



House of Commons
CANADA

Subcommittee on Neurological Disease of the Standing Committee on Health

SMND • NUMBER 013 • 3rd SESSION • 40th PARLIAMENT

EVIDENCE

Tuesday, November 23, 2010

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Chair

Mrs. Joy Smith

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•(0850)

[English]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): I call the meeting to order. Good afternoon....

Oh, good morning.

Voices: Oh, oh!

The Chair: My apologies. I had a group of people in my office and I got talking away, and my back was to the clock, so I did the 100-yard dash.

At any rate, it's a pleasure to be here. This is our Subcommittee on Neurological Disease of the Standing Committee on Health. Pursuant to Standing Order 108(2), the study on neurological diseases will be done today.

We have witnesses with us from the Ottawa Hospital, University of Ottawa, Dr. David Grimes, associate professor. Welcome, Dr. Grimes.

We also have, from Parkinson Society Canada, Carmel Boosamra and Bruce Ireland, the chair. Welcome, both of you.

As individuals, we have Chris Sherwood and Frances Squire.

Chris, I think, will be here momentarily.

Welcome, Frances. We're glad you're here.

I have some very good news for this committee, something that I think will really warm your hearts. You'll remember Greg McGinnis, who suffers from Parkinson's, who appeared before our committee last week. Now, Mr. McGinnis spoke to us at committee about the lack of funds to get treatments. After last week's meeting, the two doctors who appeared before the subcommittee, along with the Parkinson Society, made arrangements so that Mr. McGinnis could receive the treatments he needed before he returned home. If you recall, he didn't have the money for Botox. They took him into the hospital and they treated him, and said they would continue doing that.

I thought that was amazing, and I thought the subcommittee would be very appreciative of the fact that we were able to be a catalyst, to help somebody in a real-world way. It's going to be a very special day for us folks today, between this and the stem cells—I'll tell you more about that later.

We will be dealing with Dr. Duncan's notice of motion at the end of the meeting as well. Thank you.

We're starting with Dr. David Grimes.

Dr. David Grimes (Associate Professor, Ottawa Hospital, University of Ottawa): Good morning.

I'm a clinician who runs a very large Parkinson's clinic here in Ottawa. I am also involved in clinical research as well as some basic science research. I've been looking after Parkinson's patients for close to 12 years.

It became very apparent to me that as Canadians we could do a lot better in both our basic research realm, clinical research, as well as in the clinical care of patients. Two years ago I was involved in organizing a meeting for really all the players in Canada to come together, both clinicians as well as basic scientists, to look at how we could do a better job at studying Parkinson's as well as caring for individuals with Parkinson's.

Quite a few things came out of that meeting. I had all the major Parkinson's centres from across Canada there. It became very clear that the specialized Parkinson's centres actually care for less than half of individuals with Parkinson's in Canada, that a lot of the centres cover patients from a wide geographic area—so we have patients actually travelling a long way to get to see us—and that we could do a much better job if we were better organized from a basic science and clinical research standpoint.

One of the big things that came out of the meeting was, from a patient care perspective, can we do a better job of helping other physicians? If we're supposed to be the specialists and we're not seeing everybody who has the condition, how can we help other physicians care for and look after these patients?

One of the ways to do that is to look at guidelines. So we looked at all the different guidelines from around the world. It became apparent that our Canadian health care system was different from other health care systems and that we did need to come up with our own set of guidelines. We actually have now just finished the first draft of these guidelines. It has been a big undertaking and we're hoping to have them published in the spring. We're really hoping that this will be a stepping stone to developing and having more physicians understand what the best treatment options are for our patients in Canada.

The other thing that came out of the meeting was that it's a really patchwork treatment for patients in these specialized clinics. Most of the clinics have nurses, and the funding for the nurses comes from many sources, sometimes from provincial governments, sometimes from hospitals themselves, and sometimes it's from us as clinicians paying the salaries of the nurses within the clinics.

A couple of the clinics have occupational therapists and physiotherapists—they are so important in trying to care for these individuals, who are among the most complicated to look after—and then it's actually very uncommon that we have social workers involved in our clinics. Parkinson's is a chronic condition that progresses slowly and it gets so frustrating when we see individuals with Parkinson's who come into our hospitals, our acute care hospitals, when we really could avoid that. Almost all the time I have at least one of my patients in an acute care hospital somewhere in the Ottawa Valley region when it would probably not be necessary if we had a social worker, something simple like that. We could avoid that from a health care cost standpoint.

It also became very clear studying Parkinson's that there are a lot of very exciting things that are happening in basic research and our ability to translate that into clinical treatments is rapidly increasing. There is a large number of compounds that are being developed that are getting close and are now coming into clinical trials.

As Canadians we could do a much better job, I think, of being a leader in that and trying to help pharmaceutical companies develop these treatments within the Canadian context. There are a lot of exciting things happening in Parkinson's. There's still a lot more, though, that we need to do.

Thank you.

•(0855)

The Chair: Thank you, Dr. Grimes.

Who is speaking from the Parkinson Society? Would you both like an opportunity to speak?

Let's start with Mr. Ireland, please.

Mr. Bruce Ireland (Chair, Board of Directors, Parkinson Society Canada): Thank you, Madam Chair.

You mentioned earlier the treatment of Greg McGinnis. I just wanted to note for the committee that Dr. Grimes was the physician who treated him last week. On behalf of the Parkinson's community, and I'm sure your committee, we would like to thank him for doing that, for stepping up, and helping Greg with his treatment.

The Chair: Thank you, Dr. Grimes. It warms your heart.

Dr. David Grimes: It was an unusual request.

Mr. Bruce Ireland: Thank you, Madam Chair, and thank you, committee members, for creating this opportunity for Parkinson's communities to speak out.

I come to this hearing today wearing two hats—first and foremost, as partner and caregiver to my wife, Karen, who was diagnosed with Parkinson's at the age of 50; secondly, I'm a long-standing volunteer with Parkinson Society Canada and currently the chair of the board.

In 1998 my wife, Karen, slipped into a serious depression that persisted over two years and led to a complete mental breakdown,

requiring hospitalization for over eight weeks. Over the course of that two years, Karen's psychiatrist suspected that her depression might be linked to something neurological. Sure enough, Karen was diagnosed with Parkinson's on December 27, 2000.

The diagnosis was totally unexpected and overwhelming. Karen was back in the psychiatric ward in very short order. That was ten years ago, and it was an incredibly stressful time. Our son was grown, but our daughter, Michelle, has Down's syndrome and lives with us. She was 17 at the time. Karen was literally suicidal, unable to care for herself, unable to care for our family, unable to work. I was working full time on the biggest project of my career and juggling to keep everything together at home.

Since then, the non-motor symptoms of Parkinson's have been Karen's greatest challenge. Her depression is ever-present, and she has developed a severe sleep disorder. She takes a cocktail of four medications every night, without which she simply could not sleep. Her mobility is compromised by Parkinson's and by severe arthritis in her knees. She gets incredibly frustrated by her inability to move around, which amplifies her depression.

Last year I made the decision to retire early to care for Karen and Michelle. I resigned my position as the president and CEO of the YMCA of Oakville after 23 years leading the association. I attend to their daily needs and run the household. I do all the cooking, cleaning, laundry, grocery shopping, and driving.

Looking back, Parkinson's has cost our family dearly in lost income and related expenses, in the quality of our family life, and our dreams for the future. We still have a good life, but it's not what either Karen or I imagined. Ours is a common story for people living with Parkinson's.

As chair of Parkinson Society Canada's board of directors, I see and hear about similar situations playing out from coast to coast. That is why Parkinson Society Canada's unique role as the only organization providing support to individuals and families is so critical.

Through Parkinson Society Canada, Canadians with Parkinson's can connect to a supportive community close to home. They can access the highest-quality information about Parkinson's and they can take control by advocating for themselves and for the wider community of people with Parkinson's.

Parkinson Society Canada also plays an invaluable role in funding Canadian researchers, investing donor dollars to support basic, clinical, and psychosocial research that is essential to improving quality of life today, and to uncovering the treatment that will stop Parkinson's in its tracks. Often-overlooked health charities like Parkinson Society Canada play a major role in advancing neuroscience in Canada. Unfortunately, with limited donor dollars, we turn away more projects than we can fund. It can be very frustrating to see so many excellent peer-reviewed projects go unfunded. For this reason, Parkinson Society Canada is working with our NHCC colleagues to propose an innovative, five-year \$600-million research partnership with the Government of Canada to leverage private donor dollars for maximum impact.

Parkinson Society Canada also works to ensure that Canadians with Parkinson's receive the highest-quality care. In 2005 we developed a national program to better educate family physicians about Parkinson's disease. Over the past several years, we helped bring the Canadian community of Parkinson's researchers together as the Parkinson's research alliance. One of the most exciting results of this work is the development of a Canadian clinical guideline for Parkinson's to be launched in 2011.

Most recently, Parkinson Society Canada launched a program to educate hospital and long-term care staff about the importance of administering Parkinson's medication on time every time. The program is called "Get it on time", and is an excellent example of international collaboration. The program was first developed by the U.K. and subsequently shared with Canada as a best-practice tool. Like our research investment, this work is undertaken entirely with donor dollars, as Parkinson Society Canada receives no funding from any level of government.

● (0900)

In closing, I'd like reiterate my thanks to each of you for undertaking this initiative. Brain conditions like Parkinson's are devastating families in every riding across this country.

I am hopeful that in addition to the important work being undertaken through the National Population Health Study of Neurological Conditions, your work will draw much-needed attention to brain disorders like Parkinson's as an urgent health, social, and economic issue facing Canada today.

Thank you.

The Chair: Mr. Ireland, thank you. I think you're an extraordinary man, hearing what you've done with your family. There are many families who do have catastrophic illnesses and it drains the family a great deal. I think you are a real role model for a lot of us.

Thank you, Mr. Ireland.

Mr. Bruce Ireland: Thank you so much.

The Chair: Ms. Boosamra.

Ms. Carmel Boosamra (Board Member, Parkinson Society Canada): Good morning. My name is Carmel Boosamra, and I want to thank you for this opportunity to speak to you today about my life experience as a caregiver to a person who lived with Parkinson's disease for almost 17 years.

When my late husband was diagnosed with Parkinson's disease, we both could not imagine what a long road, with many twists and turns, we would travel together.

First, I want to impress upon all of you that, as a caregiver, I have lived and witnessed the full spectrum of issues that a family unit must deal with when caring for someone living with Parkinson's. I watched as my husband, Frank, transitioned from a full member of society, being the owner and operator of a small business, to a person who was totally dependent on the support from a wide range of social agencies, and finally ending his days in a long-term care home.

I could never have realized that I would become a caregiver to a man who had been previously gregarious, good-humoured, and who lived life to the fullest. Frank's mobility declined rapidly—from walking on his own, to relying on the aid of a cane, to using a walker, and finally being in a wheelchair full time. I had to assume an ever-increasing role of providing for his daily functions, attending at his many medical appointments, and management of his daily medication, while working with his neurologist to figure out which medication worked best for his Parkinson's symptoms as they progressed. I negotiated and advocated with the local community care access centre for much needed home care, and I had a continual dialogue with the many community-based social agencies for support.

I juggled all this responsibility while working full time. Upon reflection, I now realize I suffered from caregiver burnout, but during this period I was in survivor mode. I would venture to say that's a common theme for anyone who is or has been a caregiver.

After some five years, it became clear to me that I no longer had the ability or stamina to provide moral and physical support to my husband, who by now was displaying cognitive decline and for whom medication was fast becoming ineffective. I cannot state strongly enough the stress I felt each day as I left for work, knowing that my husband was on his own, and praying that he would be safe in the home.

I had to make the most difficult decision that it was time to move Frank to a long-term care home. For the next five years, I watched helplessly as he continued to decline cognitively, developing Lewy body disease. With the loss of his ability to communicate verbally, along with all the characteristics of late-stage Parkinson's, our marriage was now predicated on my daily visits to feed him and hold his hand.

In all of this there was the underlying burden of economic impact on our lives. Early on, my husband and I had to make the difficult decision to give up his working life and rely on his Canada Pension Plan disability benefits and my salary to meet our daily living expenses. There were numerous medical expenses that were not covered by provincial health plans or third-party insurance. I was always aghast each year at tax preparation time when I saw the amount of medical expenses there were to claim. Out-of-pocket expenses for such things as daily living aids, mobility aids, dictated we could not afford my taking a leave of absence from my employment, as some of the costs of these were covered through my employment medical insurance plan.

The stress of caregiving had a very substantial cost to me personally, in that two months after my husband's death I was diagnosed with invasive breast cancer. That stole the next year and a half of my life. I mention this because I had seen a very visible sign that something was wrong with my body earlier that year, but I ignored it and did nothing because I was so focused on my husband's needs.

My experience as a caregiver to someone living with Parkinson's is not all that different from others who are caring for someone. The family unit is profoundly affected when one member is diagnosed with Parkinson's because it means they must navigate the medical system to ensure the person receives proper diagnosis and care, as well as managing all the symptoms of Parkinson's and finding coping mechanisms to help ease the impact on daily living.

It causes the family to jump with both feet into a medical system that is not doing a good job of diagnosing and caring for the Parkinson's population. There is the lack of a clear, multi-disciplinary approach to managing this disease, and health care professionals receive little education on Parkinson's.

● (0905)

I now know there is a grave misunderstanding in the general public and the medical profession about this disease. This is why I have dedicated so much of my personal time to advocate for people living with Parkinson's. I want to effect change of attitudes in government policy-makers by educating them to the disease and its associated needs.

I am excited about our proposed brain strategy that seeks to address some of these issues: integrated care; caregiver support; public education and awareness, just to name a few.

It is my hope and dream that we will see this brain strategy come to fruition. It will profoundly ease the burden and provide hope to so many Canadians living with a neurological disease.

It would be the ultimate way to honour the memory of my late husband.

Thank you.

The Chair: Thank you very much. Your testimony is very compelling, and we so appreciate you being here this morning. This is why this committee is so committed to studying this issue.

We'll now go on to Mr. Chris Sherwood.

Welcome. I'm glad you made it here.

● (0910)

Mr. Chris Sherwood (As an Individual): Thank you.

First, I must apologize. I've been quite sick lately, so I'm a little less organized than I would normally be. That's why I'm reading from my laptop, because I didn't have a good chance to print it out. I hope that's okay.

The Chair: That's fine. Thank you.

Mr. Chris Sherwood: My first official introduction to Parkinson's was with a neurologist who, as part of his overall neurological assessment, at one point began to check me for rigidity. Being a nurse and knowing what he was doing, I said to him, "So you're assessing me for Parkinson's," to which he replied, "I'm not assessing you for Parkinson's, you have Parkinson's."

Suffice it to say his less than warm-and-fuzzy approach was hardly comforting, and resulted in me not going back to him.

A few months later, after starting to see a movement disorder specialist—a sub-specialist within neurology—this well-meaning person offered me what he no doubt considered assurance but was nevertheless equally unhelpful. He said, "Don't worry, Chris, you don't die of it"—Parkinson's, that is.

I replied to him, "So let me get this right. Barring other unforeseen circumstances, I'll die of Parkinson's-related complications, which I wouldn't have had if I'd not had Parkinson's. Would this mean that people with AIDS don't die of AIDS, they die of AIDS-related complications?"

Needless to say, he understood, and agreed with the point I was making.

But being well-meaning doesn't make one competent. This is not to suggest that in other aspects this person lacked competence, but in that circumstance he most definitely was not competent.

What would be the significance of his comment? I mean, what difference would it really make? I, being a palliative care professional, was able to step back and look somewhat objectively at the situation at the time. I knew he didn't mean to be unhelpful, but he was, nevertheless. He, as the professional with knowledge and expertise, had the ability to impart this to me as the patient.

Most patients are not like me. They really don't know what they don't know. The information a neurologist provides can make a huge difference to shaping their understanding of their disease and what their future will look like.

The significance is this. If a doctor can't help me see what I don't yet see, what would I do differently? For example, if ten years from now, when I planned to take the Mediterranean cruise I've always longed to go on, at that point my disease has progressed to the point at which I'm no longer able to, would I have done so sooner? One might transfer this to any number of other situations as well, including compassionate care leave, taking time simply to be with family, etc.

Some people may not want to know what they don't yet know, in which case doctors shouldn't barrage them with information they aren't prepared to hear. But neither, too, should they be the encumbrance to patients receiving information they are prepared to hear.

What does "support" mean to people with Parkinson's? We have a health care system that has historically focused on assessment data that it acquires through any number of objective means—scans, biopsies, bloodwork, and any other variety of tests that can provide very helpful information—but that tell absolutely nothing about the patient's subjective illness experiences, those being what people feel as they live with illness.

I'd like to share a quote from a physician I worked with in Vancouver who did a study many years ago on what dying people want. Although I wouldn't necessarily say that I am dying, per se, the issue transcends beyond so-called dying people to everyone receiving care. He says:

"The way health care providers talked to me caused me more pain than the disease itself."

This is the theme which came as the greatest surprise. It is one I didn't want to hear. Initially I dismissed and trivialized the experience of the co-researchers. But it is a theme that could not be ignored for long.

This was a recurrent and resounding theme throughout the entire study, and Dr. Kuhl is currently conducting further research.

Living with illness means living with suffering, whether it's Parkinson's disease or any other illness. But we have a system with health care providers who are being constantly exposed to suffering, day in and day out. Progressively over time, they experience fatigue and find it challenging to know how to respond to it.

This is where hospice palliative care fits in. Hospice palliative care is not just about caring for imminently dying people, and should not be limited to just specialized programs that focus exclusively on this type of care. The definition we work with in Canada is as follows: Care that aims to relieve suffering and improve the quality of living and dying.

● (0915)

This is not mutually exclusive to care that might aim for cure. But this is especially relevant for illnesses that do not have a cure, which includes any number of disease types, including Parkinson's.

In fact, hospice palliative care is really just good health care and provides a model for how to do this. The reason the field of hospice palliative care exists at all is simply because people made the observation that we weren't providing good health care to people who live with progressive life-limiting illness.

It is important to note that 90% of us will die of progressive life-limiting illness of one form or another. Fewer than 10% die suddenly. Societally we must ask how we want to care for those 90% of people who will one day find themselves in these circumstances. What should this look like?

I'll make one additional observation. At this point, we have a system that is grossly inequitable. People who live with chronically progressive disease types receive a much lower standard of care than people living with illnesses that are more acute in their decline, illnesses such as cancer. People with chronically progressive diseases usually, at some point, end up in long-term care. If you ask anyone if that is a place they want to go, they will almost always answer no.

It should be noted that long-term care is not long-term care anymore. It is mostly end-of-life care, such that the average length of stay from admission to discharge—that is, death—is under two years. The long-term care sector has not been equipped to deal with this hugely different demographic.

I'll ad lib here for a couple of minutes. I was speaking to a group last night, a group of people who work exclusively in long-term care. I asked them who there wanted to go to long-term care. Not one hand went up, and there were about 40 or 50 people in the room.

I said, "Wait a second. Who here wants to go to long-term care? You guys work in it." There was not one hand.

So I ask the question: why have we created a system that nobody wants, and what could be done differently?

You can analogize this to the psychiatric facilities that existed many years ago, where people were warehoused and segregated into big boxes. That's what we're doing with our dying population, as more than 60% or 70% of us die in big-box institutions. It doesn't need to be this way, but we've resigned ourselves to believing that the system we have is the only system we can have.

What could be done differently?

Create smaller boxes. Smaller boxes mean more individualized care. That's what residential hospice is—nothing more, nothing less—and it doesn't need to be limited to people who are imminently dying.

Why is this important? Because the setting matters. If the setting didn't matter, you could take all the same care you would provide to anyone in the most beautiful of settings and provide it to them in a prison cell, but their experience wouldn't be quite so warm and fuzzy.

Why can we not make settings that are more integrated into our communities, and by doing so, allow people to live within our communities in a more integrated way?

The Chair: Thank you, Mr. Sherwood. I've given you double the time, actually.

Mr. Chris Sherwood: Did I take too long? Oh, I'm sorry.

The Chair: The way it works it that there's a certain time limit.

Mr. Chris Sherwood: I apologize. I thought it had been only five minutes.

The Chair: No, no, don't; I doubled your time because you were so interesting. I think it's very important to hear what you have to say. You will have a chance, also, when questions are asked.

Mr. Chris Sherwood: No problem. I do apologize. I literally thought it had been only five minutes.

The Chair: No, no, I'm very pleased; I just thought maybe I should let you know that I have to go on to the other speaker now. I hated to even interrupt you.

Mr. Chris Sherwood: No, that's good. Thank you. I appreciate your interrupting me.

The Chair: Thank you.

We'll go to Ms. Squire.

Dr. Frances Squire (As an Individual): Thank you.

My name is Fran Squire, and I'm a person living with Parkinson's. I was diagnosed 16 years ago, when I was teaching grades 7 and 8, completing a doctoral thesis in education, and raising two young children.

The story of diagnosis is the first hurdle that people with chronic disease must face. After finding it difficult to turn and negotiate a ski hill in 1994, my husband and I ended up several months later in a neurologist's office to hear the outcome of a battery of tests.

The astonishingly young doctor, whose name I have long forgotten, peered over his titanium frames and asked, "Do you live in a two-storey house?" Yes, I answered. "Then you'd better start thinking about moving; you're going to be severely disabled in five years. The good news is you don't have a brain tumour, but the bad news is you have Parkinson's."

Parkinson's! But I'm only 49. Isn't Parkinson's for old people? What do you mean, "disabled"? What is Parkinson's, anyway?

But he was already closing my file—closing my file, just like that.

So here I am today, and I'm still doing okay. I am lucky, because I live in a city where access to movement disorder specialists is available, and the onset of my symptoms has been steady but slow, and responsive to medication. Others are not so fortunate.

My way of coping is to be involved, to be in control of something. I'm the past chair of the board of Parkinson Society Ottawa, where I have volunteered for nine years as a board member and editor of the newsletter. I have just completed a six-year term on the board of directors of Parkinson Society Canada, where my main interest and involvement was on the research policy committee. During my tenure we added a psychosocial research program to the scientific biomedical grants already in place. This strand of research focuses on quality-of-life issues for people living with Parkinson's and includes understanding and treating non-motor systems. I am encouraged by this direction, because as much as a cure is necessary, we still have to function within the world while we wait.

What I would like to tell you today is what Parkinson's is and what it isn't. It is not just a little tremor that affects old people. The tremor is the tip of the iceberg. Parkinson's is a complex disease that affects

every aspect of an individual's life. Yes, there are the visible physical symptoms—the tremor, the awkwardness, the slowness in walking. But there are cognitive and emotional challenges as well—depression, anxiety, cognitive deficits, and sleep disorders. Parkinson's also affects entire families, with different implications at various stages of the disease.

It is called a degenerative neurological disease, and the word "degenerative" is full of meaning. You never get better; you just manage the symptoms with ever-increasing combinations of drugs. Each person's progression and treatment is unique. Often the side effects are worse than the symptoms. A cause has not yet been determined, and therefore there is no cure. The major visible symptom is a resting tremor. The other symptoms have to do with the whole system slowing down: rigidity, slowness of movement, poor balance, an awkward gait, trouble with swallowing, constipation, slowness of speech, lowered voice, loss of articulation, facial masking, lack of expression, sleep disorders, and depression.

Parkinson's is not a sexy disease. The stigma attached to Parkinson's is shown to each of us who feel the sting of an accusatory stare or the laughter from those who do not understand. No, I'm not drunk; I just stagger and lose my balance a lot. I often pitch forward when I walk and I shake when I eat.

I sometimes feel embarrassed, but there is one place I feel comfortable: within my Parkinson's support group. I'm in another smaller group of women—we call ourselves "the ladies who lunch and shake a lot"—that meets for support and friendship. We were saddened last year by the death of one of our group, and now yet another single mom, 42 years old, is dependent on a wheelchair and a personal care worker at night. Although they receive no government funding, the regional organizations try to provide many such support and educational services that help both the person living with Parkinson's and their care partners.

In closing, I would like to share an entry from my journal written several years after my being diagnosed. I was just beginning to understand the word degenerative. I think it describes the future and emphasizes the need for collaborative strategies, such as the proposed brain strategy, within the health care community to provide a brighter future for those of us living with Parkinson's.

Parkinson's is like moving inexorably down a steadily darkening tunnel. There is still some ambient light as you begin moving, but it quickly disappears. There is as yet no end to the tunnel, no glimpse of light, no room for a U-turn. For some people with Parkinson's, movement can be dyskinetic, your body and mind disconnected, arms and legs flailing with jerky spasms, somewhat like being trapped in a washing machine on the spin cycle.

● (0920)

Or at the other extreme, the body can be rigid and frozen, unable to take the next step. You can't call out for help, because your voice is diminished in articulation and volume. Perhaps you see hallucinations—other people or creatures in the tunnel who may be friendly apparitions or terrifying, mind-crushing delusions.

People may misinterpret your journey because your face shows no emotion; the mask of Parkinson's distances you farther from your social world. You may become seriously depressed. You shuffle down the tunnel, walking awkwardly with a peculiar gait, lurching off-balance every few steps. If you are fortunate, you will recall where you intended to go and why.

Thank you.

● (0925)

The Chair: Thank you very much for sharing that with us.

We're now going to begin our first round of questions and answers. It's seven minutes per person to ask the questions.

We'll begin with Dr. Duncan.

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

Thank you to all of you for your overwhelming, powerful, and... We won't forget what you said today. Thank you for the courage to tell your stories.

Mr. Sherwood, you talked about diagnosis. Several of you did. I've heard this over and over.

You know, my dentist follows up when I get a lousy filling—that night. I wonder how many people the doctors phone the night of their diagnosis, or a week later, to see how they're doing.

Dr. Grimes, I know you can't share the guidelines, but could you tell this committee what you're thinking about in order to improve diagnosis and treatment for those suffering with Parkinson's, and what a multi-disciplinary centre might look like?

Dr. David Grimes: One of the things we looked at when we were trying to develop the guidelines was that, as I mentioned, some other countries have guidelines, and one of the real difficulties we have in Parkinson's, when it comes to evidence-based medicine, is how much evidence-based medicine we have for treating the depression, for treating the bladder troubles or bowel troubles, or all the other things—these non-motor things that you're starting to hear about with Parkinson's.

The answer is that there's not much evidence-based medicine. If you look at the American Academy of Neurology guidelines—they just came out this year—for treating these non-motor things, they

have six or eight different, huge topics in Parkinson's. They came out with three recommendations that were terrible.

So we have to step back and say, if there's not evidence-based medicine, we still need to treat people, we still need to diagnose people; how can we come up with the best way to do that in Canada? That's what we tried to do in the guidelines.

There's still a clear need for better research into coming up with better ways to diagnose people with Parkinson's. We still need to do a better job at it, because people have to rely on coming into my office and my telling them yes, you have Parkinson's, and no, there's no test that can confirm that this is what you have.

The people we see are very complicated and have many different issues, and I am definitely not an expert at treating a lot of those things—the balance issues, and which cane is the best, which walker is best, different things to help you get up out of bed, what the best exercise is for this individual when they have a bad hip as well as their Parkinson's, or a bad knee. These are all things that I'm certainly not an expert in.

This is where the multi-disciplinary team comes in. Do I call any patient that night after I have diagnosed them with Parkinson's? The answer is no, there's no time. Would it be nice to be able to do that? Yes. We are fortunate enough to have two nurses in our clinic who answer the phone and try to give out advice on the phone, but it's not easy. It's frustrating for people even when I see them in the clinic. I try to see them a month after I give them the diagnosis, and that's rather squeezing them in, because I don't have any appointments for six months.

There's no question that we need to do a better job as a team of treating this very complicated condition.

Ms. Kirsty Duncan: Thank you. Perhaps you could table with this committee the various international guidelines you've reviewed.

● (0930)

Dr. David Grimes: The biggest and most comprehensive ones are the U.K. guidelines. These are the NICE guidelines. They really work through all or almost all of the different aspects of Parkinson's. Those were really the basis for developing our Canadian guidelines.

The Europeans came out with some guidelines that were okay but not great. Then the Americans took the approach of, as I mentioned, only giving recommendations if they're evidence-based. That's great, and we need that, and we want to have the best evidence-based treatment options for people, but when that's lacking...

Those are really the three groups: the U.K. guidelines, the European guidelines, and the American academy guidelines.

Ms. Kirsty Duncan: Thank you.

To what extent are drugs for the treatment of Parkinson's covered under the formularies of provincial drug plans? What proportion of Parkinson's patients face catastrophic drug costs, defined as those that either threaten their financial security or cause undue financial hardship?

Dr. David Grimes: In Ontario there's a big problem. Nobody gets their drugs covered until they're 65 unless they're on some sort of assistance program, or in Ontario through the Trillium drug program, where then they are balancing out their drug costs with what their income is.

In Parkinson's, 15% of people, maybe even 20%, will have their onset before age 65. That's a large number of people who are now trying to take on drug costs. Some of them are still working, so they do get some of their drugs covered, but as you heard, that then forces them to keep working or they will lose their drug coverage, so that's not an ideal situation either.

There's definitely a big problem, with the per-drug cost for a lot of the Parkinson's medications at \$200 to \$300 per month. There can be up to four different medications, so the drug costs really add up very quickly.

There's definitely a big need there. With the new drugs that are coming out, there's one we have that most people are not covered for. The older medications are covered under certain circumstances, but again that varies quite a bit from province to province.

Ms. Kirsty Duncan: Would you say the average cost is about \$1,200 a month depending on the drugs and what people require?

Dr. David Grimes: Yes, I think you're easily getting up there when you're looking at the costs for the Parkinson's drugs, and then there are the depression drugs and the blood pressure drugs. It quickly snowballs, because people are taking drugs for other reasons as well. So the drug costs can really skyrocket.

The Chair: With the committee's permission, may I just ask a question following something that Dr. Duncan was asking?

Dr. Grimes, when you talked about diagnosing Parkinson's you made the comment—or did I hear it right?—that it was difficult to diagnose, that you're not quite sure it's Parkinson's. So if a patient goes to a doctor and the doctor says to them that they have Parkinson's, how does that square with what you just said? How does a doctor know for sure that someone has Parkinson's?

Dr. David Grimes: That's part of the dilemma. This is a real limitation for a lot of patients.

I mean, there have been studies now such that if somebody comes into my office and they have a rest tremor, and they have stiffness and slowness, I'm right 95% of the time. If somebody comes into my office and they only have some stiffness, and they only have some slowness, and they don't have a tremor, and it's symmetric, and they have a couple of other things going on, my diagnostic rate could go down to as low as 70%.

So 30% of people are not—

The Chair: But what if they have a tremor and it's an essential tremor, as opposed to Parkinson's? How do you know the difference?

Dr. David Grimes: That's a good question. That's the condition for which I most often say to people, "You came here thinking you might have Parkinson's, but you actually have essential tremor."

The Chair: How do you know that?

Dr. David Grimes: It's based on what the story is and what their findings are. If you haven't seen many people with Parkinson's, and if you haven't seen many people with essential tremor.... It's often not diagnosed correctly.

For a lot of the people who come to see me, when I will tell them, yes, I think they have Parkinson's, they will reply, "Well, okay, my dad had Parkinson's, and my mother has Parkinson's." Then you start asking what their symptoms are. It becomes quite clear that they don't have Parkinson's. They actually have essential tremor. But the family's been walking around thinking that they—

•(0935)

The Chair: So what's the difference? The outside world, when they see you with essential tremor, might think you have Parkinson's.

Dr. David Grimes: Yes.

The Chair: So how do you know the difference? You're the specialist, and we're just trying to find out.

Thank you, Dr. Grimes.

Dr. David Grimes: Well, I guess one of the things is that it certainly takes a while. It takes seeing a lot of people and it takes a lot of training.

The main features are that an essential tremor is a tremor that people have when they do things, whereas the Parkinson's people classically have a rest tremor.

The Chair: What's a "rest" tremor?

Dr. David Grimes: It's when you're just sitting there watching TV, doing nothing, your hands are in your lap, and then your hand is shaking. Essential tremor is much more common. It's when you pick up a pen, go to write, and your hand is shaking.

People with a head tremor most often have essential tremor—that's not a feature of Parkinson's disease—but people with a chin tremor actually have Parkinson's and not essential tremor. There are all these little things that go along with trying to differentiate, but unless you see people with those conditions, it's.... In the medical community, a lot of physicians will get it wrong.

The Chair: Thank you.

I'm sorry...but it was just something you said that I just wanted to find out.

We now have Monsieur Malo.

You're hoping that the chair won't interrupt you, right?

[*Translation*]

Mr. Luc Malo (Verchères—Les Patriotes, BQ): No, but your questions were entirely relevant, Madam Chair.

Madam Chair, I am very happy that you gave us this follow-up on Mr. McGinnis' appearance before the committee. You'll remember that he told us in his testimony just how much his young son didn't want him to testify before the committee because he was worried about his father. I am convinced that, when he saw his father return home with treatment, he must have congratulated him and told him that he had done the right thing by going.

Thank you very much.

[*English*]

The Chair: That's an excellent point. Thank you for sharing that with us.

Mr. Luc Malo: Dr. Grimes....

Are you fine?

Dr. David Grimes: I was just seeing if you were going to continue in French, in which case I would have to put in my earpiece, because my French is terrible.

Mr. Luc Malo: Okay. Put in your earpiece, please.

The Chair: Oh, for Monsieur Malo, I would put in your earpiece.

Voices: Oh, oh!

Dr. David Grimes: Yes, please.

The Chair: He speaks French extremely well.

[*Translation*]

Mr. Luc Malo: I simply wondered about the guidelines that will soon be published.

In particular, will we go into the point that Mr. Sherwood wanted to raise our awareness about, specifically that doctors are more interested in issues related to the collateral, subjective and emotional effects of the illness, in order to get a better handle on everything?

In her testimony, Ms. Squire said that, once the doctor told her that she had Parkinson's, he closed her file and put it away, leaving her to take in this news. That was 16 years ago and, maybe the way of giving the diagnosis has improved, but Mr. Sherwood seemed to say that there was still a lot of work to do in this area. Do the guidelines you've developed address this as well?

[*English*]

Dr. David Grimes: That is a good question. Actually, we broke it down into four different main sections. The first one is on communication. The whole section is on communication and how those in the health care system, whether it be physicians, physiotherapists, or nurses, should be communicating with individuals with Parkinson's, trying to give information that patients want to hear—but not too much information that they don't want to hear—

and trying to make sure that when they do communicate things, they actually give the instructions, writing them down.

Those may be more basic recommendations, but still they're very important recommendations to give better care for individuals with Parkinson's. As I said, we have a whole section on communication.

• (0940)

[*Translation*]

Mr. Luc Malo: Mr. Sherwood, would you like to continue your presentation? I know you still had things to tell us. Perhaps you would like to comment on what Dr. Grimes just said in response to the question you had, about whether this type of guide could be a helpful tool.

[*English*]

Mr. Chris Sherwood: Sorry, I didn't get the English translation initially.

By “problem” you're referring to what?

[*Translation*]

Mr. Luc Malo: In fact, I wasn't speaking about a problem you have, but simply about this question you asked about support relating to the collateral, subjective and emotional effects of the illness on the patient, so that this would be better addressed by the health care team. Dr. Grimes said that there will be an entire chapter on this in the guidelines that are going to be published. Did his answer reassure you and respond to this need that you brought up?

[*English*]

Mr. Chris Sherwood: I would say in response that we have a whole lot of sub-specialists, a whole lot of areas of focus, and they're all neatly packaged in nice boxes. Parkinson's is one area of specialization, and there are a whole lot of others.

I strongly suggest that if the area of hospice palliative care were to integrate with Parkinson's in a more intentional way, the knowledge of both coming together would be very helpful, specifically for Parkinson's. Unfortunately, hospice palliative care has historically been somewhat of a fringe element of health care and has not integrated into the mainstream to the extent that it could. Given that there is a lot of knowledge that Parkinson's as a specialty has about Parkinson's specifically, the area of hospice palliative care that focuses on suffering, relieving suffering, and improving the quality of living and dying has a lot to say that could be very helpful. Just as Parkinson's could inform hospice palliative care, it could be the other way around.

I think it just requires communication between these areas of specialization, taking the experts who exist within both fields and seeing where there's overlap; seeing where there are opportunities for that information to be shared and for people to grow and learn together. I think integrating hospice palliative care professionals into the interdisciplinary teams would be one way, at a clinical level, to see that it happens.

Experientially, people learn better when they learn together and have the ability to mentor each other. You can come in and do an in-service and go through a wonderful education program, but walk out and do nothing to change your practice as a clinician. But when you have people working together, sharing knowledge, and saying, “What about this? What about that?”, then you have the ability to grow together.

I think that's where the opportunity really lies for these two areas to focus on.

The Chair: Thank you, Monsieur Malo.

What wise words those were, Mr. Sherwood. Thank you.

We'll now go to Ms. Leslie.

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

Thanks to all the witnesses for being here today. I've learned a lot.

I have two sets of questions, so I hope to get through both.

The first is about environmental factors. I know that there is an increased rate of Parkinson's—if that's the right terminology—for people who work with pesticides and herbicides. My uncle has Parkinson's and he was a groundskeeper, so he's very sadly one of those statistics.

Dr. Grimes, are environmental factors something you see with your patients? Is there any kind of tracking system, or is it just informal word-of-mouth: “Yes, a lot of the folks who come in my office had this kind of job, or worked in this kind of world”? What are you seeing with environmental factors?

● (0945)

Dr. David Grimes: Environmental factors for decades have been suspected of causing Parkinson's. Scientists have been looking at trying to identify specific environmental toxins we would potentially be exposed to that we can directly link to somebody's Parkinson's. That's proven to be extraordinarily difficult.

For anyone who comes into the clinic, yes, when you hear these stories.... I had a military personnel come to see me. His job for 40 years in the military was to spray pesticides into buildings to get rid of all the different bugs in the building. It really made you think that it's probably what might have triggered his Parkinson's. Is there a way to prove that? The answer is no.

Doing epidemiological studies to identify these links has proven to be extremely difficult. The biggest one, and I think there are still court cases in the United States, is manganese exposure among manganese miners. It looked as if manganese was causing Parkinson's in all of these individuals, and there were big lawsuits and everything. Then it turned out that maybe the epidemiology wasn't as exact as they thought, and maybe the link was not as strong as we thought.

For the individual person, it's very difficult. Yes, there is probably some environmental exposure that somebody's had that might have triggered the process or contributed to the process. But is that the sole cause? Probably not. It's turning into a very difficult thing to study.

Ms. Megan Leslie: Thank you.

My next question is to all of the panellists.

We're legislators, so my great interest is in figuring out what we can do with legislation as it relates to Parkinson's. I'm wondering if you can tell me what your recommendations are. Would it be long-term care or home care?

Ms. Boosamra, you were talking about that. Would it be a pan-Canadian affordable drug strategy? Would it be banning certain chemicals that we have seen linked with Parkinson's?

I'll turn it over to each of you, if you have ideas about what we can do as legislators to assist people with Parkinson's, and caregivers as well.

The Chair: Can we please start with Ms. Squire? Then maybe each individual person could make a comment on that.

Dr. Frances Squire: I'm very encouraged by the new inroads being taken by the national brain strategy and collaborative organizations like that. Different units of interest are coming together and focusing on the brain, and organizations are sharing information.

As a person with Parkinson's, what I'm most interested in seeing is that the research is not isolated in pockets across the country. There is some overarching strategy people can feed into. I need to feel that something is being done collaboratively.

The Chair: Mr. Sherwood.

Mr. Chris Sherwood: I think we need to consider that our system of health care, which has focused largely on curative interventions, needs to focus on caring interventions. What this means at a policy level for people living with progressive illness—and I would say that it definitely impacts Parkinson's but transcends that—is that care requirements need not be something focused on prognostication.

What I mean by that is that when you go into a hospital, everything's free. It's free, because that's acute care. We can pay for that, because we know it's short-term. For people with chronically progressive diseases that result in huge amounts of functional loss over time, where's the equity? What I would suggest is that the volume of care and the focus of that care should be focused largely on function, not on the time you have in an acute-care bed.

Equity means that when you get a lot of services, because you have something that's short-term, and then you get relegated—that's the term I would use—to something more chronically progressive in its focus, such as long-term care, those programs, if that's the emphasis of health care, are going to focus on long-term care as an economy of scale. Put a lot of people in a box, and things get cheaper. What are we going to do with those programs to make sure that they're equipped to focus on the needs of those people?

Policy level means that you have to fund it more. Those people work their tails off, but it's conveyor-belt care: get them up, get them dressed, get them fed, get them back to bed. It's not good enough. I think we need more care, and we need to focus on long-term care, if that's what it's going to be, by changing the focus of those services.

● (0950)

The Chair: Our time is up, but I'm going to extend it. I want everyone to have the chance to answer your question.

Please, Mr. Ireland.

Mr. Bruce Ireland: Thank you, Madam Chair.

There are probably two areas. One is my big bugaboo, and that's research. Currently NHCC is in the process of finalizing a policy proposal for a \$600-million joint public-private partnership. I think coming from the world of the YMCA, partnerships is a very strong component of working together collectively. That partnership would see a five-year partnership building on the private donor investment of \$200 million and proposing the government match the private dollars two to one for a total government investment of \$400 million over five years.

One of the things I've learned from Parkinson Society Canada as I've gone to a couple of research reviews, peer-reviewed by the 15 top scientists across Canada, and have seen all these wonderful proposals from new researchers, thinking about what causes Parkinson's, maybe one of these researchers in fact has the answer. However, as an organization, we at Parkinson's are able to fund probably only about 16 of the 30 that we could have funded this past year.

So we're losing a great big piece there, and I think this is an opportunity for the private sector and the government to work collectively together in a very strong partnership that sends some very strong messages to the Canadian public.

I think the other piece—I think you've heard it a little bit today—is the piece to establish an advisory committee on income reform, reporting to the ministers of finance and human resources and skill development, looking at such things as introducing a refundable disability tax credit for low-income Canadians; allowing spouses to claim the caregiver amount; making employment insurance sickness benefits more flexible to allow people with chronic conditions to work part time—

The Chair: Mr. Ireland, I can't have you go through the whole list, but I think it's very important, so if you could make sure that this list gets to the clerk—

Mr. Bruce Ireland: Absolutely.

The Chair: —then the clerk will make sure it gets to all of us.

I have to go to Ms. Boosamra now.

Mr. Bruce Ireland: Thank you.

Ms. Carmel Boosamra: Thank you once again, Madam Chair.

I have three points, and I say these from my view as a caregiver. I think my pipe dream for Parkinson's, if there is one, is that it be identified as a chronic disease, the same as heart disease, diabetes, and those types of things.

I would like to see more funding for care in the home. My biggest regret is that my husband had to pass away in a nursing home. So I echo Mr. Sherwood's view on that: palliative care in the home is what everyone wants.

I would like to see more opportunities for families to take advantage of respite care. By that I mean respite care where the care home or the care facility is very familiar with Parkinson's disease and the importance of getting medication on time. I know that the few times I took advantage of respite care, I could only equate it to putting your dog in a kennel and when you get your dog back it's a mess, because that's what happened every time my husband went to respite care. His medication was so upset that it took weeks to get it regulated again.

So I think respite care is a big issue, but it needs to be quality respite care.

● (0955)

The Chair: Great. Thank you so much.

Dr. Grimes, did you want to make a comment?

Dr. David Grimes: I will make just a couple of brief comments.

I think you've been hearing that there's no question that Parkinson's is complicated and requires the expertise of a lot of different people, and the clinics that are trying to provide the care are very patchwork in different places. There are not enough clinics, and the overall care we provide could be a lot better if more support and more expertise were involved.

The other point I'd like to make is about research. We have very strong researchers in Canada, both clinical as well as in basic science, and having a mechanism to help support those.... One of the ideas we were looking at is from a clinical research standpoint. No one clinic can test a new drug. So from a Canadian standpoint, is there a way we could look at integrating that so it's more attractive to develop those drugs in Canada?

The Chair: Thank you.

Ms. Leslie, that was lots of time.

Now we'll go to Mr. Brown.

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

Thank you, Mr. Grimes, for treating, as was mentioned, Greg McGinnis last week. He comes from the city of Barrie, which I have the honour of representing, and I know that meant the world to him. So thank you for your support and indulgence of his needs last week.

But I'm sure there are thousands of other individuals like Greg. I know he had his own private drug plan, and Kirsty commented on the extent to which drug plans don't meet the needs of many Parkinson's patients. That's something that we hadn't really heard before last week when it was first brought up to us by Greg.

What sense do you have that this is very common across Canada, and how many people do you think are in the same position as Greg in that their drug plans significantly don't meet their requirements?

The Chair: Dr. Grimes.

Dr. David Grimes: I think it is very common.

Again, it's not uncommon that I see people coming into the clinic and I'm looking at, "Okay, can I add that drug on or can't I?" And maybe I can't: they can't afford it.

In Ottawa I think we're lucky that there are so many government agencies and people here, and I think more people in Ottawa have federal government drug plans. I'm sure that in many parts of the country there are a lot of people who have no private coverage for drugs, so it's even worse. I think the patients I see here are some of the better-off population. As I said, I'm sure there are lots of places in Canada where the private coverage is very much lacking. There are a lot of people who are having to make tough decisions about whether they want to start a drug that we think is the best drug or they want to start with choice C because they can afford it.

That really shouldn't be happening in Canada.

Mr. Patrick Brown: One thing you mentioned, Mr. Ireland, which I found interesting, was that last year you were able to fund only 16 of the 30 new research applications. One thing I've asked every time we've had different disease groups before this committee was how many good ideas are being left off the table. I like to try to put it in a fiscal context to give us an idea of what type of investment is required to really put all our hard energy into this.

For Parkinson's, I understand the CIHR last year invested \$9 million, with \$72 million since the year 2000. So with a \$9 million investment, how many applications do you know that we're able to touch, and what percentage of them do you believe we're not able to get to? Of the ones we're not getting to, is it your sense that there are some very interesting concepts that we're not able to examine?

• (1000)

Mr. Bruce Ireland: From Parkinson Society Canada's peer review process, I would say there were probably 16 different projects that should have been funded, that were rated highly enough by the reviewers. How many of those, in terms of what we left on the table... That's happening every year, so there could be answers in some of those projects. People from across Canada collaborate, and the peer review process is such that we know that those projects, if we had the dollars, would have been funded.

I would say that it's millions of dollars, and I think the proposal of NHCC helps to answer some of those questions. I don't know what the percentage would be overall, but we've listened to the proposals, and it sounds as though—wow—there are some great things here that we could be looking at that we just aren't able to fund.

Mr. Patrick Brown: I heard one statistic last week, which I found interesting, which was that for many people involved in research,

one-half of their time is spent simply on applications. I heard one person mention that 80% of the applications were being turned down because the pot was only so big. I think that's something important for us to get a better handle on.

Is that something you've heard as well, that there's a tremendous amount of time consumed simply by the application process?

Mr. Bruce Ireland: Absolutely. I had the opportunity of visiting one of our smaller researchers at Laval this past summer. I was overwhelmed by the small amount of space, but then we started to talk about the amount of time she spends on this. I would say that well over 80% of her time is spent trying to get applications in for research.

Mr. Patrick Brown: So 80%?

Mr. Bruce Ireland: Absolutely.

Mr. Patrick Brown: It's mind-boggling that the intellectual energy is used on....

Mr. Bruce Ireland: The demands for the applications are very significant. She was on our board for a while. She would come to our board meeting, and she would be up till two or three in the morning writing a proposal that was due the next day or two days from then.

So I would say the amount of time that our researchers spend doing the applications is very significant, when they could be doing a lot more around research.

Mr. Patrick Brown: On that note, I've never heard about the process for putting in an application. You mentioned it's very demanding. Could you share with us why the way it's currently set up is so time-intensive?

Mr. Bruce Ireland: From a Parkinson's perspective, and that's probably the best one I can share with you, the researcher has a time limit in which she or he has to submit the documentation, put it all together, and then our researchers come two at a time to review all these proposals, and they do it on their volunteer time. They review them, then they come together and spend a whole day in Toronto continuing to review them and rating them, and trying to get to where they can at least fund a proportion of them.

Because there are so many applications—and I learned this from the researcher at Laval—they're constantly going after funding because the dollars aren't there unless they get the research funding. The hospitals are taking a large proportion of their dollars in terms of the rent and all those sorts of things, so she spends a lot of time just writing proposals to get the dollars to be able to carry on with her research.

Mr. Patrick Brown: Is there an example you could share with the committee of the type of research project you weren't able to undertake because of all the details?

Mr. Bruce Ireland: I honestly can't help you with that. There are so many of them that it would be difficult. We could probably put one together and give you an idea of the kind of thing we didn't fund, but to answer that question, it would be difficult.

Mr. Patrick Brown: Did you have a comment?

Dr. David Grimes: Yes. We've tried a couple of times to put in...

Parkinson Society Canada is great in terms of trying to fund projects, but the projects they fund are still not considered big projects. You go through \$100,000 pretty quickly when you're trying to do things, when one post-doc is costing you \$45,000 in your lab and you haven't even paid for reagents for them to do any experiments.

I think the success rate last year was 16% or 17% for the bigger projects we look at through the CIHR. Those are 20-page, 30-page applications. We've had a couple of tries at trying to put a Parkinson's one together. It was a big national collaborative effort, and we have not been successful in trying to bring all the different researchers together and trying to come up with a better national effort for bringing all the researchers together.

•(1005)

The Chair: Mr. Brown.

Mr. Patrick Brown: One comment is that the 16% to 17% figure that Dr. Grimes just mentioned is consistent with the 20% figure we heard last week. It would be neat to have CIHR here so we could delve into some of the questions with them.

The Chair: We'll deal with that later. Thank you.

Ms. Squire, you wanted to make a comment. I just wanted to give you a chance to comment to Mr. Brown.

Dr. Frances Squire: I was just going to say that in terms of the research, the applications that were coming forward...

I've lost my thought. I'm sorry.

The Chair: That's okay. Just take your time. I know it's kind of hard; I saw your hand raised, and I knew that the interval of time might be challenging for you.

I think Dr. Grimes was talking about the research and the difficulty of trying to get research accepted. He wanted to connect all the researchers across this country. Then Mr. Brown commented on that and suggested we needed to put another element into our presenters, our witnesses, for another meeting.

I'm trying to give you some connections to maybe help you remember what you were saying. If you remember, let me know, and I'll watch for your hand.

Dr. Frances Squire: All right. Thank you.

The Chair: So if I interrupt other people, you'll know I'm trying to get Ms. Squire's attention.

If you think about it, just raise your hand.

Dr. Frances Squire: Thank you. Okay.

The Chair: I do this all the time, by the way. You might call it Parkinson's, they call it aging.

Voices: Oh, oh!

The Chair: All right, now we'll go to Dr. Duncan.

Ms. Kirsty Duncan: Thanks, Madam Chair.

I'm going to pick up on some of what Mr. Brown has been saying. Over and over we have heard about the importance of research dollars, and perhaps, Mr. Ireland, if you could table the specific "ask" that you're working on, the \$600 million in the private-public partnership, that would be terrific.

Dr. Grimes, if you could describe your ideal research ask, is it to fund multiple centres? Is it to fund new researchers? What would you like to see the funding for?

Dr. David Grimes: In Ottawa we have a lot of very bright basic scientists who have a tendency to want to focus in on the one little aspect they're working on. I think they lose track of what the bigger focus is, and sometimes they lose track of the applicability of what they're doing. So one of the things we've been able to do in Ottawa is to provide seed money for researchers doing other things, and tie them into Parkinson's.

I think one of our ideas on a more national basis is to really try to bring people together who have very good ideas and who are working on very exciting things, and to make sure those things have clinical applicability. It's amazing how many scientists are out there doing a fantastic job in their very small area, while it has much wider applicability than, I think, they currently think it does.

This is one of the areas in which we could do a much better job on a national basis, really bringing more people together to share ideas, to say "You know how to do that. That's fantastic. Could we tap into that? Because I have this idea, and we could use your experiments to help us do this kind of thing." This collaborative effort would speed things up a great deal.

Ms. Kirsty Duncan: So they are multidisciplinary, and they have applicability to the care side.

Do we currently fund multidisciplinary care? Or are you cobbling together money and people to deliver integrated care?

Dr. David Grimes: This meeting that I mentioned earlier on—I try to look at that, and also what all the different specialty clinics are doing in Canada.

Take the clinic in Manitoba. The Manitoba provincial government has said, yes, we'll give you funding to have a more integrated clinic approach. People feed into that. They really have a fantastic set-up and they really do care for a lot of people.

But they're the exception. At most of the clinics it's very cobbled together. I'm scraping money together to keep my nurses funded, so I have no money for anything else in terms of occupational therapists or physiotherapists or speech—all those other things.

So on a national basis, it's very cobbled together. It's kind of all over the place. I think on a national basis, we could do a lot better.

•(1010)

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

Dr. Frances Squire: Thank you. I remembered my point.

Talking about the researchers at Parkinson Society Canada, the money that we can give out for the grants is so limited that we focus on new pilot ideas, small projects that can be funded, so they can then go on to CIHR and the bigger funding institutions.

We have a lot of grants for graduate students to try to get them involved in realizing that Parkinson's research is good for their careers long term. So for pilot projects and graduate students and new researchers, we try to get them involved in Parkinson's. The \$1 million that we have available in the pot to fund Parkinson's research goes largely to those categories.

The Chair: Thank you.

We have Ms. Boosamra.

Ms. Carmel Boosamra: I just wanted to answer your question on "multidisciplinary".

In Ontario, the Minister of Health recently decided that he would no longer fund speech therapy for Parkinson's. I can tell you that speech therapy is important and it goes a long way to ensuring that people living with Parkinson's are able to speak. If they don't have access to speech therapy, their ability to speak is going to be diminished pretty fast.

Right now, the Parkinson Society Ottawa regional office is subsidizing speech therapy for our clientele. We also subsidize and give physiotherapy classes with qualified physiotherapists. I can speak from my own experience as a caregiver trying to get an occupational therapist to come into the home to do an assessment on the safety in the home. That was something I had to pay for out of my own pocket. This is probably true all across Canada.

Ms. Kirsty Duncan: Can I ask a question?

The Chair: Yes, go ahead.

Ms. Kirsty Duncan: Thank you so much for that.

Dr. Grimes, what could we do at the national level to ensure that a family gets all of that support, from swallowing and speaking to moving, and all of the pieces? What could we do?

Dr. David Grimes: I think it really is maybe pointing out that it is definitely a necessity, that it's definitely lacking, and that it could make significant improvements to the quality of care for individuals.

Really, I think having a real drive for having more support services for individuals with chronic diseases is something that.... As I'm sure you've heard, with our aging population, this is something that will be even a bigger problem, and we're just not doing a good enough job of it, as you've heard already.

The Chair: Thank you.

I think Mr. Sherwood would like to make a comment.

Mr. Chris Sherwood: Just in response to your question about multidisciplinary care, I would not focus on terminology too much. There are a lot of multidisciplinary teams, but that doesn't mean that individuals within those teams are working together very well. That's where perhaps, whether you call it interprofessional or interdisciplinary or multidisciplinary, it really doesn't matter.

So it's perhaps a matter of finding ways for those individuals to really communicate well and to collaborate. I think part of the issue

is that when there is one physician, for instance, and I go to visit that one physician in her office, she's one person. And that's part of the lack of support for her. I think it becomes difficult when you feel as if you're working in isolation. That's part of why people shut down emotionally from the suffering of their patients.

If you build supports within the teams where people actually work together and don't bear that burden on their own, then you actually start to build systems and structures that people can work with and help them to respond more effectively to the suffering of their patients, and that involves nursing and all the other groups—OT, PD, and all of that stuff.

Just having them isn't really good enough. Having them, and having systems that allow them to work together—that's part of the solution to the problem.

•(1015)

The Chair: Thank you so very much.

With the committee's permission, before Mr. Brown asks his next question, would you indulge my asking one more question?

Thank you.

Regarding a lot of the things we've talked about today, some are in federal jurisdiction and some in provincial jurisdiction. When you talk about home care and palliative care, those are primarily in provincial jurisdiction.

I just wonder if it wouldn't also be helpful to make sure that everybody makes this type of presentation to the provinces as well. You're talking about connecting the dots and collaborating between federal and provincial jurisdiction. No matter how much we scream and yell, we can't go over those jurisdictions, because you get hit really hard and everything shuts down.

Have you made these presentations in a systematic manner to all of the provinces across our nation? It's a very profound presentation you folks have.

Would anyone like to comment on that?

Mr. Ireland.

Mr. Bruce Ireland: I can certainly talk about Ontario, and I think other regions are certainly working on it. They probably haven't got it to the stage yet where we are, but in Ontario we've had consultations. The Ontario government announced start-up funding for a new Ontario brain institute last week—

The Chair: Wonderful.

Mr. Bruce Ireland: — and our NHCC committee has been working very closely with that.

I think, from the point of view of a Parkinson Society Canada model, we are using that to work with our regional partners from British Columbia to St. John's, Newfoundland, to do the same kinds of things with their provincial governments.

The Chair: Yes. Once you have that one model, if one province does it, it's kind of like a domino effect, I find.

Mr. Bruce Ireland: Absolutely.

The Chair: You know, "You're doing it, and you're real good. Well, we're better. Guess what we're doing?"

Mr. Bruce Ireland: Exactly.

The Chair: It reminds you of school sometimes.

Mr. Bruce Ireland: Absolutely.

The Chair: But good for you.

I just wondered about that.

Now we'll go to Mr. Brown.

Mr. Patrick Brown: One question I'm always interested to ask, and I know there's always a hesitation to be optimistic on this, is what type of progress are we seeing when we look at the money that's been invested? When we go back to our ridings and people ask about government investments, we always hear people wanting to know if these investments are going towards successful causes.

So when we talk about the \$72 million that has been invested since 2000, and if we're going to make a pitch to grow beyond that and make a pitch that we need to see a greater envelope with CIHR, are there examples you can share with us that we can be hopeful there's elementary progress and exciting new ideas? Could you sort of help paint us a positive pitch?

Dr. David Grimes: Yes, I think there are definitely a lot of success stories out there. I still cringe when people say we're going to have a cure for Parkinson's in five or ten years, because nobody knows. Nobody knows which area it's going to come from. I think you have to be very open to different ideas.

If you look at some of the trials that are starting up on different compounds, there's a whole new wave of treatments that are starting to get into clinical trials. I think you heard a little from my colleague Michael Schlossmacher last week about things like alpha-synuclein in the brain. We now have the ability to recognize and identify compounds that will affect alpha-synuclein levels in your brain, so we're now trying them out in people. This is something nobody dreamed of five years ago. If we can give somebody a compound that directly decreases the amount of this abnormal protein that's accumulating in people's brains, is that going to work? Well, it's certainly exciting, but we don't know yet.

I'm doing a clinical trial right now where one line of evidence in some mice identified that it looks like there's a problem with calcium homeostasis, a calcium problem in the main energy cells in the brain. You do a big drug screen because you've identified this brand new pathway, and it turns out there's a blood pressure pill that's already on the market in the United States that affects this very particular receptor. So we're now trying this out on people. Can we change how the energy cells part of the brain are working by giving a compound?

This was only discovered three years ago, and we're already trying it on people, because we now have the technology to screen drugs that are already on the market and see if they already have an effect. Instead of waiting 20 years to go through all the safety data for all the different things that could potentially go wrong with a drug, let's

screen the 10,000 drugs that are already on the market and that might have an affect on this brain process.

There's no question that we're better. There's no question that we have made a lot of improvements. There's no question that we've identified new pathways that we can test new compounds in.

So we're doing a much better job, but as I said, do we have the answer yet? No.

• (1020)

Mr. Patrick Brown: Do you have a comment, Chris?

Mr. Chris Sherwood: Yes, and I hope I'm not taking too much time.

When you ask about "success", I would ask what does success mean? If we think about it in terms of pursuing a cure, that's great—except that, as I always like to say, life is a sexually transmitted disease that ends in death. Everybody is going to die. So what does success mean for somebody living with Parkinson's now, where a cure really may not be an option?

I think that's really part of the answer to your question. Success for them isn't necessarily anything other than being cared for well, and what does that look like? How do you then make sure that the outcomes for someone coming to terms with their dying process, which is what it is, are as good as they could be, and what does that mean for them? Because that is where all of us are going.

What does success mean for those people?

Mr. Patrick Brown: I certainly imagine that success is trying to make that process more bearable for those who are living with Parkinson's, to improve their quality of life.

On that same note, last week when we had Greg McGinnis here, he said his greatest fear wasn't about what he is going through, it's about the fact that he's heard all these stories about how it gets passed down in families and that his son is going to get it. I guess one element of success is that if we invest \$144 million in the next decade instead of \$72 million, can we move the yardstick forward?

On that note, what do we know about the passing down of this disease? Greg mentioned this last week. Is there anything we've learned on that front about it being shared within families?

Dr. David Grimes: I think that's one of the real success stories in Parkinson research. Had you asked a Parkinson doctor 15 years ago if Parkinson's was inherited, they would have said no. At conferences, some of my senior colleagues were laughed at because they suggested there was a strong genetic component to Parkinson's. Now it turns out there are at least eight different genes that we can currently test for that cause Parkinson's disease.

The trouble is that there's a whole bunch of issues there—i.e., who should we test, why should we test it—but there's no question that there are genes that cause Parkinson's disease that we didn't know about. The first one was discovered in 1997, so this is relatively new information.

Mr. Patrick Brown: How was that discovered?

Dr. David Grimes: It was through doing genetic studies in families. This is identifying and narrowing down what the region—

Mr. Patrick Brown: Was that discovered in Canada?

Dr. David Grimes: It was a joint discovery between an Italian group and an American group, who identified the first gene. The second gene, actually, was one called parkin. It just turns out that we hired, here in Ottawa, the researcher who just discovered that.

So this is definitely increasing.

The Chair: Thank you.

Mr. Malo, I'll give you five minutes. We're going to go into committee business at 10:30 a.m.

[*Translation*]

Mr. Luc Malo: Thank you, Madam Chair.

Dr. Grimes, you may continue.

• (1025)

[*English*]

Dr. David Grimes: This whole area of genetic research in Parkinson's is one that, again, we didn't know about 15 years ago. This is where the major strides are being made in terms of developing better models. We need better models in Parkinson's; we can't test everything in people, and using some of these genetic things that we had no idea existed 15 years ago and putting these abnormal genes into mice and in flies and in fish and figuring out what happens to them—this is where we've been making these more recent discoveries. This is where we really have been getting to the point now where we're turning these discoveries into treatments that we're trying in people.

We talked about diagnosis and the struggle for people when they have to see me, whom they've never seen before, and have to rely on me telling them they have Parkinson's, believing what I have to say versus having a test.

Some of the basic research in this whole discussion of biomarkers is one that we desperately need in Parkinson's, but we're definitely making progress. The first gene I mentioned, alpha-synuclein, my colleague has the potential to measure in your blood and spinal fluid. Part of his work is funded by Parkinson Society Canada, and he's looking at can we have a measurement and can we accurately predict who might have Parkinson's and can we use some of these biomarkers and follow progression that we desperately need.

So yes, there are definitely success stories. I'll just maybe tie back to an earlier question. Yes, the Parkinson Society has been key for funding pilot studies. The funding base that Parkinson Society Canada has is relatively small for the amount of work that needs to be done. Researchers apply to Parkinson Society Canada to fund their ideas. The success rate is considered not too bad; you have a 50% success rate. The trouble is going to the next step. I think this is

where the CIHR has run into big trouble; there are so many scientists out there who say, "No, I'm not staying up until 3 o'clock in the morning and writing a proposal to the CIHR when I have a 16% chance of having it funded."

So we have a bunch of great ideas, and we have some pilot money that we can get, but how do we carry those ideas forward? If your success rate is so low, there are a lot of frustrated scientists out there saying, "I'm just not doing this any more. This is crazy."

That's a big problem.

The Chair: You have another minute and a half.

[*Translation*]

Mr. Luc Malo: I would simply like to say that I want to give the witnesses an opportunity to comment further because we have almost reached the end of the committee session.

So I am giving them the floor.

[*English*]

The Chair: Dr. Squire.

Dr. Frances Squire: I would like to talk for a moment about the other side of their research agenda, which is the quality of life research for people living with Parkinson's and their caregivers. I think we are on the cusp of finding out a great deal about depression in Parkinson's and how a person's life can be made better in the time they have left through the arts, music, dance, and drama. Very interesting studies are showing that a person who is severely disabled with Parkinson's, who is given the chance to make music or paint, loses the tremor and can be engaged in that activity.

These are more program ideas and functions that can take place at a local level, but it's important that we not have a picture of a person with Parkinson's in a wheelchair; the person is functioning, and can use perhaps this way of becoming part of society again.

The Chair: Thank you so much.

We want to take the opportunity to thank all our guests for coming. Your testimony is very meaningful, and this committee is extremely interested in everything that you have to say. You make a difference, you make a very big difference, and I want you to know that.

As chair of this committee, I have to deal with some administrative things. I am going to suspend the committee for two minutes, and I must have this committee out of here by 10:45, so I will see that we do that.

We need to attend to that business right away, but thank you so much.

I'll suspend for two minutes so that you'll have an opportunity to leave.

• _____ (Pause) _____

•

• (1030)

The Chair: We shall begin again.

We have one thing that we need to attend to, which is a notice of motion submitted by Kirsty Duncan on November 19.

Would you like to read that into the record?

Ms. Kirsty Duncan: Yes, please. Thank you, Madam Chair.

The motion reads as follows:

That the subcommittee ask Dr. Alain Beaudet to provide, as soon as possible, an update regarding the science of chronic cerebrospinal venous insufficiency; the conclusions of the August 26, 2010, meeting; and the progress of the expert working group to date.

The Chair: Thank you. It is a very good motion.

Do we have some comments on that?

Go ahead, Mr. Brown.

Mr. Patrick Brown: I think that's a no-brainer. Obviously we want to have the CIHR, and I think there's a standing offer. I recall that in the summer they said they'd be willing to come in any time, so let's take them up on it.

I understand they're coming to discuss Alzheimer's already. They're already scheduled, but obviously we want to get their input on the whole matrix that we're studying, so I even wonder if we should add a day and have just a day with the CIHR. If they mean what they said in the summer, they will have no problem with that, because it was their standing offer.

The Chair: Oh, yes, absolutely.

Go ahead, Dr. Duncan.

Ms. Kirsty Duncan: I agree with Mr. Brown. I think it's really important we do this and I'd like to give you my reasons.

We have to look at that decision leading up to the August 26 meeting and at what evidence was weighed, what was included, and what wasn't. I know there was fear of biasing the sample, so they didn't include experts who had actually done the procedure, but we had people who had actively spoken out against it. It was a very limited focus: it was only published papers, and they did not go to the experts. They did not ask for unpublished data. They did not ask how people around the world were doing those procedures, what the safety was, or what the efficacy was.

I think it's important to find out what the doctors doing the follow-up, the neurologists, had to say. There are questions. The MS Society had been asking for \$10 million for clinical trials since the spring and have stopped asking for that. There have since been three international conferences on CCSVI at which a lot of science has been presented. I've been to two of those; I chose not to go to the third because it was a week later. The expert panel is meeting for the first time today.

The last point I want to bring up is that we have got to ask questions regarding follow-up care. This is a real issue. We can't have people coming home and not getting treated. I got an e-mail last night from a mother saying they wouldn't look at her son—and then, after going to the college of physicians, being no further ahead.

Those are my reasons.

• (1035)

The Chair: I think we all agree, and those are very good reasons.

Monsieur Malo.

[*Translation*]

Mr. Luc Malo: Madam Chair, in fact, when we met with Dr. Beaudet and the other witnesses about this, we were certainly told that we would be able to get the minutes of that meeting.

So it seems to me that if we started a meeting at 8:00 a.m., for example, we would have 45 minutes to talk to Dr. Beaudet about this. We would then move on to all the other items on this subcommittee's schedule.

[*English*]

The Chair: Okay.

These are very good discussions. It's a very good motion, in my opinion.

First of all, are we all in favour of passing the motion...?

Yes, Mr. Brown.

Mr. Patrick Brown: Are we limiting this to only asking questions on MS? I'd like to ask questions of CIHR on the five—

The Chair: Can we deal, first of all, with the motion? We can add those others at the end. This is the motion as it stands.

Mr. Patrick Brown: Unless there's a friendly amendment.

The Chair: Could you do a friendly amendment?

Mr. Patrick Brown: That's what I'm asking.

The Chair: Ms. Duncan.

Ms. Kirsty Duncan: I think Mr. Brown is right, maybe we need to do more with CIHR, but I really think we've got to do....

I like Mr. Malo's suggestion of maybe those 45 minutes just on the MS piece, because we've got to follow this.

Is that okay?

The Chair: And then we'll make a motion on the CIHR?

Mr. Patrick Brown: Sure. I just think we need to do both.

The Chair: I absolutely agree. I think everyone does agree.

Let's deal with this motion.

All in agreement with the motion?

(Motion agreed to [See *Minutes of Proceedings*])

The Chair: Great, it's passed.

Can we do something with the CIHR piece now?

Mr. Patrick Brown: I don't have a motion, but is there consensus that we find some time to have the CIHR here alone?

Some hon. members: Agreed.

The Chair: Okay. Great. We've all agreed on that.

Now we have to look at the scheduling.

This is what we've done, so this is a decision we have to make. We have two presentations from Alzheimer's, then we have two presentations from autism, and then we have the break. We are now scheduled on February 1 to go to MS again. That's what our schedule looks like right now. To do anything else we'd have to bump Alzheimer's and autism.

On December 16 we have nothing, though. If we're still here on December 16, we could plug it in on December 16, which is a Thursday. What would you think of that, at 8:45 in the morning?

Mr. Patrick Brown: I can't do Thursdays 9 to 11 a.m.

The Chair: Okay. I know.

We are scheduled for February 1. If we could be patient and do it February 1, we could do it then or we could bump something else. It's really the will of the committee.

Yes.

• (1040)

Ms. Kirsty Duncan: Thank you, Madam Chair.

I'm wondering if we might consider Mr. Malo's recommendation just because, as I said, this expert panel is meeting for the first time today and—

The Chair: Okay, just be precise: when do you want this to happen?

Ms. Kirsty Duncan: Within the next few weeks.

The Chair: Before we break?

Ms. Kirsty Duncan: Absolutely.

The Chair: Why don't we then do one on autism on December 9...? Or maybe we could put this on December 9 instead of autism, then do one autism before we break, and then one later on.

Mr. Patrick Brown: I think Kirsty's suggestion is not to bump anything, it's just to add 45 minutes before.

The Chair: Is that what you're thinking?

Ms. Kirsty Duncan: Yes. I'm okay with that, yes.

The Chair: Okay.

So when would you like it, the 14th of December?

Ms. Kirsty Duncan: The 14th would be ideal.

The Chair: Okay.

Are you all in agreement?

Some hon. members: Agreed.

The Chair: We're going to start at 8 o'clock. Are you all going to be bright-eyed and...?

Mr. Patrick Brown: We want to spend five hours with each other that day, instead of four.

The Chair: You all are going to bring me a Christmas gift, right?

Some hon. members: Oh, oh!

The Chair: Fine wine is on the table.

Ms. Kirsty Duncan: I think you deserve it.

The Chair: Are we being recorded? I hope we're not.

Mr. Luc Malo: We'll have wine at 8 o'clock in the morning. Yes, a good idea.

Some hon. members: Oh, oh!

The Chair: Oh, sure—you're talking to virtually a non-drinker. I'm really going to want wine at 8 o'clock in the morning. You can bring me bottled wine, and I can drink it later.

Ms. Kirsty Duncan: I'm assuming all this is not on the record.

The Chair: On the 14th, then, starting at eight o'clock: are we all in agreement?

Some hon. members: Agreed.

The Chair: There, this is efficient. We will do that, and we will send the new agenda to everybody.

Now we'll have a bit of a break. We have health committee at the far end of the hall, in room C-110.

This is our stem cell meeting. This is a very special one. I guess I have to tell you that one of the doctors coming today is my husband's doctor. It's going to be a little hard for me sometimes today, but he's a real expert. I can't believe he's actually flown in to Winnipeg to give this testimony today. He is a leading expert in cancer all across this country. We were lucky enough that he lives in Winnipeg and he was our doctor. He's very, very good, and I'm hoping that from this presentation we'll have a better understanding of what this stuff is all about.

We'll see you at 11 o'clock. Thank you.

The meeting is adjourned.

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