada played a lead role in establishing Neurological Health Charities Canada, a growing coalition of organizations that represent and serve Canadians living with neurological conditions.

As you may know, the NHCC has proposed a framework for building a national brain strategy to the Government of Canada. This framework has unanimous support from the 24 members of NHCC because it addresses the most need across the continuum of neurological conditions. I'm sure that in the presentations you may get a sense that there are differences, but there certainly are a lot of commonalities that can benefit all conditions if we look at it in a holistic way.

We sincerely hope that this subcommittee will support the community's call for a comprehensive and coordinated brain strategy. We are very pleased with this government's commitment of $15 million to fund Canada's first ever national population health study on neurological conditions. I sit on the implementation committee for this study, and am delighted with the level of collaboration and innovative thinking that have shaped this project being co-led by Neurological Health Charities Canada and the Public Health Agency of Canada. So thank you.

We are also grateful for the work of this subcommittee, and for the individual interest and dedication each of you have shown this cause. We appreciate the opportunity to present the specific issues and needs facing Canadians with Parkinson's and their families. We hope this subcommittee shares our perspective regarding the urgent nature of this work.

In 2013 the World Parkinson Congress will be coming to Canada. We will have an opportunity to showcase to the world what we in Canada have done in Parkinson's. We will have an opportunity to lead the way and profile and enhance what we do as an organization supporting people with Parkinson's. We will be able to stand proud that the results of the neurological subcommittee's work and the work of this committee will hopefully result in actions for the benefit of people living with Parkinson's.

Thank you.

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

I don't have a copy of your presentation. Could you ensure that a copy of your presentation gets to the clerk? She will have it translated and give it to all the subcommittee members.

Ms. Joyce Gordon: Absolutely.

The Chair: Thank you.

Now we'll go to Dr. Michael Schlossmacher.

Dr. Michael Schlossmacher (Scientist, Neuroscience, Ottawa Hospital Research Institute): Good morning. *Bonjour.* Thank you very much for the opportunity to address members of Parliament in the context of this subcommittee to talk about something that each of us feels very passionate about, namely, neurological diseases and how to fight them, particularly with respect to Parkinson's disease.

I'd like to give you a very brief background on my role and the work that we do on Parkinson's research, and then maybe finish with a few thoughts from an international perspective.

I grew up in Vienna, Austria. I went to medical school there and did internal medicine training. I then went to the United States and spent 16 years there training in scientific research on Alzheimer's disease, learning to become a neurologist and then focusing on becoming a physician for Parkinson's disease patients and other patients with movement disorders.

In late 2006, I had the opportunity to come to Canada, in large part through the support of the Canadian government, to join the neuroscience community here. For the record, I wish to state that I'm extremely grateful and very happy to be here and to be part of a very vibrant community. I fully identify with the Canadian values, not just regarding societal priorities but also regarding Canada's scientific conduct.

What I really like about being in Canada is that, in my opinion, it's very innovative and collaborative. I think you've heard it already from Joyce and you'll hear it from the other two speakers. By that I mean that our scientific approach is often very much team-based. That is a critical element for succeeding in research today.

Canadian science is also invariably of high quality and is internationally respected. It is also, in some areas, underfunded. Such a comment, one could argue, is typical of a researcher, but in the following minutes, I'd like to draw your attention—Dr. Stoessl is going to do this too—to the fact that we actually see ourselves also as innovators and as engines of a knowledge-based and health-care economy rather than as self-serving occupants of an ivory tower.

In my work I spend approximately 70% of my time directing a laboratory, and 15% to 20% of my time is spent working with patients. I spend a small amount of time directing a program that I've built in Ottawa, namely a Ph.D. program that allows students to become proficient in two languages—the language of medical care and the language of scientific conduct. That's a passion that all of us share.

When I finished residency training in Boston, having focused on Alzheimer's disease, I switched to Parkinson's disease for a number of reasons, one of which was that at that time, in 1997-98, in the study of Parkinson's disease a genetic revolution was taking place. In other words, we all of a sudden had unprecedented opportunities to gain new insights into this critical illness. As you've heard already and as you will hear, obviously our society will be faced with many more patients with dementia and Parkinsonism over the decades to come. When you get genetic clues or insights, they give you great new opportunities, because you can try to understand the disease better and translate it into better models, and then come up with new regimens and drug therapies to combat it.

To give you an example, when people first found out how cholesterol is abnormally regulated, a team led by Brown and Goldstein tackled the problem of how cholesterol is normally internalized and processed. Ultimately that led to a new class of drugs that are called statins, which many of us take and our patients often take to lower cholesterol and prevent heart attacks and strokes. This was a critical insight whereby a disease process was understood and translated successfully into new drugs. It started a whole new industry and helped economies around the world.

So in many ways, in Parkinson's disease we had this genetic revolution that started to take place 15 years ago. Believe it or not, today we have more clues as to how faulty genes lead to Parkinson's than the Alzheimer's field has. That gives us a great opportunity.

If you look at one hundred people who have Parkinson's, 10% to 15% will have inherited a faulty gene from their mother or father, and 5%—five out of a hundred—may have had a horrible environmental or occupational accident and had too much manganese exposure or pesticide exposure and will get Parkinson's. For the remainder, those in the middle, the 80%, there is a combination of environment and genes playing together in what constitutes a complex disease.

So you can see that in many ways Parkinson's is complicated and also complex. But that's not new to us. The same thing happens in Alzheimer's, diabetes, coronary heart disease, and in hypertension obesity: environment and genes. The real challenge will be how we understand it better to ultimately translate it into a cure, which we all are passionate about.

● (0900)

The further thing that complicates Parkinson's is that the incubation time, if you will—the time these diseases develop—is 15 to 20 years. Sometimes it starts with loss of smell, and sometimes with constipation, believe it or not.

For us to capture the whole animal, to see the whole elephant, will take a lot of work from different angles. I strongly believe—and that's the one thing I want to convey to you—that although it's complex and complicated, we can solve that riddle. We can crack that nut. We have the expertise in Canada to make a major contribution to this.

The community of Canadian researchers is well positioned to further explore the mechanisms that lead to Parkinson's and translate that into drugs. That will be done in conjunction with big pharmaceutical companies, with small biotech companies. It will generate new economies, and new businesses as well, as I'll point out to you in a moment.

Essentially what we do today, in part initiated by a former teacher of mine, Dr. Oleh Hornykiewicz, who worked in Toronto for many years, is the same thing that was put in place for Parkinson's 50 years ago. We know how to treat tremors or slowness a bit, but we haven't stopped the disease.

When you have pneumonia, you can now cure the disease because you give an antibiotic that stops the bug, the virus, the bacteria. We can't do this with Parkinson's. We can only treat the tremor a bit. We really need to go to cause-directed treatment. We have to kick at the root cause.

I think in terms of the effort, although it sounds daunting, we can succeed. We have certain elements in place that are unique to Canada. A famous bacteriologist once said that to succeed in science with a medical problem, you need four things: talent, endurance, monetary support, and luck. In Canada, we have talent. We have endurance. With the proper infrastructure and support, we can force the luck. We can crack the nut and make a difference.

Why am I optimistic? We have these critical elements in place and we have the precedent in Canada. I want to mention two things that I think are fantastic examples of how we can solve and proceed and succeed.

One is the Centre for Stroke Recovery, which was built with a large support from the Canadian government. It allowed Dr. Hakim and his colleagues, in the larger province of Ontario and elsewhere in Canada, to change how we deliver stroke care, to come up with new rehabilitation efforts and models, and to research how we help stroke patients.

The second one is a series of national centres of excellence that were built in Vancouver: the PROOF concept, which is led by Dr. Bruce McManus. It has revolutionized how we think about heart disease and kidney disease. Now the United States is copying it and the FDA has approved their approaches.

We can generate new economies, new approaches by succeeding in putting our heads together and collaborating.

In closing, I want to mention two small but very significant examples from the south of the border. I have come to admire how the Americans tried to tackle this. One is the program that is called the Morris K. Udall Centers of Excellence for Parkinson's Disease Research. Mr. Udall was a House of Representatives member for many years, and he was revered. He died of Parkinson's.

The United States put research grants together and generously funded ten centres to tackle Parkinson's. One particular example led to an amazing new economic development, such as at my centre. I was at the Brigham and Women's Hospital in Boston, which received one of these Udall centre awards. One of my patients teamed up with one of our scientists; an angel donor started a company that subsequently attracted $40 million to do Alzheimer's and Parkinson's trials.

The return on a $5 million investment by the government, now having $44 million invested in new research and clinical trials for cause-directed treatment, was unprecedented. Given the fact that the Canadian research dollar goes much further than the United States research dollar, the return on investment in our situation under similar circumstances could be 25-fold to 27-fold bigger.

Why not, for instance, think about the idea of creating something similar to that within the Canadian Institutes of Health Research? It could be called the "Pierre Elliot Trudeau Centre of Excellence in Parkinson's Research", given the notion that the former Prime Minister died of complications from this disease.

I want to convey to you: yes, we can. With this attitude we can not only solve the problem, we can also benefit as a society from it.

A second example, briefly mentioned, is in Alzheimer's disease, where a collaborative effort between—

● (0905)

The Chair: You know, Dr. Schlossmacher, I've gone double the time. What you've said is just so fascinating, but if you could conclude, that would be great.

Dr. Michael Schlossmacher: Yes, I will conclude.

The Chair: I've been very generous with the time with Ms. Gordon as well.

Dr. Michael Schlossmacher: Thank you, Madam Chair. I apologize for going over time.

I want to conclude by saying there is enormous excitement and patriotism in this country that I've experienced since I've come, and I think this could be a fantastic effort to rally the nation, rally the troops, and take this on as a fight to—

The Chair: Do you have your presentation in written form?

Dr. Michael Schlossmacher: Yes.

The Chair: I'd like you to give the clerk a copy of that.

Dr. Michael Schlossmacher: I will do that.

The Chair: We'll get it translated and distributed to everybody. What you say is very valuable, and it will be very good to revisit your comments.

Thank you very much, Dr. Schlossmacher.

Dr. Michael Schlossmacher: Thanks.

The Chair: There will be ample opportunity for our committee to question you. I'll be very generous with the time as well.

Now we'll go to Dr. Stoessl.

Dr. Jon Stoessl (Professor, Head of Neurology, Director, Pacific Parkinson's Research Centre, Canada Research Chair in Parkinson's Disease, University of British Columbia): Thank you very much, Madam Chair.

Good morning, and thank you for the opportunity to be here.

I would like to start by outlining my interest in the problem of Parkinson's. I'm a clinical neurologist. I've devoted my entire career to Parkinson's disease. I'm also a researcher in Parkinson's and now do pretty much clinically oriented research, although in the past I did more preclinical research.

I'm the former chair of the Parkinson's Society scientific advisory board. In my current administrative role I'm responsible for academic and clinical deliverables for neurology in an urban centre, but I spend a great deal of time thinking about the challenges of delivering care to largely disenfranchised communities that face these enormous geographic problems Joyce has already alluded to.

I'm sure this committee is well aware that brain diseases represent 28% of disability-adjusted life years worldwide. This is for non-communicable disorders. This compares with 22% for cardiovascular diseases and only 11% for cancer. Brain diseases are extremely expensive, both financially and in terms of social consequences, yet they have largely been ignored.

Brain diseases include psychiatric disorders. I understand that the focus of this committee is neurological disorders, but I would just like to remind the members that there are enormous co-morbidities. Most chronic neurological disorders have psychiatric co-morbidities, and the converse is also true. The mechanisms underlying these conditions are likely to be very similar, and in some cases identical.

I'd also like to emphasize that, in my view, clinical and research activities are not divisible. Excellence in one has to inform the other. For many of us, the clinic is in fact our laboratory.

On the research that's being conducted in neurological disorders, Michael has already indicated that Canada has an extraordinarily distinguished history of research in Parkinson's disease dating back to the fifties and sixties. That record of excellence has been sustained, despite the fact that we're a relatively small country, in terms of our economy, with limited resources. I'm happy to outline some examples, but I'll leave that for questions from those who might be interested.

It's also worth remembering that research in one neurodegenerative disorder is likely to inform advances in all the other neurodegenerative disorders, because we're really looking at the mechanisms that contribute to the selective death of isolated groups of nerve cells. Once we understand the mechanisms that are true for one, there are likely to be lessons that can be learned about the others.

In fact, the cross-talk is probably more extensive than that. As Michael was talking, I jotted myself a note that probably the greatest single advance in the last few weeks in terms of understanding Parkinson's is an example of a master regulator gene. That knowledge can be immediately applied because there are drugs that can be used to test the hypothesis in patients. But those are drugs that were developed for diabetes, not for neurological diseases.

The other point that Michael also raised is that while there is a great history of successful researchers, research nowadays will only very rarely succeed using the old model of the single investigator who's in their lab and is brilliant. What we really need are teams of people from multiple disciplines who work together and who actually cross disciplines, but we have very few models right now to support that kind of activity.

CIHR used to have a team grant program, but that has largely been eviscerated. There are only small emerging teams left, or ones with specific goals, so that capacity has been lost. The networks of centres of excellence is another model. Those are difficult to get. I'm currently in the middle of three NCE letters of intent that are going forward in the next week because of Parkinson's involvement, and I'm aware of others. But these are very difficult to get with very limited funding. So they're really not doing what we need.

● (0910)

Additionally, I think a huge problem in Canada, compared to the U.S., is that we do not have good mechanisms for supporting clinician scientists. It's difficult to convince people to do this. We don't have a good track record of training them or of recruiting them. MD Ph.D. programs, such as the one Dr. Schlossmacher just mentioned, are obviously one important mechanism for doing this.

Finally, if I can just talk briefly about the clinical challenges, I understand that health care delivery is a provincial mandate, but I also understand that the federal government plays a critical role in establishing the expectations and setting the standards for delivery of care across the country. I'm sure I won't be the first person to suggest to this committee that our health care system does a superb job of managing acute and critical illness, with care available for all who need it. That's why we love Canada. I, too, am an immigrant, by the way, and am very grateful for the opportunities this country has offered me. But I'm sure you all know that we fall very short in terms of providing care for those who have chronic diseases.

Parkinson's, I want to emphasize, affects not only the individuals who formally carry the diagnosis but all those around them. It affects their ability to work, to be parents, to interact with others, and it affects their sense of dignity. The disease and its treatment may be associated with cognitive and behavioural complications that can be absolutely devastating for the members of their families.

These are complex disorders that are best managed by a multidisciplinary and interdisciplinary approach, but getting funding for the delivery of multidisciplinary care is an enormous challenge, despite the fact that these approaches can save money.

I actually just asked my own hospital to pull out data from 20 to 25 years ago as compared to the present. The number of admissions, or hospital days, where the most responsible diagnosis was Parkinson's, declined from nearly 5,000 between 1984 to 1986 to just over 1,300 between 2006 to 2008.

That's a reduction of 73% in hospital days, despite the fact that the number of people in my province with PD has doubled in that time, and that the more recent figures include hospital and forced hospital admissions for surgical treatment of Parkinson's. But this is only possible if infrastructure can be provided to allow for outstanding ambulatory care, and we fall dangerously short in that matter.

I will close and thank you very much for the opportunity to be here and for your attention.

● (0915)

The Chair: Thank you, Dr. Stoessl.

Now we'll go to Mr. McGinnis, please.

Mr. Greg McGinnis (As an Individual): Good morning. Thank you for allowing me to be here.

Fifteen years ago, I would never have dreamt of sitting here to talk to you about Parkinson's. I was diagnosed six years ago, and they told me I have had it 10 years plus, so that puts me back in my 20s.

When diagnosed, I wasn't told of the things that come along with Parkinson's, such as the depression and anxiety that you have to deal with on a daily basis. It has forced me out of my job. I was in my prime, making $50,000 to $60,000 a year; now I'm making $20,000 a year on disability and long-term leave of absence.

This disease can also rip a family apart and pull it together. My mom, her husband, and my brother I have not seen in six years because they cannot deal with this disease. My wife's side of the family has rallied around me and really picked up...and anything that we've needed, they've always been there.

We had to sell our house. We had a two-storey house on a nice lot. Because I was starting to fall down the stairs due to some of the problems with Parkinson's, it was unsafe for me, so we moved to a bungalow. Financially, we are mortgaged to the hilt.

I have a 10-year-old son who worries about me constantly. I have had difficulties when picking him up where I haven't been able to move, and my son thought I was going to die because of this. He is constantly worried. He did not want me to come here today because he is so worried about me.

My wife and I have drug plans and we've capped out on my wife's plan. I normally get Botox for the dystonia in my foot. However, because we have capped out, I cannot afford to get this treatment. So now I have to wait until January before I can have this treatment and start walking a little more easily.

Things that people would normally plan at this age, such as retirement, we don't plan. What we're planning is where I'm going to be in the next 10 to 20 years. Am I going to be in a home? Am I going to be able to take care of myself in my own home? Are we going to have to look at going to a nursing home? This is not what we had planned on or envisioned.

We try to do things that aren't quite as hard on me, right now walking being the biggest thing, so it really limits my family as to what we can do. We used to camp all the time. Due to the medications I'm on, and the heat, I cannot function.

This disease is just.... Nobody tells you what it is and how it's going to affect you. It doesn't affect two people the same way. The main problem I have, as you can see, is the tremor, and of course the dystonia. There are problems with swallowing. There are problems when you can't walk or you can't stop walking. There's the embarrassment of...well, the way I am right now, but I'm not going to apologize for it. I think everybody needs to see this.

People don't understand it, and because they don't understand it, they're either afraid or they're rude. I've had a lot of rude comments put to me: they think I'm an alcoholic, because I do shake, I do have problems walking, I do stagger a bit. When those comments come out, if my son's with me, I don't need to say anything, because my son will tear a strip off the person. He's very good that way.

At home, with the family, we try to add a little levity to it, because you can only cry so much about this. My son constantly makes remarks that I'm giving him a milkshake when I go to pour his milk for him. It's little things like this that we try to do.

● (0920)

I run a golf tournament every year. I play golf; I don't know if it's actually the game I play, but.... The tournament I run is just a community tournament, but we've grown every year. In five years, this was the first year I could not finish my speech because of the disease. But everybody at that tournament was all right with it, and they all told me that they needed to see this.

This is a tournament that we started on a Sunday, and we've grown from 40 people to 95, last year. We're getting the word out and we're touching different areas. People from London and Oshawa come up to Barrie for this tournament. We try to raise the funds.

My biggest thought is that we need awareness. There's this thing where everybody thinks this disease is a disease of the elderly. When I tell them I have Parkinson's, they ask me my age. They don't believe that this is it. It's not a disease of the elderly.

Another thing people think is that your mind is not intact because you have the shake or you can't get the words out of your mouth. You know what you want to say, but everything just stops. They believe that your mind has left you. It hasn't. I've always said that my mind is intact; it's my body that's turning against me. And it is. The trip here today was very, very difficult for me. I've always had family with me to help me, and this is the first time I've done anything without them, so it's been a bit of an adventure for me.

But I'm honoured to be here to let you see what people with Parkinson's go through. This is sort of a mild day for me. There are days when I really can't do a whole lot. I know from the time I get up how my day is going to be. I live on medication. I take medication every three hours to keep me in a better state.

We need the research. We need to find a cure for this. I do not want to have to see or hear of my son or anybody else having to go through this.

With that, I think I'll leave you. I think everything I've said and what you've seen lets you know what is going on.

Thank you for the time.

● (0925)

The Chair: I thank you, Mr. McGinnis. I'm very honoured that you would come here today.

This subcommittee is a very special committee, because each and every member in the subcommittee is extremely concerned about brain disorders, neurological disorders, and Parkinson's is a huge piece of that. There are many stories out there like yours, but for you to actually come and talk about what people go through, from the depression to the degeneration of muscles and things like that, it does mean a lot and it helps a lot people. So I want you to know that.

We'll now go into our first round of questions for seven minutes, and we'll begin with Dr. Duncan.

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

I'd like to say thank you to all of you.

Mr. McGinnis, I hope you'll thank your son for sharing you with us this morning. You raised so many issues, from awareness to research strategy and urgency. I'm going to try to comment on those.

The European Brain Council is advocating that the EU declare 2013 the Year of the Brain. In March 2013 we will have the Consensus Development Conference, the conclusion of the four-year national population study of neurological conditions, and in October 2013 there will be the World Parkinson Congress in Montreal, with 4,000 delegates from around the world.

I'm wondering if the researchers will comment on whether or not the Government of Canada should declare 2013 the Year of the Brain. It can be used to raise awareness and be a real galvanizing point for awareness, education, research, and dollars.

The Chair: Dr. Stoessl, did you want to take that one?

Dr. Jon Stoessl: Sure.

I'd be happy to thank you for that and of course speak in support of it. I think we do require a lot more awareness of brain health and brain diseases, because this affects so many people, not only as individuals, but all those around them, with six degrees of separation. I think it's critical, and it's a great opportunity, so thank you.

Ms. Kirsty Duncan: Thank you.

Perhaps Ms. Gordon can comment on whether we need a national brain strategy—and that would mean working with the provinces and territories—and how the charities are working together. You also talked about your six recommendations, particularly for Parkinson's. Perhaps those can be tabled, as well as the genetic fairness piece, but on the need for a national brain strategy...?

Ms. Joyce Gordon: As you know, Parkinson Society Canada has taken a lead, with the other neurological organizations. We had come to some common consensus on seven key areas that we would work on. I mentioned earlier that it's very easy for us to talk about our differences, but when we came together on what's common across all the neurological diseases, we saw several things, which we've all touched on today, that each charity in themselves agrees with.

We have come together, the example being the genetic fairness coalition. That applies to those conditions where genetics play a major role, and as Dr. Schlossmacher said, it's most of them. We can move forward and make a difference together there.

There are some provinces that have indicated an interest in setting up an equivalent in their province with neurological health charities, which we will mentor at the national level, with our partners. I think it's very important that we have the opportunity to have people come together around the brain as a common focus and around those commonalities that we can all benefit from in each specific condition, but that will better neurological conditions overall in Canada.

● (0930)

Ms. Kirsty Duncan: Thank you.

As you've pointed out, the Government of Canada, in collaboration with Neurological Health Charities Canada, invested $15 million to conduct the four-year population study. In your opinion, is there enough information right now to begin to develop a national brain strategy or should we be waiting the four years?

Ms. Joyce Gordon: I would hope that we wouldn't wait the four years. There is information available now. The study that completes in 2013 will better inform our decisions and give us far more detail and data than we have now, but there's a lot of work to do. We need to do a lot of strategic thinking about how we want to coordinate this. How are we going to be positioned to be able to address the outcomes of the research that will be brought forward?

The other opportunity is how do we put into action some of the work that will need to happen? I worry that if we wait four years, it could be another five to ten years before there's any activity out of this investment. I think government would want to see a return on its investment relatively soon after the project completes itself.

Ms. Kirsty Duncan: Thank you, Ms. Gordon.

I'm guessing...would the two researchers like to talk about the urgency, as Ms. Gordon has, and particularly the urgency for research?

Dr. Michael Schlossmacher: I'd like to make one comment in terms of putting it in the context of what it takes to bring a new drug to the market. In other words, let's say we were to have a breakthrough finding today that we utilized to team up with the biotech industry or with large pharmaceutical companies to take a very specific target identified within the brain. Let's say that this would be perfect to treat Parkinson's disease. If such a breakthrough discovery were made today, as Dr. Stoessl alluded to, a breakthrough that's very interesting, the test of time would show whether it really was the big thing.

If the big thing were to be found today and if one were to look across the landscape of pharmaceutical development, we would see that it would take between 10 to 13 years to bring a new drug to the market, at a cost upwards of $750 million. Therefore, we would encounter an enormous scale of time and scale of cost to actually arrive, then, at that drug being licensed in the EU, in the United States, and by Health Canada.

So time is of the essence. As I remember vividly when the whole issue of stroke management came up—how we could treat stroke better—the central theme was that time is of the essence. I think this is exactly the same thing we face, because with every year that's passing, the expectation is that the numbers will rise for people with dementia or with neurological disabilities, Parkinson's among them. So the longer we wait, the more difficult it will be to stop the train and to reverse the trend. Time is of enormous essence.

The Chair: Thank you.

And Dr. Stoessl, you've mentioned....

Ms. Kirsty Duncan: I am going to ask for your top research asks, and perhaps that will be to you and Dr. Schlossmacher. You have mentioned the centres of excellence model, you've mentioned multidisciplinary grants, and new mechanisms for clinical researchers. Perhaps you want to elaborate on those.

Dr. Jon Stoessl: Thank you for that question.

Yes, I think that really would be my top request. I think that within centres, there's a need to support multidisciplinary teams, and we came close to such a mechanism, I think, with the CIHR team grants, but we've lost that. So I think it's very important to see that opportunity resurrected. It's kind of ironic to me in some ways that we're pulling down that capacity at the same time as other countries are building it up.

I also want to emphasize the importance of having collaborations across multiple centres. So something that I think both Michael and I touched on, but maybe didn't emphasize enough, is that while Canada has a very strong track record of individual researchers, we are also regarded as highly collaborative. In fact pharma likes doing studies in Canada because the health care system actually enables cooperation. We're not competing with each other to get patients, so we can enter a lot of people into studies, and we have certain strengths. Some centres have strengths that other centres do not.

● (0935)

The Chair: Thank you, Dr. Stoessl. I'm going to have to cut you off: the time is so over.

I will now go to Monsieur Malo.

[*Translation*]

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

[*English*]

The Chair: Please—I don't like to cut you off, but I will—do try to keep an eye on the chair.

Thank you.

[*Translation*]

Mr. Luc Malo: Thank you very much for being here this morning.

First, Mr. McGinnis, I would just like to go over one of the elements of your presentation. You said that Canadians are lacking information about Parkinson's and that awareness should be raised about the disease. I was stunned when you said that a lot of people still stop you in the street and say that you're drunk. That's very shocking to me. I was also struck by the fact that your 10-year-old son has to put people in their place. He's a very brave boy. Please send him our best wishes and hang in there.

I see the golf tournament you're organizing and you being here this morning as only the very first steps you're taking on the road to raising awareness about the disease. We are grateful to you for your efforts. Bravo and keep it up.

I would like to continue with Ms. Gordon. You talked about issues related to genetic discrimination. First, I would like to know if you have encountered any cases of genetic discrimination toward people with Parkinson's disease?

[*English*]

The Chair: Go ahead.

Ms. Joyce Gordon: Yes, we have. We've had several individuals come forward who have faced insurance issues, insurance applications when they were requested to check off what conditions they had. Some were requested to either have genetic testing, or when they checked off that they had genetic testing, were asked whether they had the results. Then they were asked to share some of that information.

Some of this relates to hiring, an individual applying for a job who basically did not get the job. We can't say it's a direct cause and effect, but we do know of several cases where this has come forward and we were asked to provide our opinion about whether we could help in this.

We're just starting to gather information now about this in the workplace, and looking at whether or not other individuals across Canada have had this experience. I know we've worked closely with the Huntington Society and other groups who have also experienced similar things. So we will come together to talk to the insurance industry in particular.

It is about raising awareness with the employment sector, the workforce, around what the legal obligations and responsibilities are in terms of what they can ask from individuals. There is no genetic legislation at the moment that will protect individuals from these types of questions and potentially from this type of discrimination.

[*Translation*]

Mr. Luc Malo: What do you think are the most important elements that should be addressed regarding genetic discrimination?

[*English*]

Ms. Joyce Gordon: Well, first of all, when individuals take these tests....

I'm not the expert on this. Actually, Dr. Schlossmacher is better positioned to answer this question, because this is his area of expertise.

The one thing I would say is that if individuals have genetic testing available to them, the whole issue of what is disclosed to them and the counselling that's provided and the ethical issues that are raised....

Greg and I were talking about it this morning at breakfast. If I have genetic testing—it was an issue of cost, to start with—and I get information back and find out that I'm carrying the gene, what do I say to my son? What do I say to my other family members? What are the disclosure issues?

There are all of those pieces around understanding what that means. If I know I have the gene, what can I do about it?

This is an area that Dr. Schlossmacher has expertise in.

[*Translation*]

Dr. Michael Schlossmacher: Thank you very much for your question. May I answer in English? It's easier for me.

● (0940)

[*English*]

Thank you very much.

I think this is a really important issue. There are two aspects that come to my mind. I had the opportunity in the past to write, with a colleague of mine, guidelines for neurologists about genetic testing and Parkinson's disease. There are two issues, as follows.

First, as Joyce just said, the key question is if we learn genetic information, how does it change our management? How does it change our communication? The problem in Parkinson's disease is very similar to what it is in Huntington's disease: unless we have a new strategy and a new way to treat the disease differently, sometimes having information, in and of itself, can increase anxiety and add to difficulty, including, then, issues of confidentiality.

So we are not yet in a position to drastically change our management and how we care for patients with Parkinson's disease when we have additional genetic information. As a researcher, I always want to know what the genetic problem is in an individual. As a caretaker, as a physician, I have to respect that if I can't necessarily utilize that knowledge, I have to respect the dangers and the complications and the problems, both medical and non-medical. At the same time, it's very important to encourage people to participate in studies to find out more about the genes. That can be done anonymously so that the information doesn't necessarily get back to the participant.

Second, any time we consider genetic testing, it is done as a team, with genetic counsellors and experts, to prepare the families and the patient as to what potential things to consider and how it potentially changes the future.

[*Translation*]

Mr. Luc Malo: I have one last question, perhaps for you, Dr. Schlossmacher and Dr. Stoessl. Are we close to a cure? I noticed that an announcement will be made this afternoon at the University of Ottawa regarding new funding.

Dr. Stoessl, you also talked about the importance of working in multidisciplinary groups, as the issue is very broad and multifaceted because various elements are involved in the potential causes of the disease.

Could you tell us how close researchers are to finding a potential cure?

[*English*]

Dr. Jon Stoessl: I'm always anxious about this question, because while on the one hand it's the holy grail for all of us, and enormous strides have been made, I'm also always very nervous about setting inappropriately high expectations. People have been saying for many years that the cure is five years away.

So enormous advances have been made, largely because, I would say, of the advances in genetics and because they give insights into mechanisms of cell death. If you have more than one genetic cause, you can look at how they interact and at common pathways. As I mentioned, the other example related to the diabetes drug.

Yes, I would like to say that we're close, but it's complicated, because it's not one cause, not one disease; it's multiple causes. To translate understanding the mechanisms into effective treatments is also a non-trivial challenge.

The Chair: Thank you, Monsieur Malo.

We'll now go to Ms. Hughes.

Mrs. Carol Hughes (Algoma—Manitoulin—Kapuskasing, NDP): Thank you very much.

I greatly appreciate your input today, Greg. I want to commend you for your courage and strength in coming to share your story with us. You must have a very special son.

Mr. Greg McGinnis: He's pretty awesome.

Mrs. Carol Hughes: I don't remember hearing, in the conversations you've shared, about support.

How important is it, and how difficult is it, at this point, to get the necessary support network in place for people to come and care for or have someone do some tasks for those who are stricken by this disease? What are the challenges out there at this point in that respect?

Mr. Greg McGinnis: As far as support goes, I've had somebody come to my house to teach me about, to help me with, the swallowing issues I have. In terms of accessing support, within our communities it's pretty good, really. We can get in contact with the proper channels. They'll come out and assess what needs I have, whether it be handrails or things like that. That's there, and they will help with that.

I guess the problem I have with things like that is that when you go in, or you call them and they come out, they look at you as if to say, “Right: do you really need this?”; it's that type of attitude. It's still that horrible thing where they think you're not the proper age to have this kind of disease. That's the biggest problem.

In terms of support through the family and that, the family is fantastic. After I was diagnosed I didn't go to any group meeting or anything—I was told not to—but my wife went to some of the group meetings. She learned a lot through those group meetings, through Parkinson Society Canada, Barrie chapter. She learned a lot, and she actually convinced me to go, finally, and I did a lot with it. I was vice-president of the chapter for a while. We did a lot of things. I had to leave it because of the heath issues I was having, but the chapter is very supportive. Parkinson Society Canada is very supportive of what happens within their chapters. They have set up caregiver support too.

● (0945)

Mrs. Carol Hughes: Now, you mentioned the challenges with the drug that you need. How important and how beneficial would a national drug program be for patients who have Parkinson's or Alzheimer's?

Perhaps others can weigh in on this as well.

Mr. Greg McGinnis: From my end of it, to have something like that covered would be phenomenal. Right now my drugs are covered through my benefit package, but to have something like that covered would be phenomenal.

Dr. Jon Stoessl: I can only support that.

I'll just say that I had never met Mr. McGinnis before this morning, and as I watched him walking down the stairs, I thought, “He needs some Botox”. You may have seen the startle on my face when he said that he normally would be getting it but that the funding to support it has run out. I'm absolutely appalled.

I understand there's a balance between expensive new drugs, and that this is not entirely affordable, but it's also not right for people with chronic diseases to not have access to powerful and potentially helpful therapies. We need to be careful, diligent, and responsible in managing those resources. I fully understand that.

Mrs. Carol Hughes: On that note, do you find there's an ignorance on the part of governments about the need for a quality of life and providing those necessities? Is it like a failure to provide the necessities of life?

Dr. Jon Stoessl: Well, in my view it is, and medication is only one part of that. For me, the other very important part is multidisciplinary care. Physiotherapists, social workers, nurses, occupational therapists, speech language pathologists—these people may provide more useful input to people with Parkinson's than we do, or at least different input, that's extremely valuable, and the funding for that is simply non-existent.

Mrs. Carol Hughes: This is basically what we've been hearing at the HHR study that we've been doing with respect to how to better the health care system in Canada, and I think this basically ties into it.

The Chair: Dr. Schlossmacher, you wanted to make a comment on this.

Dr. Michael Schlossmacher: I just wanted to say that this doesn't even stop there, because people with Parkinson's also may have bladder function problems or orthopedic problems or dystonia that may need a tendon release. I can't get a urology appointment for my patients. I get physiotherapy appointments rejected because they're only good for a week and the disease is not going to be cured or the condition is not going to be cured in a week. And to get a hold of an orthopedic appointment is next to impossible as well.

So this is a multidisciplinary problem where we'd love to rally the troops and different resources to maximize what a patient can do at home to be independent, fully independent, and we don't have those resources.

● (0950)

The Chair: Ms. Gordon.

Ms. Joyce Gordon: I'd just like to say that we'd also like to see a range of therapeutic products available to people with Parkinson's, because there are some decisions made where there's only one in a class, and another product that would come forward, that would be beneficial to individuals who might not respond to that one particular drug, the individuals cannot get.

There needs to be a view to having more therapeutic options available so that clinicians can have an opportunity to look for the best fit in terms of pharmacological intervention that works best for the individual.

Mrs. Carol Hughes: There was a comment made with regard to research funding. I'm just wondering how much was actually cut back and the impact that this has had.

Dr. Stoessl, you're the one who mentioned that.

Dr. Jon Stoessl: I can't give you the dollar amount, but I think you're aware of the CIHR budget constraints. In an attempt to try to fund more researchers, which was an understandable aim, the individual dollar amounts have been cut back. But perhaps most importantly, from my perspective, the team program has essentially been eliminated.

Mrs. Carol Hughes: How much of a setback is that for...if you were to say timelines?

Dr. Jon Stoessl: For my program, enormous.

Dr. Michael Schlossmacher: There was, for instance, an effort that was initiated through a Parkinson's alliance two years ago, where several researchers, two in Ottawa and then team members elsewhere, tried to put forward an application for a national centre of excellence. This would have actually been a major milestone event to make teams collaborate and share data as soon as it becomes available and not wait for the year two until it's publicized or published in the literature. So this was an opportunity that couldn't be utilized. Essentially the application was denied: (a) there was not enough funding there, and (b), it wasn't felt that PD, Parkinson's disease, was a priority at that time.

What these setbacks mean is that vital communication and vital collaboration cannot move forward. Sometimes it's a small seed program, a small idea. We today do not know what will ultimately cure Parkinson's disease, so we need to support a lot of high-risk and low-risk programs, big collaborative efforts and small graduate student fellowship programs. We have to essentially come up with a multidisciplinary but also multidimensional approach to find the needle in the haystack that will ultimately change the game, as it did with the discovery of how cholesterol was being handled.

The Chair: Thank you.

Now we'll go to Mr. Brown, please.

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

Thank you to all the witnesses today. We certainly have some excellent guests here today.

Joyce, if may I mention it at the outset, it's great, the lead you've taken on the neurological charities with Shannon. I think having that common voice has been so helpful as we look at neurological disorders.

Greg, you've certainly been an inspiration in Simcoe County for all the advocacy and fundraising you've done. We're so fortunate to have you here today, because I think you put it all into context about how insidious this disease is. Certainly your message is inspiring to certainly motivate anyone who hears your message that there must be a means to do more, that there must be a means to try to grapple with this in some form. So thank you for sharing; I know how difficult that may have been.

A few things that you mentioned that I found interesting, as Carol mentioned, were about the drug plan being capped out. Is that something that you believe is common with Parkinson's patients? And are there other limitations with your drug plan and coverage?

Mr. Greg McGinnis: I don't know if it would be common with other Parkinson's patients. I guess each company benefit program is different.

I was lucky with mine. I have an unlimited amount of drug coverage, but my wife, on her plan, only has $3,000. To get the Botox formula this time around would have cost us about $700, and with what we bring in right now, with my funds that come in, I can't justify putting my family in a bit of hardship just because I need the Botox.

Mr. Patrick Brown: And you have your own drug plan that covers this?

Mr. Greg McGinnis: Yes.

Mr. Patrick Brown: I can't imagine the straits someone would be in if they didn't have that. That's certainly interesting to know, because when we've looked at this, we haven't really looked at the lack of totality in terms of the drug coverage. That's something very interesting, I think, for the committee to hear.

Joyce, you had a comment there too?

● (0955)

Ms. Joyce Gordon: Madam Chair, may I?

The Chair: Go ahead.

Ms. Joyce Gordon: Parkinson Society Canada has been contacted by individuals who have notified their employer that they had Parkinson's only to find a very short time later that they were without a job. They were either laid off or there was a restructuring. They end up without any plan such as Greg's, and they have to rely—specifically in Ontario—on the Trillium program, if they're under 65, and on the drug benefit plan if they're over 65. Therefore they are significantly limited in what they can afford.

We talked earlier about discrimination and some of the things that happen in the workplace. If you're fortunate enough to have the kind of plan you have, there is support. And even those are being cut back in the types.... I talked with Greg about the Botox treatment, and what he's experiencing now is just unacceptable. But somebody who would be on a government plan, the benefit plan in the province, would not even have access to that and would be relegated to an extremely poor quality of life.

Mr. Patrick Brown: Michael, you had mentioned Alzheimer's as well and some of the commonalities. I'm curious about that, because as we look at the national strategy on the brain, obviously the hope at the beginning, I think, was that we could find areas in which to invest in order to help all these neurological disorders.

What type of research do you think is available, and what possibilities exist? It's always interesting to hear what possibilities would be available if the research could be funded in a much larger context. What research studies might cross both areas?

Dr. Michael Schlossmacher: I can give you one very specific example of how research in Alzheimer's disease has completely changed the game for research in Parkinson's. The genetic revolution in Alzheimer's began 10 years before it began in Parkinson's, so they had a leg-up. And the disease is four times as common as is Parkinson's.

A specific example is what happened through an effort initiated by the U.S. Congress in a program called ADNI, the Alzheimer's disease neuroimaging effort, which brought together people from the pharmaceutical industry interested in developing new drugs, imaging people, and people who understand the analysis of biological fluid, such as spinal fluid or blood, to come up with better measures of who has that disease, who is in what stage of the disease, and how we can get X-ray analysis.

What ADNI did, as a consortium of industry and academia, was set new rules. One of the rules, which is wonderful, is that every single data point that's being generated through this effort has to immediately be made publicly available so that people can access it. So that's now being copied for Parkinson's disease through an initiative that's called PPMI, progressive Parkinson's markers initiative, funded through the Michael J. Fox Foundation.

The second thing that happened with that is that the quality assurance and the quality-control elements that went into this Alzheimer's research are now also being adopted in Parkinson's research. So the research that Dr. Stoessl does in Vancouver can be directly compared to what is being done in Ottawa or in Göttingen, Germany, or in Uppsala, Sweden, so that we don't have the reproducibility difficulty or the unified data analysis difficulty. Everything is now done according to very strictly defined principles, and we in Parkinson's disease research have learned how to do it from Alzheimer's disease researchers.

Another thing we learned is more about disease progression and the opportunities we have due to changes in X-rays. For instance, in the imaging of Alzheimer's disease, we are trying to get a picture of the culprit, the amyloid buildup in the brain. Last week we had we had a large meeting in New York and then another one in San Diego, at which people from industry and researchers of Alzheimer's disease and Parkinson's disease sat together and discussed how we could come up with the right X-ray analysis or brain analysis to image the difficulty that Greg has in his brain so that we have better X-rays and we can follow the disease course and make the diagnosis better and see whether that person responds to a new drug, yes or no.

The overlap and the cross-fertilization and the cross-information opportunities are unbelievable. So national strategies that encompass diseases such as ALS, Alzheimer's, and Parkinson's in which there are a lot of similarities—because sticky proteins build up in the brain—are fantastic.

And this is really exciting, because it also changed the game for how academia acts. In the past, and particularly in the United States, to be promoted you had to be the best and beat everybody else to the finish line in making a discovery. Now Canada has taken a lead on this, and they realize that team science is better than individual science, so we have to reward and recognize a team leader, like Dr. Stoessl, who led a fantastic consortium in a number of research arenas. That has to be rewarded as a major significant contribution, and it should help people to advance their career interests.

So a lot of things have changed, and Alzheimer's disease has told us what to do and has often told us what not to do.

● (1000)

Mr. Patrick Brown: I'm glad you pointed to the examples in the U.S., in New York. Are there other countries that Canada should look to that are doing exciting work in Parkinson's research? Are there areas that we can learn from?

Dr. Michael Schlossmacher: I liked one example in particular in Germany, and not just because I grew up next door. But with Parkinson's disease, if you live in Canada or the United States, you will never be admitted to a hospital unless you have severe pneumonia or you have a hip fracture and need acute care.

There are a few centres in Germany that actually admit people for one week with Alzheimer's or Parkinson's and give them the entire workout to make sure the diagnosis is as good as it can be, that the support and ancillary services are initiated immediately, and that all the diagnostic elements and treatments, from occupational therapy to drug therapy, are all put in place.

An in-patient stay per 24 hours is of course expensive, but they've done some cost analysis and realized that the more effort they put in at the get-go, the outcome is better and the utilization of health resources can actually be diminished by doing it right at the very beginning.

The Chair: Thank you.

If the committee would permit me, I'd like to ask a question right now.

What is the difference between Parkinson's and essential tremors? I've seen people who have very pronounced essential tremors. People assume they have Parkinson's when they don't, they have essential tremors. What is that?

Dr. Jon Stoessl: Mostly, essential tremor is a condition that's poorly understood but results in tremor without the other problems that are associated with Parkinson's. The basis for essential tremor is not well understood. There is currently some controversy as to whether it may be associated with pathological changes in the brain, including, to a milder degree, some similar to those seen in Parkinson's. Although it can be a very difficult and embarrassing disorder, I would say it's a more benign disorder.

You're well aware of history, that Prime Minister Diefenbaker had essential tremor, and Katharine Hepburn, but it doesn't produce the slowness, poverty of movement, and the other problems associated with Parkinson's.

The Chair: Thank you.

We'll now go to our second round, five minutes.

At 10:30 a.m., we are going to bring to a close this part of our presentation because we do have to discuss Dr. Duncan's report as a committee. I'm going to be a little tighter on the time to get as many questions in as I can.

It's five minutes of Q and A, starting with Dr. Duncan.

Ms. Kirsty Duncan: Thanks, Madam Chair.

Several of you have mentioned care teams. I'm wondering if you can talk about what an ideal care team would look like, including specialists, including working with the patients' families. Can there be something different the federal government is doing to fund those care teams? Also, can you talk about the wait times for the various specialists, and how that might vary across the country, and what that means to a family?

Dr. Jon Stoessl: You've heard from me what I think are the necessary components of a care team, and I think Michael would have expanded that to include other specialists. For me, it is also very important to have psychiatric care incorporated.

In fact, we're trying that at the University of British Columbia. We have a new centre for brain health that's in the planning stages with architects to combine psychiatry, neurology, and rehabilitation, both from a clinical and scientific perspective, because we feel the cross-fertilization is critical.

Waiting lists vary quite a bit. One of the problems is that much of the specialized care comes in urban centres, where people have university appointments and academic appointments, so there's an expectation that they're doing other things besides delivering patient care.

In my case, although theoretically I spend 20% of my time seeing patients, it's of course more than 20% of a 48-hour work week for sure, and my waiting list is well over a year. And that's seeing people in follow-up once a year.

We try to accommodate that by doing a lot of telephone coverage. Our nurses provide advice and I then review that advice. Apart from the fact that this is all unfunded, it doesn't work as well as it should. There are other centres that I'm sure do a better job of it, but we're trying to deal with a problem that's bigger than we can really handle.

● (1005)

Ms. Joyce Gordon: I would like to suggest that there should be consideration to having neurological centres. There are several centres in ALS, MS, Parkinson's, that aren't connected and may not even be in the same location, that could come together and share the multidisciplinary expertise where there may be some specifics to one condition that might need a different cadre of individuals, but could be housed within an area in which you could have that benefit of synergy and best use of resources for more conditions than, say, Parkinson's. I know that happens in existing communities, but we know of many where they stand in isolation.

I think if those were pulled together, we could see better efficiencies for the person who has the condition but also for the service providers in making best use of resources.

Ms. Kirsty Duncan: Thank you.

You've briefly touched on the issue of loss of income—going from $50,000 or $60,000 down to $20,000—and what that does to a family, and not being able to pay for much-needed medicine. We've also heard about this with ALS.

Ms. Gordon, I wonder if you can talk about Parkinson's disease and loss of income and poverty.

Ms. Joyce Gordon: You've heard from Greg the impact on him. I'd like to table with you—I don't want to spend a lot of time on them here—six recommendations. I could tell you quickly a couple of them. Really, we would like to see an advisory committee that would look at income reform. We have a number of suggestions that I can leave for the committee. I don't want to take up the time, because I know you have only five minutes, but I'm very happy to share and further discuss that with you. This is also shared with the MS Society. We're part of the group that's looking at income security together.

So it is about CPP benefits, the disability tax credit, how we can better address the caregiver, and so on. It's a package that bridges a number of the things you've heard from all of us today.

Ms. Kirsty Duncan: Okay.

I'll come back one more time to Dr. Stoessl. If you could give us your top five research asks, what would they be? And could you outline how much money would really be involved?

Dr. Jon Stoessl: I think, again, it's collaborative: Mr. Brown asked about other countries, and I just want to emphasize that there are, of course, many other countries doing work. We are always looking at collaborations. I'm going to a meeting next week in Montreal that is trying to bring together German and British medical research council people, looking at imaging neurodegeneration, together with Canadian. We bring in people from many countries for our own studies.

So funding for those collaborative things, for networks across the country, and funding for teams, are the biggest priorities. As to the specifics of what they do, it will be genetic research, genomic-based research, imaging research—a self-serving response—and, I would say, cell death biomarker.

I was very glad that Michael brought up the example of biomarkers, both fluid and imaging function in that role, mechanisms on cell death, pathways. Canada has strengths in all of these, but it's difficult to combine them all in one centre. We could either expand the centres or enhance collaboration between existing centres, with infrastructure to handle the information, because it's almost impossible to do, otherwise.

The Chair: Thank you, Dr. Stoessl.

Would you mind, committee, if I asked one more question? Sorry, I don't usually do this.

Is that okay with you? Thank you.

First, have you presented this...? When I listen to what you're saying, I think, “Federal jurisdiction: we could do this. Provincial jurisdiction: can't touch it.” So I don't want you to be under the false impression that you can simply give us your grocery list of everything you want—and we want—because there are limitations between provincial and federal jurisdictions. That's reality.

So have you presented to the health ministers in the provinces as well? And do you know the difference between what is federal jurisdiction and what is provincial jurisdiction? Because that's how you get things done, right?

Ms. Gordon.

● (1010)

Ms. Joyce Gordon: Absolutely. You have Jon from British Columbia here, who knows the provincial jurisdiction really well, as many of our colleagues do.

We realize that today we've kind of slipped back and forth between them.

The Chair: That's okay.

Ms. Joyce Gordon: We really recognize, though, that the issues we raise also have federal mandate and influence with the provinces and territories through the FTP process. We were hoping that in terms of our working with provinces, that could percolate up, and also that the federal government could give leadership to those that could affect all Canadians in all those jurisdictions. Inasmuch as they slip back and forth, there are pieces—I just look at the disability tax credit—that are both federal and provincial. There are things that overlap.

So thank you for that reminder; we tend to move in that direction, because it's where we live.

The Chair: Okay.

Go ahead, Dr. Stoessl.

Dr. Jon Stoessl: Thanks.

Just briefly, yes, of course we have gone to provincial governments. Parkinson Society British Columbia is constantly engaged with the provincial government.

There are a couple of things here. One is that I'm responsible for delivery of neurological care, and not just for Parkinson's. So I see my programs in MS and ALS and Alzheimer's disease struggling with the same problems. I think we would all be better served at the provincial level if there were a coalition for neurological disease advocating at the provincial level as well as nationally.

I did have another point that I wanted to make, but....

It's the middle of the night for me.

Voices: Oh, oh!

Dr. Jon Stoessl: Oh, right: you raised the question about the national drug program. That's an example of where I think federal direction can help. Each province has a drug program, and people are covered to varying degrees, but the specifics vary from one province to another. If there were a federal program that set out expectations, that would be enormously helpful.

The Chair: Ms. Gordon.

Ms. Joyce Gordon: I have one other point. In Ontario, we've worked in a parallel process with the neurological health charities, and there is an Ontario brain strategy that parallels the national brain strategy. That has been extremely effective in terms of Ontario government investment. Yesterday there was an announcement about one of the pillars of the Ontario Brain Institute.

So we're beginning to see results, and other provinces are very interested in moving there.

The Chair: Thank you.

We'll go to Mr. Brown.

Mr. Patrick Brown: I have a question for Greg.

I know that you have been doing some volunteer work with the Fox foundation. You were telling me about it a little bit last year. That's what your golf tournament was raising funds toward. Are there any projects they are undertaking in Canada? There was talk that they might be doing something. Has that ever materialized?

Mr. Greg McGinnis: They just celebrated their first year here in Canada. As far as what they are doing, I couldn't answer that. The contact I have with them is more with Team Fox, and that's on the organization and planning of golf tournaments and getting supplies from them. I talked to them to see if we could get some initiatives going. They don't do that type of awareness. They're more for research, so anything I send to them would go right to research.

In terms of talking to the actual foundation to see what's going on, I haven't done that aspect of it.

Mr. Patrick Brown: As someone living with Parkinson's, what guidance can you give our committee? What other things can you think of that you believe are missing or needed in terms of what government can provide that hasn't already been mentioned today?

Mr. Greg McGinnis: What's missing or needed? I think I would go back to this drug plan. I look at the cost of some of the medications; thankfully I have my own coverage, but I do know people who don't have coverage. They're not getting the medications and they're living a very hard life.

I think that's one of the big aspects, the medication end of it. We need that. That's critical for us.

● (1015)

Mr. Patrick Brown: Yes.

Joyce, with regard to that $15 million for the neurological charities, is there anything you're learning now from this neurological study that has been embarked upon? Is there anything you could suggest to us as we look at a national strategy on the brain? What types of things do you think we've learned in the last year or year and a half that we should start examining now?

Ms. Joyce Gordon: Most of the research projects have just started. The first year was really getting together with regard to RFPs and selecting projects and going through the whole process of granting opportunities for people to explore key areas within the study. It's very early to talk about any results or where they are, because they just started in the last month or so.

However, the benefit of this is that we have the cross-disciplinary work of individuals working with all the neurological conditions. It is an opportunity for this group to learn from each other but also to bring forward those common areas we identified in the study, from caregiver support through public awareness and education through the genetic fairness issue, research, prevention, and integrated care and support. Those are the key focus areas of these projects, and we have built the study around them.

As we go, we will be informed, and we will have check-in milestone points where we can share the learning. Also, as we finish this report, we can have recommendations that can help us provide far better integrated services across Canada, and hopefully we can have recommendations for the Government of Canada.

The Chair: Dr. Schlossmacher.

Dr. Michael Schlossmacher: Mr. Brown, perhaps I may add something to Joyce's comments.

One of the really exciting things that's going on right now that Parkinson Society Canada is starting to fund as well is that within pharmaceutical industries, we know that a Tylenol not only treats headache but can also bring down fever. We know that Aspirin not only can prevent heart disease but also can cure our aching bones. That effort of using one drug for multiple purposes is called drug repositioning.

One of the exciting things that began in the ALS and Huntington's disease arena is to come up with strategies of how can we reposition drugs that are already approved by Health Canada and the FDA and European commissions to apply them to Parkinson's disease. That's something that is going on worldwide now and is pursued by a number of foundations.

Just four days ago, in San Diego, I was approached by the head of neuroscience research from Pfizer, who asked me to help them confirm what drugs they have that could work in Parkinson's disease models.

So this whole notion of drug repositioning could cut down ten years of development of a new drug and could cut the cost from $750 million down to $5 million or less to actually bring a drug to market. Drug repositioning is part of a portfolio of many foundations and national institutions, and that's something that I think Canada could contribute to as well.

The Chair: Thank you.

Now we'll go to Mr. Malo.

[*Translation*]

Mr. Luc Malo: Thank you very much, Madam Chair.

I have one last question, which follows from my previous ones. I was wondering about something in relation to genetic discrimination. I assume that work has been done in other countries.

Can we draw some conclusions or examples from what's being done abroad?

This is my last question, and you may use whatever time is left to answer it.

[*English*]

Dr. Michael Schlossmacher: If I understood your question correctly, you're asking what lessons we can learn from other countries. To me, when I think about this big problem of Parkinson's disease, Alzheimer's disease, dementia, and immobility in western societies, one of the most wonderful things from an international perspective that I experienced here, being newly arrived in Canada, was the amazing amount of talent, creativity, and willingness to work hard to change the plight of people with illnesses.

One thing that really struck me, in some European countries, such as Finland, where I lived for a few months, is the identity of a nation to embrace a difficult challenge and make change happen. In Finland in the late 1980s, the country lived essentially off fishing and forestry. Then the notion was embraced to start platforms for technological advance, children's education in terms of electronics, and all of a sudden the country developed this amazing knowledge-based industry. Every single Finn is as proud as he can be that he—or she—contributes to changing the economy and the future of the country. Finland now ranks number one in the PISA study of Europe in terms of level of education and knowledge. What I was struck by was how a country can embrace a challenge and bring change and make it happen.

When I came to Canada, I think equally inspirational was what Mr. Terry Fox did in his fight to bring more research dollars to fight cancer and understand cancer better.

Then we have a young woman here in the city of Ottawa who has young-onset Parkinson's disease. She goes from school to school—her name is Shelby Hayter—and she won the national hero award and was recognized by the Prime Minister as well. When I see how she can mobilize young children who are in second, third, fourth, or fifth grade with the message that we have to do something about Parkinson's disease, I feel all of a sudden that there's this opportunity for us as a country to embrace the challenge of Alzheimer's disease and Parkinson's and other disorders as a national fight. We can change that. We can advance Canadian interests, both because of our patients who live here and our economy that stands to benefit from breakthrough findings from the investment that we want to make, and we can set an example for the world of what Canada can do. I know we can do it, because we have the resources, the talent, the endurance, the willingness to collaborate.

The number one thing I'd love to see translated is the spirit of a Mr. Fox—Terry Fox, Michael Fox—and the idea that a whole nation embraces a fight. I commend Mr. Daniel Alfredsson, who takes the flame of psychiatric and mental health. Yesterday the daughter of one of his coaches committed suicide, and they're all coming back to show that mental health needs to be addressed and changed.

Likewise, I know that if we were to embrace as a nation, with federal and provincial support, we can show that Canada can make a difference and contribute to change that affects Alzheimer's and dementia and Parkinson's patients.

That's the number one thing I'd love to communicate to you: we can do it. The challenge is big, and we need additional resources, but we have all the talent. We can lead the world in terms of how we fight this disease.

● (1020)

The Chair: Dr. Stoessl, did you want to say something?

Dr. Jon Stoessl: Perhaps I can respond briefly specifically on the issue of genetic discrimination.

While I don't want to downplay the advances made in other countries, I should emphasize that Canada has played a leadership role in this and should continue to play a leadership role. Probably many of the lessons came from Huntington's disease, where all kinds of issues were opened up by having this genetic information and the potential for discrimination. We should definitely take a page from that book.

What this does is it opens up complex ethical issues, and Canada also has a leadership role in neuroethics. We want to promote that. We want neuroethics to be a part of every collaborative team that unfolds, because what we're seeing, actually, is that other countries haven't thought through these questions as well as they should have. If you can mail off a saliva sample to get a DNA analysis, and nobody actually knows how to handle the results, we have a problem, both scientifically and ethically.

So we should be the leaders, not the followers.

The Chair: Thank you so very much.

I must thank Mr. Brown, who has so generously, Ms. Hughes, given you his time. I noticed on my list here that you would not have a chance to ask a question, and he was happy to do that.

If you would like to ask some questions, go ahead now.

Mrs. Carol Hughes: Well, thank you again, Mr. Brown. I'll have to buy you a glass of wine at some point at one of our receptions.

The Chair: Never mind him; what about me?

Voices: Oh, oh!

Mrs. Carol Hughes: One for Mrs. Smith as well.

There were a couple of comments made, one of them by Joyce and I believe by Dr. Stoessl as well, with respect to geological differences. I call them geographically challenged ridings; I come from one of those. Rural areas is what Ms. Gordon mentioned. I have something like the third-largest riding in Canada; it takes me two days to get through it.

You also talked about the mental health aspect. I'm trying to get some sense whether you have any recommendations as to what the federal government should be directing itself towards, or about how to better service these regions. For mental health problems in my area, people are put on waiting lists even though they might be suicidal.

Do you have comments on that?

● (1025)

Dr. Jon Stoessl: Sad to say, it's true in my area, which is Vancouver; the same thing happens.

I'm not sure I can give you specific recommendations, but here is an area in which we can possibly learn from what happens in other countries. There are many possible approaches. Telemedicine is one; it's not without problems. The other approach in Holland is to have networks—I think it's referred to as a "cluster delivery model"—whereby you have networks set up in which people in the smaller centres are trained by people in the big centre. Patients only come into the big centre once, or maybe once every four years, and for the rest of the time the delivery of care is provided at smaller centres.

These are all models worth exploring, but it's a lot to expect that people who are already overstretched will try to learn about those models and take them on. I think this is a huge challenge.

I can't comment on the role of the federal government in this, as opposed to that of the provincial governments. We all recognize that it's a problem.

The Chair: Ms. Gordon.

Ms. Joyce Gordon: In the area of innovation, there has been some work with Dr. Ivar Mendez on robotics, which has a wonderful application internationally whereby a specialist can coach other specialists from afar about techniques. It shows how you can transfer clinical practice into having the expertise of somebody in a remote location available to you. That has received significant foundation funding, but government funding as well.

The other one I would mention is a model in the U.K. in which nurse specialists—in this case, in Parkinson's disease—move out into the community and are available to individuals in an outreach capacity that has been very successful. They're just evaluating that study. These nurses are able to prescribe and to follow up on prescriptions in consultation with specialists.

So there are models that we can learn from.

We also have, as Dr. Stoessl mentioned, examples of telemedicine in northern communities. Dr. Mark Guttman does a telemedicine piece with Sudbury and northern communities, and Dr. Mandar Jog moves into Thunder Bay and brings a team twice a year.

So there are ways that these things can happen. They're not perfect, and it would be great if we had the specialization in the community, though it really may not be realistic. But we should be using innovation and technology to maximize interactions with individuals.

The Chair: Okay, Mr. Brown, Ms. Hughes is all finished her questions, and you have this rare opportunity to ask one just before we finish.

Mr. Patrick Brown: Oh, perfect. Thank you, Joy.

There was one question that I asked when we had some representatives from the ALS Society. When we look at the limited scope of the CHR funding, it's interesting to know how much is left off the table. I realize that there could be many projects that merit investment.

I understand that since 2000, there has been $70 million invested—I guess last year it was $9 million—in Parkinson's research. But how much has been applied for? And in your opinions, what amount of research that should be examined isn't being examined? Are we leaving a lot on the table?

Dr. Michael Schlossmacher: I can tell you from a personal perspective that just since July 1, I have applied for $2.5 million in research that covers different arenas, just in my laboratory of eight people. That was internationally, not just within Canada. I hope I will get 50% of this, or if not, even 25%; then I'll reapply next year. One of the things we do is reapply and reapply, or try to reposition ourselves with other sources.

I think it has never been done before, actually, to tally how much time we spend and how much money we apply for on an individual basis and then on a group basis per year. But I can tell you that probably 50% of my time is spent on writing grant applications to raise money, from which, if I have a 50% return rate, I feel like a king; if I have a 25% rate, I can still survive and move on.

Mr. Patrick Brown: You said 50% of your time?

Dr. Michael Schlossmacher: Yes.

Mr. Patrick Brown: That's a lot of manpower.

The Chair: Dr. Stoessl, you may respond quickly.

Dr. Jon Stoessl: The overall success rate at CIHR is a little below 20%, which doesn't sound bad. It's pretty good, compared with other places. The problem is that there are no longer poor grants being submitted to CIHR. It's all excellent, all very good stuff, so the question becomes whether it is superb or just good.

The other problem is that CIHR, unlike NIH, does not fund faculty support. So in response to the question before from Dr. Duncan, if the need is for training people, and particularly to train clinician scientists, we need to make this more attractive to Canada.

● (1030)

The Chair: Thank you, Dr. Stoessl.

I would ask each of you to submit your written talk to the clerk so that we can get it translated and distributed. This was a very important topic today, and I'm very excited about the fact that you've been here. We have things on record now, and this committee is very attuned with and concerned about neurological disorders. You just confirmed today some of the things we thought: that the different disciplines interact, and that with more research we could perhaps put a lock on the mystery that connects them.

I thank you so much for coming.

I'm going to suspend for one minute so that we can clear the room and go into our committee business, or allow you to move back.

Thank you.

● (1030)

_____ (Pause) _____

● (1035)

The Chair: Let's resume.

The notice of motion submitted by Dr. Duncan reads as follows:

> That the Subcommittee adopt the following report and that the Chair present it to the Standing Committee on Health for its consideration and for presentation to the House:

—and this is the substance of it—

> The Committee recommends that the Government of Canada declare 2013 as the Year of the Brain.

What we have to do is adopt this report, then it goes to the major committee.

(Motion agreed to)

The Chair: Thank you.

We have officially adjourned. You can all clap and warm up.

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