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Tuesday, December 7, 2010

Chair

Mrs. Joy Smith

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● (0805)

[*English*]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): Good morning, everybody, and welcome. Everybody looks wide awake, so this is a good sign.

Pursuant to Standing Order 108(2), we are doing our study on neurological diseases.

Dr. Beaudet, we want to welcome you.

Dr. Beaudet, as you all know, is from the Canadian Institutes of Health Research.

Doctor, I will give you as long as you need to make your presentation this morning.

Dr. Alain Beaudet (President, Canadian Institutes of Health Research): Thank you, Madam Chair.

I'm pleased to appear before you today in my role as president of the Canadian Institutes of Health Research to provide you with an update on recent activities related to multiple sclerosis research in Canada. This devastating disease affects, as you know, thousands of Canadians. CIHR is committed to fund research that will alleviate the suffering of Canadians with MS and their loved ones.

First, I would like to share with you what CIHR has been doing on the issue of chronic cerebrospinal venous insufficiency and MS during the last three months.

As you may remember, in early September 2010, the Honourable Leona Aglukkaq, Minister of Health, accepted my recommendation that this issue be investigated in a standard scientific step-wise manner, first by determining whether or not there is an increased prevalence of venous malformations and impaired brain venous drainage in patients with MS as compared with healthy controls, and second, should this association be proven to exist, by proceeding with a clinical trial to evaluate the safety and efficacy of Dr. Zamboni's procedure. This position was endorsed by all provincial and territorial ministers at their September meeting in St. John's.

Already, seven studies sponsored by the Canadian and U.S. MS societies have been launched to determine whether there's a link between chronic cerebrospinal venous insufficiency and MS. To monitor the results from these studies, as well as from related studies from around the world on venous anatomy and MS, CIHR has set up a scientific expert working group.

This group is made up of the principal investigators of the seven MS Society-sponsored studies, the scientific leadership of CIHR and U.S., Canadian, and Italian MS societies, and a representative from the provinces and territories. The working group held its first meeting on November 23 in Toronto.

[*Translation*]

At this meeting, members of the Working Group reported on the progress they were making on their initiative, funding for which was provided in June 2010. Six of seven studies have been approved by the ethics committee and the seventh is in the approval stage.

The patient selection process for the trials is going very well, with two studies having already met their patient quota. Judging from the reports I have received, Madam Chair, I can say that stringent protocols are being followed and committee members can be assured of the quality and serious nature of the studies now under way. I am confident that these studies will determine whether or not there is a link between cerebrospinal venous insufficiency and MS and thus help us to decide if clinical trials on the procedure itself should be funded.

The experts did stress, however, that it was important to give researchers all the time they needed to conduct these trials, without putting any undue pressure on them. The Working Group also noted that Dr. Zamboni's proposed treatment wasn't without risk, as evidenced by the growing number of complications reported by Canadian patients after they were treated abroad and following the recent tragic death of one such patient.

Consequently, the experts recommend that all future therapeutic clinical trials include a treatment safety assessment.

[*English*]

The seven projects are progressing at an appropriate pace to meet their targets. The members of the working group agreed to meet next June to review preliminary results, and the MS Society of Canada will be posting summaries of these seven research projects on its website in the new year.

In the meantime, CIHR will continue to work closely with the MS Society of Canada and other stakeholders, such as physician associations, to share research evidence as it becomes available to build greater understanding of this devastating disease.

Patients should be discouraged, however, from seeking treatment abroad until more is known on the safety and efficacy of this treatment. But they should also be made aware that no physician will refuse to see and treat them for complications of a treatment received abroad.

I would also like to inform your committee that I will be providing an update of the working group's first meeting to provincial and territorial deputy ministers of health at their meeting on Thursday of this week in Toronto. This meeting will be a good opportunity for all participants to share information on any new developments with regard to this issue.

In conclusion, I would like to highlight the fact that CIHR is currently funding numerous research projects aimed at better understanding and at eventually developing a treatment for MS. In fact, CIHR has funded approximately $49 million in MS-related research since its inception.

Madam Chair, in closing, let me assure you that CIHR and all researchers involved are working as fast as possible to investigate this issue and provide the best science-based advice possible to patients and their families.

I will be pleased to keep the members of this committee apprised of our progress.

Thank you.

● (0810)

The Chair: Thank you, Dr. Beaudet.

Now we'll go into our seven-minute Q and A, beginning with Dr. Duncan.

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

Thank you for coming, Dr. Beaudet.

Thank you for clarifying that no patient will go without follow-up in this country, because they have been going without. I'm aware of one patient who was denied treatment by four different specialists. So thank you for that reassurance.

Before I begin, could I ask you to table with the committee an agenda from the August 26 meeting, all the papers reviewed and any presentation or notes from it? Thank you.

Could I also ask that you table with the committee the work plan from the expert working group, who the panellists are, the mandate, schedule of meetings, timeline, what evidence will be reviewed to reach a decision about clinical trials—hopefully, a registry—and how much evidence will be necessary to reach a decision to proceed with clinical trials?

Dr. Alain Beaudet: These are very good questions. Actually, they're all the questions that were discussed at the inaugural meeting that was held in November.

Certainly, I will be pleased to post the documents regarding the composition of the committee and a summary of the discussions at our meeting.

It's a very unusual situation. As you know, usually when researchers receive a grant, they do the research, and they're very silent about their progress because there's intellectual property involved, as you know, and there's also competition involved. Don't try to imagine that there's no competition between these groups. They publish the results, and it's only when the results are published that they start talking about it.

We're doing things very differently this time—very differently. We're asking them to share their results at every step along the way and to be totally open about them. I must say, the response has been fantastic. At the end of the meeting, they all agreed that they were a tad reluctant to proceed in that way, but it had been a fantastic day because they actually learned and shared and got ideas that will allow them to go faster.

They also agreed that they would—after what was, as you can imagine, a very long discussion—reveal their results in six months. Why six months? Why not faster? It was because they all felt that there would be so few results before the end of June that it could be misleading. But they felt that at the end of June they'd have a sufficient amount of preliminary data that it will be meaningful.

Now, we're talking about blinded studies that they will agree to "unblind", so they can share. It's a very unusual situation, and we won't be able to share those results with the external world, for intellectual property reasons that you can understand.

The Chair: The time is limited.

Ms. Kirsty Duncan: I'm also concerned that the new expert panel website has been down for a week, and I'm wondering when it will be up and running again.

Dr. Alain Beaudet: I wasn't aware of that. I'll make sure that—

Ms. Kirsty Duncan: Thank you.

Dr. Alain Beaudet: It went up yesterday, I'm told.

Ms. Kirsty Duncan: It didn't, because I checked at about midnight last night.

I would like to know who the Canadian neurologists are on that website, please.

● (0815)

Dr. Alain Beaudet: The Canadian neurologists are basically the researchers who received a grant from the MS Society.

Ms. Kirsty Duncan: Is Dr. Freedman on that list?

Dr. Alain Beaudet: Dr. Brenda Banwell is on that list. She's one of the recipients. They're all the grant recipients.

Ms. Kirsty Duncan: Is Dr. Freedman on the list?

Dr. Alain Beaudet: There's no Dr. Freedman on the list.

Ms. Kirsty Duncan: Thank you.

I am wondering if you will require every member of the new expert panel to declare their conflicts of interest.

Dr. Alain Beaudet: That's a good point. It has been asked and it will be done.

Ms. Kirsty Duncan: That's good, because just as ECTRIMS does, it eliminates the possibility of real or perceived conflicts of interest.

Dr. Alain Beaudet: You're absolutely right. It's an issue that was discussed, and we agreed they would all sign such a declaration of conflict.

Ms. Kirsty Duncan: I really appreciate that.

At the third international scientific conference on CCSVI that I attended—I've attended three of the four, and I didn't attend the fourth because it was a week after the third—we learned that neurologists are admitting that their patients are improving. This is the fundamental question we have.

I'd like to know if you can table with the committee whether we have heard from these neurologists. Have they followed their patients? How have they responded? What if any improvements have they tracked on EDSS scores?

A prominent Canadian neurologist has written that the veins of MS patients are no different from those of anyone else. I would like to know how Dr. Beaudet responds to this, when Dr. Mark Haacke of the U.S. has identified 48 different venous abnormalities of the chest, neck, and spine.

Dr. Alain Beaudet: That's the issue we're facing. There's a lot of anecdotal evidence.

Ms. Kirsty Duncan: No, I've seen the MRI images.

Dr. Alain Beaudet: There's also a neurologist who last week asked me, "What do I tell my patient who says he's really feeling better after the procedure? I've actually seen the EDS score and the NMR, and both have worsened. It's going to be heartbreaking if I tell the patient the truth. What do I do?"

We have to be very careful about the subjective "feeling better" and the objective way.

But let's come back to the veins. The problem is exactly that. On the one hand you have people who say there's a huge difference between patients with MS and healthy subjects. On the other hand you have people who say they're exactly the same and there's no prevalence in MS patients. That's exactly what we're trying to solve. That's what we need to solve.

The Chair: Thank you, Dr. Beaudet.

We'll now go to Mrs. Hughes.

Mrs. Carol Hughes (Algoma—Manitoulin—Kapuskasing, NDP): I'm sorry I missed the beginning of your speech. I would like to have heard a bit more of it. If I'm asking you to repeat, I apologize for that.

Dr. Alain Beaudet: There's no problem.

Mrs. Carol Hughes: You indicate that no one goes without treatment. I'm wondering how you're getting the message out there in the medical field. We want to make sure the message is out there, and we don't want to hear of another case where someone was refused.

My view is that if you're not feeling well, no matter what the reason that may have brought you there.... We could talk about someone who was a drug addict and may have taken drugs. Does it mean that because they took drugs we shouldn't even go there?

How is that message being put out there? Is it something that will be repeated?

Dr. Alain Beaudet: It's an important message. I'm communicating with the heads of the various professional associations and colleges to ensure that the message is sent or transmitted.

It's very interesting that in the working group, most of these researchers are also physicians. They all see patients, they all see patients with MS, and most of the these researchers are linked to major MS clinics in Canada. They're the ones who noted that something had been carried in the press to the effect that they were not seeing patients who were coming back, that they were refusing to see them, and that they didn't treat patients with complications. It's absolutely false. Among these physicians and their colleagues certainly, they haven't heard of anyone refusing to treat a patient.

What has happened, however, and I think we have to be clear about this, is that in some cases patients have come to a doctor and asked for a specific test, by saying, for instance, they believe they have a restenosis and need a venogram to demonstrate it. If the doctor doesn't feel a venogram is warranted, he won't order a venogram and the patient will sometimes complain they didn't get treatment—which wasn't the case. So it's very hard to tell, because it's a "he said, I said" situation.

But it was very clear that these physicians in the working group were very concerned about this issue and asked us to make sure that the message was sent out that there's no patient who will not be seen by a physician, even if they had treatment abroad.

That's what I'm trying to do today, to send this message back to you.

I think it's a very important message.

● (0820)

Mrs. Carol Hughes: Just on that note, are you, or is there a group, working with the provinces on this as well?

Dr. Alain Beaudet: I will inform the deputy ministers of this message on Thursday when I meet with them to debrief them about the working group, because I think it's a key message.

It's one of the key messages. The other one is that it is not a very safe procedure, as we are starting to realize. It's been claimed to be totally safe. It's not as safe as we thought it was, so we have to be careful.

Mrs. Carol Hughes: When you're talking about it not being as safe as you thought it was, which procedure are you talking about?

Dr. Alain Beaudet: The opening of the veins and either the angioplasty or the insertion of a stent.

Mrs. Carol Hughes: So you're saying it's both of them?

Dr. Alain Beaudet: Yes.

Mrs. Carol Hughes: How much has been invested so far in the research?

Dr. Alain Beaudet: At CIHR—and we're certainly not the sole investors in MS research—we've invested $49 million in the past 10 years in MS-related research.

Mrs. Carol Hughes: I understand that, but I'm talking about research on this specific procedure so far.

Dr. Alain Beaudet: Right now, $2.4 million has been the total amount invested by the Canadian and U.S. MS societies in the seven projects looking at the association.

Mrs. Carol Hughes: What is the breakdown of dollars on that? I'm trying to figure out if all of that is administrative or—

Dr. Alain Beaudet: No, no, it's actually to do the research. That money is actually to do the research.

Mrs. Carol Hughes: Are there any patients involved at this point?

Dr. Alain Beaudet: Oh, yes, they're all clinical trials.

Mrs. Carol Hughes: How many?

Dr. Alain Beaudet: There are seven clinical trials going on.

Mrs. Carol Hughes: But how many patients are the trials working with?

Dr. Alain Beaudet: It all depends. We're talking of several hundred patients altogether, for sure. The number of patients varies between the studies.

I couldn't tell you the exact number of patients.

Mrs. Carol Hughes: Have any of those undergone the procedure?

Dr. Alain Beaudet: Let me remind you that the seven studies are meant to demonstrate whether there is an association between venous malformations and venous blood flow in the veins of the neck and MS, that is, whether there is an increased prevalence of that in patients with MS as compared to healthy controls. Basically, with some variations—some are in kids and some are in adults, and there are some variations in the protocols—all of these studies compare a group of MS patients with a group of healthy subjects. They look at the anatomy of the veins and at the blood flow to see whether there is a blockage of the blood flow. It's all done in a blind fashion, so they don't know whether the patient has MS or not. When the study is unblinded, they'll see whether there's a difference in the incidence of the malformations and blood flow in the two groups. That's the principle.

Mrs. Carol Hughes: So no procedure has been done?

Dr. Alain Beaudet: There's a procedure. The procedure is a diagnostic procedure, and that's a very important one because it's another major issue. We really don't know what the best approach is to diagnose this condition. Is it, as Dr. Zamboni claims, ultrasound imaging? Is it venography? Is it nuclear magnetic resonance imaging?

What these projects are doing is comparing the various techniques. Most of them use, as a baseline, the ultrasound approach done by Dr. Zamboni to try to at least reproduce these results. Most of them, actually, have sent their technicians to Buffalo to get the proper training to read these Dopplers in the same way as Zamboni did, and that's their baseline. They're comparing that with venographic studies, and in some cases NMR studies.

We want to establish the best possible approach to diagnose the condition, so when there's a trial in phase two we know exactly what the perfect, true inclusion criterion is and what the standard used in terms of diagnosis will be.

● (0825)

The Chair: Thank you, Dr. Beaudet.

Dr. Alain Beaudet: Sorry, it's a bit technical.

The Chair: That's okay. Don't apologize. This is what you're here for. Thank you so much.

Dr. Carrie.

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

Thank you very much, Dr. Beaudet, for being here today.

As you know, in another life I actually treated people who had MS, and for me and so many people it's about real people, real families. I was wondering if you could take a moment and discuss the importance of ensuring that the science is sound before moving ahead with these clinical trials, and maybe explain to people who might be listening or might read this what the risks are of not waiting for the signs.

Dr. Alain Beaudet: It's very clear. The risk of not waiting for the signs is subjecting patients to a treatment that is not innocuous—and we have proof of this—and that could have a number of complications, without having the proof that we're actually improving their condition. Some of these complications could be serious.

We're talking about blood clotting. We're talking about internal bleeding, because in most of these patients there are thinning agents that are used as drugs before the procedure and after the procedure. In the case of a stent insertion, indeed the safety is probably even less because stents, as you know, are meant for arteries. The wall of the vein is really thinner, and the danger, of course, is that the blood flow is not as rapid and there's a danger of clotting.

All of these things are serious, and we don't have a real appreciation because it's not very common to do angioplasty of veins and to put stents into veins. We don't have a good idea of the incidence of complications and negative events. There's no question that a good clinical trial will have to include, either as a phase one or into the trial, a measurement of the safety component.

Mr. Colin Carrie: All right.

You also mentioned the research associations in your opening statement—and you've been in touch and in good communication with the different associations. I was wondering if you could let the committee know what the positions of the different physician associations, the MS associations, and other stakeholders is on the need.... You mentioned that you're working to try to demonstrate the link between CCSVI and MS before conducting these clinical trials.

What are the experts saying in these different associations?

Dr. Alain Beaudet: By and large, it's really the position of most MS societies. And it is certainly the position of the U.S. and the Canadian MS society. The German MS society had a very harsh statement. On the other hand, the international MS society had a more balanced statement, stating the importance of furthering clinical trials, clinical research, to establish the validity of the procedure.

I think it's important to note that in Italy the MS society is sponsoring a very large study on several thousands of patients, involving a large number of sites in the country, to do exactly what the seven studies are attempting to do here. It's association studies to try to demonstrate whether there's a link between patients with MS and this entity called CCSVI. So we're in contact, and we'll be monitoring the results of that very large study, as we're monitoring the ones from the studies carried out in Canada and the U.S.

Mr. Colin Carrie: Because you mentioned Italy, I was just curious. Dr. Zamboni came up with this procedure, so has he received authorization to proceed with it? If he has not, why hasn't he?

Dr. Alain Beaudet: I think this is an important point. First of all, Dr. Zamboni was originally part of the very large association studies that involved I think around 20 sites in Italy, and he withdrew from the study. The scientific director of the Italian MS Society told us that he withdrew because he asked that all the images from all the sites be vetted by his own laboratory, which obviously the committee didn't feel was appropriate. Dr. Zamboni, however, is also applying for a therapeutic trial, a trial this time to investigate the treatment. As far as I know, the study doesn't have all the funds necessary to be fully carried out. He did receive a bit of money from the province where his lab is, but I don't know about the status of the ethical approval of this study. He was supposed to receive ethical approval at the beginning of December. I don't know whether he did receive it.

Do you know? We don't know.

The last time we spoke to Dr. Battaglia, the scientific director of the Italian MS Society, Dr. Zamboni still hadn't received the ethical approval for his studies. It was pending, and we were told the beginning of December. What we know, however, is that right now the funding from the province that he's receiving for that study is not sufficient to carry out the type of study that would be necessary to prove or disprove the efficacy of the treatment.

● (0830)

Mr. Colin Carrie: Do I have time for a little more here?

The Chair: Yes, you do.

Mr. Colin Carrie: I believe there was a study done in Sweden, and I was wondering if you were familiar with that and are able to elaborate on the process there and the results of that study.

Dr. Alain Beaudet: Yes, there were studies in Sweden and Germany that actually showed very different—as, Kirsty, you know—results from those of Dr. Zamboni. Actually, essentially, they found no difference between the venous anatomy of patients with MS and that of normal controls.

Mr. Colin Carrie: How many people did they do that study on? Do you remember, off the top of your head?

Dr. Alain Beaudet: I don't remember. I don't want to venture a number. I'm not good at remembering numbers. I can't remember my phone number, so I won't go there.

But that's why we're doing these studies. When you have a controversy like this, and you have one group finding one thing and another group finding the other thing, you have to try to devise a very strict protocol. What's really great about these studies is the use of several diagnostic approaches that will be compared to determine whether (a) there's a problem with the anatomy, and (b) there's a problem with the blood flow, and trying to associate that with MS.

The Chair: Thank you, Dr. Beaudet.

We'll now go into our five-minute rounds of questions and answers, beginning with Dr. Duncan.

Ms. Kirsty Duncan: Thank you, Madam Chair.

And thank you to Dr. Beaudet for coming.

I want to pick up on a couple of things. There really has been follow-up missing. I gave one example; I can give many examples of where patient appointments have been cancelled and then they were told they would no longer have their specialist. There have been tests that are repeated every six months for drugs that have been cancelled, and people who have had clotting issues are being refused treatment.

I want to pick up on the expert panel that was talked about for the August 26 decision. If you're going to have an expert panel, I would like to see people who've actually been involved in the imaging and done the procedure be involved. I know there was fear of biasing the sample. Having said that, there were people on that panel who had actively spoken out against the procedure for over six months. We absolutely must have evidence-based medicine here in Canada. We have to. We do need to establish protocols around imaging, whether it's ultrasound, whether it's MRI. We need to know if we are going to be using stents. We need to establish these protocols.

As you know, I have concerns because I do think we're doing replication work, work that's been done elsewhere. If people had gone to the international conferences...Bulgaria, Canada, Italy, Kuwait, and the United States are all presenting the same data. That data is as follows: 87% to 90% of MS patients show one or more venous problems if ultrasound or MRI is used. Now the outlier to that was in Buffalo, and you have to look at those results. How was the study undertaken? Did you have someone who was trained in the operations? They also looked at first-degree relatives, and we know that venous problems may run in families. So there were issues.

Dr. Carrie brought up the Doepp and the Sundström papers. You have to look at the history of that. Those papers were published in six weeks. That's highly unusual in science. Dr. Simka's work out of Poland has done angioplasty on 381 patients, which people would describe as the gold standard; 97.1% showed one or more venous problems.

I'm going to hand that over.

● (0835)

Dr. Alain Beaudet: There are several elements to your questions. I'll try to go through them rapidly.

First, I want to tell you how important it is that MPs care and how important is your statement about the need for evidence-based practice.

Ms. Kirsty Duncan: We have to.

Dr. Alain Beaudet: It's the basis of our medical practice in this country, and at times it's tough to follow. You feel for those patients who have very few options right now. Quite frankly, the last thing I want to do is blame the patients, because I understand that. We have a role to explain to them why we believe they shouldn't go abroad at this point to get a treatment.

I really do believe that the majority of physicians will never refuse to see a patient who is sick and wants to see them, whether they've been—

Ms. Kirsty Duncan: I can give you case after case after case.

Dr. Alain Beaudet: You may well be right, but I can tell you that it's not acceptable; we will not condone it, and we'll try to, as I said, by working with the professional associations and colleges, impress upon these groups the importance that patients are seen and are treated. The only thing I can tell you is that the working group—as I said, most of them were actually physicians—said they would never refuse to see patients, and a lot of their patients had actually undergone treatment abroad. But it's an issue. We don't accept it. We have to try to change that, and there's a message that must be sent.

The other thing is the composition of the August working group. I don't really want to go back to that, but since you bring it up again, our criterion was very simple. We invited physician scientists that were funded either by CIHR or by the U.S. NIH. That was simple, clear. They're all—

The Chair: Thank you, Dr. Beaudet.

We'll now go to Dr. Carrie.

Mr. Colin Carrie: There has been a lot of attention given to chronic cerebrospinal venous insufficiency. I was reading in the paper today—I get up really early, and I'm one of those strange people who actually reads the paper before I get to work—that there is a new drug out, and I believe it's called RXR-gamma.

Could you bring us up to date on what else is going on in MS research around the world?

Dr. Alain Beaudet: Actually, there are several.... An article came out yesterday about another breakthrough study by a British group using stem cells to regenerate myelin on the demyelinated fascicles. There are several drugs in the pipeline. One was recently accepted by Health Canada. We learned at the August conference that there are several others in the pipeline that are being investigated. You never know before the trial is completed whether it will work or not, or how good it will be. But it's not as though there is nothing coming.

So there are two avenues: the pharmacological avenue, on the one hand, and the stem cell avenue. Splendid work on stem cells is done here in Canada by Sam Weiss at the University of Alberta.

Mr. Colin Carrie: I remember that in anatomy class we did a lot of work on the venous system, especially at the base of the skull and the upper part of the spine. What I was told was that there was a lot of "normal variance". I look around this room, and if everyone in this room had these tests....

What's the difference between a normal variant and an abnormality? Do you know?

● (0840)

Dr. Alain Beaudet: That's one of the huge issues.

There are two problems. We didn't worry a lot about the variation in the anatomy of neck veins until this happened. That's one thing. And why didn't we worry? It was because there is a huge redundancy in the number of veins and capacity for drainage, and it's normal. The veins have to be able to drain whether you're sitting, whether you're upside down, or whether you're standing. So the neck vein system has often been referred to as the "delta of the Nile". You can block a number of rivulets, but in the end it drains perfectly. And that's one of the big issues.

So even if there are a number of anatomical differences in patients, we'll have to ensure (a) that these differences are truly, systematically, more numerous than in controls, and (b) that they truly impair drainage. That's why some of the techniques that are going to be used in these seven studies that I keep referring to should give us some information regarding blood flow and the anatomy.

There are also two groups that are doing post-mortem studies on patients to look at the vein anatomy in much greater detail than we've done so far. They will do this by moulding, by injecting silicone into the venous system, by being able to make very accurate measurements. They will be comparing—I can't say healthy controls because it's post-mortem, but comparing normal individuals with people who died from MS.

Mr. Colin Carrie: You mentioned the process you've put in place. Actually, it sounds very impressive. You mentioned how you're getting the researchers together, and you said, "They've learned, they've shared, and they've revealed."

I was wondering, with this new process, this unprecedented research process, how is it going to benefit the MS research community and MS patients?

Dr. Alain Beaudet: It's certainly going to benefit patients. The work is going to go faster as they benefit from one another's experience. I would say that it's a microcosm of what's going on more and more in science. There is always a mix of collaboration and competition, but there is more collaboration as we realize that we're dealing with complex issues, and that we are way better equipped to deal with them if we work together instead of against each other.

The Chair: I'm sorry, we will have to end it there.

Dr. Beaudet, I have to say that it's an honour to have you here on our committee.

Dr. Alain Beaudet: Thank you very much.

The Chair: You know what struck me? It's that the very important work of the subcommittee has brought awareness and is bringing some very good dialogue. It's great to see the different countries doing different studies. Because this is a collaborative medical community or a scientific community, we can actually get the answers that we want rather than the political debates about it.

I think that's what's so important, and I think that's what this committee wants. There are very good questions this morning.

With that, I'm going to suspend for two minutes, and then we'll go into our next segment, which is with the Alzheimer Society.

Dr. Alain Beaudet: Thank you, Madam Chair.

● _____ (Pause) _____ ●

● (0845)

The Chair: Could I ask everyone to please take their places?

Some people are not quite here yet. Sometimes security is a little difficult downstairs, so we might have some people joining us. However, if we don't begin, we won't get through our agenda. So we need to make the decision to begin and get everything on the record.

This is the Alzheimer Society of Canada. We have with us Deborah Benczkowski, the interim chief executive officer. Welcome, Deborah. And Dr. Jack Diamond is the scientific director. He will be here.

A voice: He's here.

The Chair: I was calling you, Dr. Diamond. I'm so glad you arrived.

You know what? I taught school for about 23 years—junior high—and I always made it a point to note the people who.... I'm just teasing you.

● (0850)

Dr. Jack Diamond (Scientific Director, Alzheimer Society of Canada): I went to the ladies' washroom by mistake.

Voices: Oh, oh!

The Chair: That's more information than I need to know, Dr. Diamond.

However, we're really glad you're here. Here I was blaming security for not letting you through.

We also have Jim Mann, member of the board of directors for the Alzheimer Society of Canada. Welcome. I understand we're awaiting Dr. Robert Lester, who will be here in a timely manner.

We have Neurological Health Charities Canada, with Shannon MacDonald, director of policy and partnerships. Welcome. We're very glad you're here today.

We're going to begin with our five- to ten-minute presentations. I'm going to be a little lax on the time, but I will not let you over 10 minutes because we'll run out of time.

We'll start with Deborah Benczkowski. Thank you.

Ms. Deborah Benczkowski (Interim Chief Executive Officer, Alzheimer Society of Canada): Thank you. Good morning.

I'm really pleased to be here, Madam Chair. I want to thank all the members of the committee very much for giving the Alzheimer Society of Canada an opportunity to speak before you today.

Before I begin, I just want to comment that over the last several weeks I've had the distinct pleasure of being here in Ottawa to meet with many members of the House of Commons, including visits I've made recently, along with my colleagues at the Health Charities Coalition of Canada. We had a recent day on the Hill.

We came to Ottawa to discuss with parliamentarians three things of incredible importance to our organizations: one, the need for a national dementia strategy; second, the need for increased funding to the Canadian Institutes of Health Research; and third, to discuss specific improvements to income health security. All are of extreme importance to caregivers who are caring for people with dementia.

Overall, I've been very encouraged by the reception that we've had here in Ottawa that we've received to our petitions. I hope the work of this committee and the work of members of Parliament—mostly all of you around this table—will result in real benefit to Canadians who are affected by neurological diseases.

Alzheimer's disease is not a disease that we can ignore. It has an overwhelming impact on those people who develop it and also on the families who care for them. There is a good chance that one of you in this room knows somebody with Alzheimer's disease or a related dementia. Some of you may have been affected by it, be it a friend, a relative, a colleague, or someone you work with. Alzheimer's disease affects more and more of us every year, and the number of cases continues to rise with our aging population.

Alzheimer's is a form of dementia with no known cause and no known cure. It's a fatal disease; it's terminal. People can live with it for five to seven years after their diagnosis. It's also a degenerative disease, which robs people of their intellect, identity, independence, and dignity.

Right now we know that there are currently 500,000 people in Canada who have Alzheimer's disease or a related dementia. We know that this will more than double within a generation, so we're looking forward to 2038.

While there's still much unknown about the disease, we have learned that Alzheimer's disease results in a progressive decline in multiple areas of function. These areas of function include memory, but also reasoning, communication skills, and the skills that people need to carry on their everyday activities. Alongside this decline, unfortunately, many individuals develop psychological symptoms, including depression and changes in mood and behaviour, which can significantly complicate the kind of care they need.

While the number of people affected by dementia in Canada and the associated costs in dealing with this disease are daunting, the impact on those with the illness as well as their families is quite profound.

In our view, Alzheimer's disease and other forms of dementia should no longer be misconstrued as inevitable consequences of aging, nor can it be acceptable any more to pretend that there's nothing we can do about it.

Alzheimer's disease presents a huge challenge to society, both now and will increasingly in the future. Through the Alzheimer Society's study, *Rising Tide*—which I hope you've all had the opportunity to have a look at, and if not, we'll be sending it to you—we know that dementia imposes a cost of $15 billion a year today, but within a generation and without concerted government action, the costs will climb to over $150 billion a year.

I know that you, at this committee, have already heard that people who are caring for someone with dementia will experience the challenges associated with the disease in their own unique way. I've heard it said that if you know a person with dementia, that's all you do: you know one person with dementia.

It is important to recognize that there are many different approaches to supporting someone with the disease, and caregivers often need to explore a variety of techniques and strategies to determine what works best for them. Everyone is unique.

The cumulative opportunity cost of informal caregiving for people with dementia represents a substantial cost to our economy. As you've already heard, this burden is not unique to the families of people with dementia. People with Parkinson's disease, multiple sclerosis, amyotrophic lateral sclerosis, and other neurological conditions also require tremendous support from family members and other informal caregivers. This, of course, translates into a huge economic cost for caregivers.

● (0855)

To address these problems, the Alzheimer Society is calling for a national strategy to address all neurological conditions. In public policy terms, it seems to us that Alzheimer's disease, along with many of these other neurological conditions, has been largely ignored by policy makers in Ottawa. Today, there is no national or federal strategy for Alzheimer's disease, and the federal programs, research funding, support, and income assistance pale in comparison to the enormous and rapidly escalating health, economic, and social costs and impacts of this devastating disease.

I congratulate all members of the committee for your study on the state of research and the impact that neurological conditions have on Canadian families. The Alzheimer Society urges you to recommend a national brain strategy, a coordinated approach to assisting all those who are living with brain conditions, in your report to the health committee.

We at the Alzheimer Society have been working together and collaborating with Neurological Health Charities Canada, the NHCC, and its members, who I believe are now up to 24.

The aim of a national brain strategy in Canada is to ensure that significant improvements are made to research, prevention, and support services. The simple goal of a brain strategy should be to create a catalyst for change in the way that people with neurological conditions are viewed and cared for in Canada.

We have been told by politicians that there is no appetite for another national health-related strategy. However, we know that national strategies have been hugely successful and have been developed for a long list of other health issues, many of which have a lesser impact on Canadians' health than neurological conditions do.

We know that a rising tide is coming. We know that the need to act is now. The need for a national brain strategy will never be more important nor more urgent than it is at the present time.

Thank you.

The Chair: Thank you so much.

We'll go to Dr. Jack Diamond.

Dr. Jack Diamond: Thank you. I'm very pleased to be here.

My ultimate endeavour is to make you join us in thinking this is the right time to put more money into research. My specialty is taking the mystique out of mystical things, and if you don't mind, I'm going to do this with Alzheimer's disease.

I will remind you that 100 years ago, Dr. Alzheimer had a patient with what was then called senile dementia. It was later called Alzheimer's disease. She was only 49, by the way, and when she died a few years later, he did something that was relatively unprecedented at that time; he looked at her brain in the microscope and he saw things he did not see in the normal brain. It was as if you'd taken a pot of pepper and shook it all through the brain. You had all these little dots that you saw in the microscope, and he called them the “plaques”. Then he looked inside the nerve cells, which you also can't see by eye but you can see in the microscope. They were as if you had a ball of wool inside that started to unravel, which he cleverly called “tangles”. The plaques and the tangles that he described are often called the hallmarks of Alzheimer's disease.

Since then, in that 100 years, we've discovered that the plaques, first of all, are made of a protein. It's called beta amyloid—it doesn't matter whether you remember the name or not—and it's a normal protein. We all have it in our brains, but in Alzheimer's disease the concentration of this protein goes up, and as it goes up, the molecules start to stick together until enough of them stick together and they deposit down as a plaque. The tangles he saw in the nerve cells tend to come afterwards. Finally, it was discovered that the real toxicity that was going on was not due to the plaques as such but due to the molecules even before they had stuck together and formed the plaques. In fact, as they start sticking together, they become toxic.

I hope this background will allow you to understand why research has had one primary objective in Alzheimer's disease, and that is to get rid of this suspect protein, this amyloid that accumulates. If you get rid of that, you won't get the toxic effect on the nerve cells, you won't get the tangles, the nerve cells won't get sick and die, and we won't get the dementia.

That's what the dementia and the brain has been all about in Alzheimer's disease, until the last year and a half to two years. We're at a crossroads now. I'll explain this by telling you about two or three phenomena, and you'll see immediately what the point is.

First of all, they looked at a lot of very old people, people in their nineties and hundreds, who did not have a dementia. They did not have a dementia, but they looked at their brains and they were full of plaques and tangles. If a pathologist had looked at their brain, he would have said they had Alzheimer's disease. Well, they had Alzheimer's disease of the brain, but they didn't have a dementia. The dementia is what we're concerned with—the sort that Debbie just spoke about. That's what we're worried about: the dementia. I don't care what's in my brain as long as I don't have a dementia.

The second observation comes from 10 years ago. One way to get rid of this suspect protein was to make a vaccine against it. A vaccine, essentially, is to create antibodies in the body. They circulate in the body. They recognize the dangerous molecule or virus, or whatever it is you're trying to get rid of. They neutralize it and then the cells of the immune system carry off the neutralized product.

So they made a vaccine. The vaccine worked well on animal models, so they tried it on humans. They ran it for two years, and then some of the people started to get a potentially lethal inflammation of the brain. All over the world the vaccine studies were stopped. But the people didn't die; they continued on. Then some of them started to die, and when they looked into their brains, the vaccine had worked. The plaques had virtually disappeared. To all intents and purposes, they'd cured Alzheimer's disease, but the dementia was unchanged.

There are more and more examples where we're seeing that these classical signs of Alzheimer's disease in the brain don't necessarily match up to the thing we're worried about, which is the dementia. Although this sounds very dismaying, we have now realized there were three or four other things that Alzheimer didn't see in the brain that were looked at—some people have always worked on them—which are also characteristic of Alzheimer's disease, but they haven't been the primary target of the research. Now they're coming into focus as what should be a very urgent target for research, not just to get rid of this amyloid, which has driven the research, as I say, for the last 10 years, but to attack these other areas.

To give you just one example of these other areas, for every nerve cell in your brain, there are 10 cells called glia cells; I call them the caregiver cells. They are the cells with all the intelligence in the brain. The nerve cells are kind of dummies, really; they can't do much at all. Compared to a skin cell, a nerve cell is a real idiot. But the reason it does so well is because of these caregiving cells. They tell it everything. They tell it to grow, they tell it to stop growing, they tell it to make branches, they tell it to make new connections.

● (0900)

So the glia are really the bright guys in the brain, and it's now been discovered that they are impaired in Alzheimer's. If they were the primary target of the disease, you can understand why the nerve cells get sick and die. This is just one example of a new approach to research, and it's very exciting.

Now in the Alzheimer Society, one of our main thrusts is to produce the researchers of tomorrow. We have a very active training program. Those researchers are absolutely primed now to begin their careers with this new thrust into Alzheimer's research, which I believe is going to produce the cure—along with the original thrust. But of course we can't do it unless they have the money to do the research.

Right now, 40% of 100 hundred applicants to most agencies get funded—although the agencies would like to fund the other 60%. It happens with us; it happens with CIHR. That's where we need it.

And they're young, they're ready to go, they're bursting with enthusiasm, and they're dedicated to Alzheimer's research—but they can't get the money.

I think I'll leave you with that thought as to how we can really combat this disease by just injecting money into the research.

● (0905)

The Chair: So you'll leave us with that thought, Dr. Diamond.

Dr. Jack Diamond: Yes.

The Chair: That's a rather profound thought. Thank you.

By the way, Dr. Diamond, I said so because it was just a delightful way you described it. You really walked us through the brain in a way that we could all understand and relate to. So thank you. It gives us a clear understanding of what's going on, and we appreciate that.

Now, we'll go to Mr. Jim Mann, a member of the board of directors.

Mr. Jim Mann (Member, Board of Directors, Alzheimer Society of Canada): Thank you, Madam Chair and members of this subcommittee, for holding hearings on this important topic, Alzheimer's and dementia.

With the increasing prevalence of dementia in Canada and the impact on families, employers, and the economy, as detailed in the *Rising Tide* report, this event is very timely. The numbers are staggering, but so is the disease to each person. I know this because I have Alzheimer's. I was 58 years old when I was officially diagnosed.

Today I appreciate this opportunity to personalize the disease, to put a face to the name “Alzheimer”, and to shatter the stereotype of a person with Alzheimer's. You know it, the image that comes to mind when you hear that a person has Alzheimer's. For many, it conjures up a vision of a person in the final stages of final disease, and probably that person would be well into their eighties. Well, I read about a woman in Canada being recently diagnosed with Alzheimer's at the age of 39. I dare say that stereotypical person with Alzheimer's is not an accurate reflection.

But let me personalize this discussion and tell you a bit about my story. My new world of reality started in February 2007, when my doctor informed me that I have Alzheimer's. That was the official date of this journey. But there were clues much earlier.

Could my symptoms have been as early as the early 1990s while working here in Ottawa? I will never know for sure, but I recall a few occasions when I would be speaking with a member of Parliament only to realize that I could no longer remember his name or his party affiliation. I would be frantic as I scanned the office for clues to the person's identity, but found none. Where was the picture of that member with his leader when I needed it? Needless to say, the meeting would not last as long as planned, and I'm sure the impression left would be less than favourable.

But I continued. I retired, and with my wife, who is with me here today, returned to my hometown of Vancouver and set up my company. And still there were more clues. As for about the three years prior to my diagnosis, I did no business and made no money, which is not a good economic model to follow. In fact, a year or two before my diagnosis, I said to my doctor as I was leaving his office that we needed to talk about my memory problems. We didn't, until I forced myself to confront the reality—the stark reality, as when standing in the middle of a regional airport and feeling as I did on my first day of school: I was so confused, I almost cried. Or as when getting into the car and a minute later not remembering where I was headed or why; sometimes I would have to pull over just to get my bearings.

Hopefully you get the sense that these memory lapses were affecting my daily living. They weren't momentary "where are my glasses?" or "where did I put my keys?" events; these were profound, and they were scaring me. That is what finally took me to my doctor's office and to the official start of this dementia journey, this three-year-plus journey—a journey that is not a vacation, believe me.

I have been asked, why worry about getting a diagnosis when there is no cure? It's because getting it lets me plan for the future while I can still have a say in my future. It's all about being proactive and being in control. An early diagnosis of Alzheimer's or related dementia can offer early treatment that may stabilize or slow the rate of decline. You get a chance to be educated on the disease and to learn, for example, that socialization and physical activity such as walking are excellent programs.

So how have I adapted? First of all, the reminders are daily. I become disoriented in my own neighbourhood of 17 years while walking my dog and periodically find myself on a route I had not planned to take. After the first time, I registered immediately with the Safely Home program offered through the Alzheimer Society. For a person who loved business and the accompanying stimulation, and who thrived in that environment, I am now very limited in my daily activities. Is that frustrating? You bet it is.

● (0910)

My company, after 14 years of operation, has been officially dissolved, as paid work is no longer feasible. I only use the stove when my wife is around. I no longer drive a car. I write notes for everything. I take notes on the bus with me to remind me where to get off, and then I have a note for what my tasks are when I reach my destination. Otherwise, life continues, and I try to stay active.

I volunteer as a board member with the Alzheimer Society of Canada as well as the provincial society of British Columbia, and I have returned to my first love, advocacy. I advocate to educate, as today at this hearing or with the person sitting next to me on the bus or the airplane. I only need a minute to take advantage of what I call "teachable moments". Through this short interaction, the person will learn that a person with Alzheimer's or a related dementia has a contribution to make and that Alzheimer's is not an old person's disease.

By telling my story and recounting my personal experiences, I hope people will see a new picture of a person with dementia. Perhaps, too, that lesson will be passed on to others.

I appreciate this opportunity to give you a glimpse into my world of Alzheimer's and to let me take advantage of another teachable moment.

The Chair: Thank you very much, Mr. Mann. Indeed, it is a very teachable moment. I'm wondering how many people experience these kinds of situations and aren't courageous enough or brave enough to take the steps that you take to take control of your future. I think what you've said here at this committee is of paramount importance to all of us, because you never know which one of us will be the next person to have those kinds of experiences. Thank you.

Now we'll go on to Dr. Robert Lester, please.

Dr. Robert Lester (As an Individual): Good morning. Thank you very much for inviting me.

I'm going to be echoing many of the things I've just heard. Interestingly, I will also refer to this as a journey, and I've written something I've called *A Journey into Dementia—The Absence of Presence*. Let me introduce myself. I'm a professor emeritus of medicine at the University of Toronto. Until recently, I was executive vice-president and chief medical executive at Sunnybrook, and currently I'm a consultant with the Ontario Hospital Association. I only mention this to illustrate that no matter how easily one can access clinical or research expertise, there really is very little help in terms of navigating this journey.

My interest in dementia was triggered by my wife's development of advanced frontotemporal dementia. I feel that my experience of over 45 years in health care, together with my experience as a caregiver, has equipped me to address you today.

As you may have heard, Alzheimer's disease represents only one form of dementia. All forms of dementia are diseases of the brain. As you have heard, they are not a normal part of aging, and no one is immune. My wife was diagnosed at 62, and as I think back, the process likely started in her mid 50s. Dementia erases memory, alters personality, steals the ability to think, and makes simple daily tasks such as eating or getting dressed impossible. It robs independence and eventually takes life.

Judy, who just turned 70, is currently confined to a wheelchair, is incontinent, is unable to speak, has to be fed, and does not recognize me, her children, or her grandchildren. I always thought the worst thing in life would be losing a loved one to cancer or heart disease. I now realize that as painful as that must be, there is an end and to some degree life can go on. For me, watching Judy deteriorate slowly over several years seems so much worse. Death seems to be occurring in an incremental fashion.

Perhaps the only good thing is that I believe and fervently hope she is unaware of what is happening to her. Yet in some way I pray that she feels comforted by my touch and the love that surrounds her. As difficult as it is, it is important for us to remember the Judy she was: wife, mother, friend, successful professional. We have strived to respect her for both who she was and, importantly, who she is now.

As you've just heard, the scary part is that the prevalence of dementia is increasing at an alarming rate. As the prevalence grows, so does the community of families and caregivers who look after loved ones. For every person with dementia, 10 to 12 others are directly affected.

With the increasing incidence, it is likely that each of you in this room will be touched by this disease. You will develop dementia, or a close family member will, your spouse or your parent. Caregiving is a critical issue for people living with loved ones suffering from dementia. Family caregivers are the invisible and hidden backbone of the health and long-term care system in Canada, contributing over $5 billion of unpaid care. Caring for someone with dementia is difficult and distressing and it often leads to financial, mental, and physical health problems, further taxing the social and health care systems. It currently is costing me approximately $70,000 per year to provide the care that I believe my wife deserves.

Let me give you another example. My wife is currently in a world-class, long-term care facility. Nevertheless, the vast majority of their clients have either family or private caregivers to support the limited number of staff necessitated by budgetary constraints. I recently spoke to another husband who comes in several hours every day to look after his wife. With tears in his eyes, he said he realized his obligation, but the days were getting longer and he was getting so tired. His comments reinforced for me the tremendous burden that many family member caregivers suffer. Paralleling the three stages of dementia, three stages of caregiving have been identified. The early stage is a time of surprise, fear, denial, confusion, and sadness. In the middle stage, caregivers experience frustration, guilt, and resentment. By the late stages of caregiving, there is sadness, guilt, regrets, relief, solace, and eventually closure.

For my part, my immediate reaction to Judy's diagnosis was denial. This could not be happening to us. Judy was so bright and vibrant. Certainly she would not progress in a way that would affect our lives for many years to come. I was wrong. As her disease progressed, denial was replaced with anger. All those years of work and planning for retirement, our trips, our sharing getting old together, our enjoyment of our children and grandchildren, all going up in smoke.

● (0915)

As the Judy I knew is now gradually but inexorably disappearing, despair and sadness have supplanted anger. More recently, I have been introduced to a concept known as ambiguous loss. Although all losses are touched with ambiguity, those who suffer ambiguous loss, a loss without finality or resolution, bear a particular and challenging burden. Such ambiguous loss can occur in dementia that takes a loved one's mind or memory away. The person you care about is physically present but emotionally and cognitively missing. As there is no end to ambiguous loss, it freezes the grief process and prevents closure. It tends to paralyze functioning. Tensions build up as those of us who are experiencing ambiguous loss can be filled with conflicting thoughts and feelings as well as guilt. We may dread the death of a loved one who is hopelessly ill while at the same time longing for closure and an end to waiting. We can be both angry and sad—angry at the demands of caregiving while at the same time sad because we are losing a loved one. Of all losses experienced in personal relationships, ambiguous loss, to me, is the most devastating because it remains unclear and indeterminate.

Dementia is more than an important health concern. It has the potential to overwhelm our health care system if fundamental changes are not made in research funding and care delivery. Delaying the onset of symptoms of dementia by only five years could, over time, decrease by 50% the number of people with more advanced diseases requiring complex community or institutional care. The savings of health care dollars would be huge. Is there another disease where the investment in research, health promotion, early detection, and intervention could have a greater payback to society?

I believe I was asked to make a few recommendations, so let me do that at this time.

Number one is the one you've already heard, which is to ramp up research spending to a level that is at least commensurate with the scale of the disease. It has been estimated that this would involve a 15 times increase to match research in heart disease and a 30 times increase to match cancer research. We need to identify people at risk and introduce interventions before they are symptomatic and experiencing brain cell deaths. We can't do this without a massive concerted effort on the research front.

Patients, especially chronically ill patients, such as patients with dementia, are journeying through very complex care systems, and we too often drop the ball. Hand-offs do not go well. Patients get confused. We get confused. Systems are not modernized. To me, the hallmarks of the care system that we need are integration, cooperation, and seamlessness. Unfortunately, they are not present and will require change.

Some of the things one could look at include increasing or redistributing resources to increase the number of long-term care beds, to relieve the alternative level of care problem in acute care hospitals that allow both patients in acute care and long-term care to receive appropriate treatment in the appropriate setting; assigning case managers to people with dementia to help them navigate the complex health care system we have; improving education of primary care providers in the public regarding the signs of dementia and the need for early diagnosis and intervention; enhancing programs that bring people to care, such as adult day programs; enhancing programs that bring care to people, such as Meals on Wheels, transportation to appointments, assistance in shopping, assistance in care for their homes, supportive housing; protecting and supporting caregivers, recognizing the importance of their role, both in terms of keeping families intact and in terms of reducing reliance on the public health care system; giving caregivers the tools they need, knowledge and training, and protecting them from poverty and giving them a break from time to time, so they can stay engaged without falling apart themselves; and finally, improving the quality of lives of people living in long-term care homes.

Thank you very much for listening to my presentation.

● (0920)

The Chair: Thank you very much for coming today, Dr. Lester, because that was a very profound presentation, a very real-world presentation that many people, unfortunately, have experienced. It was very direct and truthful. So thank you so much. I appreciate that.

We'll now go to Shannon MacDonald, director of policy and partnerships for Neurological Health Charities of Canada.

Ms. Shannon MacDonald (Director, Policy and Partnerships, Neurological Health Charities Canada): Thank you, Madam Chair.

I'm delighted to be with you today. I was joking earlier that it's nice to be invited up to the big table, because I've had the pleasure and privilege of observing some of your hearings and have been very moved and compelled by much of what you've heard.

I'm honoured to work on behalf of Canadians living with neurological conditions and their families. I know that members of this subcommittee really appreciate the weight of the phrase “and their families”. You've heard compelling testimony to the fact that the population impacted by neurological conditions is far greater than the five million Canadians who are actually diagnosed with a condition. Bob, this morning, has referred to ten to twelve people affected for every one person with dementia. And I don't think I'll ever get Greg McGinnis' story out of my mind. Nor do I want to.

As the NHCC lead, I also have the pleasure of co-chairing the implementation committee for the national population health study of neurological conditions. I work in partnership with the federal health portfolio and my co-chair, who's the director of chronic disease at the Public Health Agency of Canada.

I'm pleased to report to the subcommittee that the study is well under way. It will ultimately consist of survey elements led by the Public Health Agency; up to 13 research projects led by pan-Canadian teams right across the country; community-building and knowledge exchange led by the NHCC; and economic costing and micro-simulation work that will come together in the final phase of the study, which concludes in 2013.

I have provided you with a couple of copies of the newsletter *Brain Matters*. This is a communication piece we put out specifically about the national population health study. Some of you will have seen it previously, when it was originally circulated.

Given the testimony the subcommittee has heard to date, I thought the most value I might contribute to your study would be to share information about the NHCC's vision of a national brain strategy. I know that the concept has been raised this morning, but it has also come up in some of your other hearings. I thought it would be helpful to talk about what it could entail.

Neurological Health Charities Canada, as you know, is a growing coalition of health charities, each with a particular interest in one or more neurological conditions. We began in 2008 with just 12 members. I believe that Madam Chair was kind enough to share some remarks at the launch of the coalition that took place on Parliament Hill in June 2008.

From 12 members just two and a half years ago, we have grown to 24, with the vast majority of our membership providing service and support directly to individuals and families living with a neurological condition, and many, if not most, organizations funding innovative biomedical, clinical, and population health research.

The coalition came together with two primary objectives. The first was to generate support for a national population study, because we simply do not understand the picture of neurological conditions in Canada. I know that's part of your work and some of what you're working to uncover. We simply haven't been tracking or monitoring data that would tell us the full story.

The second objective was to really sincerely address key issues facing Canadians living with neurological conditions and thereby address some very significant issues facing Canada overall.

Our organizing principle was simple: we focus on needs, not diagnosis. We learned quickly that regardless of the condition or the name of the diagnosis, people with neurological conditions experience remarkably similar situations and needs. I know that you've heard this from other witnesses, and I'm confident that if you had all 24 organizations represented here today you would hear the same message, whether they were talking about people living with Huntington's, dystonia, epilepsy, a brain injury, or any other neurological condition.

From this position of common need, we developed the document you have before you, entitled *A Brain Strategy for Canada*. This document identifies seven themes that make up the framework the NHCC proposes for a national brain strategy. The issues are ones you've heard all around this table: research, prevention, integrated care and support, caregiver support, income security, genetic privacy, and public education and awareness. These themes are unanimously supported by the NHCC membership.

People are often surprised that we have been able to build such strong consensus, when you consider the number of organizations involved and the number of stakeholders represented. But I can tell you that the NHCC membership unequivocally agrees that these are the areas we must work on together to make a difference to people living with all neurological conditions in Canada.

Let me be clear: we must work together. This work requires the collective commitment of health charities, industry, and governments at all levels.

● (0925)

Having said that, I recognize that this subcommittee has a particular interest in what the Government of Canada might contribute to the process. We believe the Government of Canada is in the unique position to lead in four important ways: first and foremost, by acknowledging and recognizing the brain as one of Canada's most important health, economic, and social drivers; second, by investing appropriately in brain research, given the significant population affected, the massive impact that you've heard about, and the NHCC will be coming forward to the government with a proposal for a five-year public-private partnership that builds on the annual investment of donor dollars that the NHCC members currently make in neuroscience research; third, we believe the Government of Canada can demonstrate leadership by raising these issues at the appropriate federal, provincial, and territorial tables, starting with health, human resources and skills development, and finance; and fourth, we believe the government has a role to play in bringing constituents together to work on what's possible, including the health charities' industry and all levels of government.

By recognizing that provinces and territories will play an important role in any brain strategy that has a national scale, the NHCC has been working with the Ontario Ministry of Health and Long-Term Care to develop the foundation for an Ontario brain strategy that might inform a larger national project. Our hope is that this work will demonstrate the role that provinces and territories can play, in alignment with and as part of a national strategy.

In closing, I'd like to suggest that we think about a national brain strategy in a new way. As Debbie has mentioned earlier, the default position seems to be focused on cost containment and the very real need to control expenditures in an incredibly difficult economic environment. But this is more than a cost issue, and I'd like to suggest that we start talking about a brain strategy as an innovation, inclusion, and prosperity strategy. Generating knowledge, maximizing brain power, enabling independence and productivity, educating Canadians to be well, to be inclusive, and to be supportive of one another—that's what I think about when I think about a national brain strategy. It's fresh, it's emergent, it's collaborative, and it holds real potential for transformative change.

The NHCC envisions a comprehensive strategic approach that connects the collective pool of work, builds on existing programs and investments, and calls on elected representatives from all parties to work collaboratively to develop a brain strategy for Canada.

On behalf of the NHCC and all of our members that you haven't been able to hear from, thank you for your interest, for your sincere commitment to making a difference, and for the opportunity to speak with you today. I look forward to your questions.

● (0930)

The Chair: Thank you very much.

We'll now go to our seven-minute Q and A round, and we'll start with Dr. Duncan.

Ms. Kirsty Duncan: Thank you, Madam Chair.

And thank you to all of you. Thank you for saying we need to focus on the needs, not diagnosis, and hopefully this committee will address those needs. I want to thank all of you for your science, your humanity, your caring, and your recommendations.

I had the privilege of hearing Mr. Mann before, and to hear you again—your comments touch deeply and profoundly.

And Dr. Lester, thank you for making this human.

I'm going to start with research today.

Dr. Diamond, could you comment on whether the current funding environment supports large teams of multidisciplinary research, and if not, what recommendations you would make to address this?

Dr. Jack Diamond: This is a recurrent theme as to how much we should support collaborative, large team efforts versus the usual, which we see in our universities and institutions, which is two or three, at most, people collaborating together. The large one, in principle, is an excellent idea. It can take a theme, which can be broader than one person or two people can handle, and it brings in a number of disciplines to attack one problem.

In Canada we have a special problem that makes this a bit more difficult to achieve, and that is that we have relatively few laboratories. It would be very easy, if we were not careful in organizing our large teams, to find that we were putting all the strength into three or four institutions in Canada; the smaller players, so to speak, would lose out. In principle, it's an excellent idea, but it has to be carefully achieved so that we don't lose the impact that the outriders can give. When I mentioned the four things that we now realize we had ignored, that's exactly the sort of thing that has happened as a consequence of the focus. So I'm not against large teams, and obviously they can do things that small teams can't, but I just ask that it be treated with some caution, because if all the money goes into the large ones, the small ones disappear.

And interestingly, so many breakthroughs have happened in small laboratories with two or three players, that are somehow missed, accidentally or whatever, by the large teams, where the focus is very strenuously directed from above.

Ms. Kirsty Duncan: Could you comment on the need for combined clinical programs in research and on how this could best be achieved?

Dr. Jack Diamond: That's a very urgent need. Right now the clinical and the basic research are, and always have been, traditionally, rather separate. For example, we have animal models of Alzheimer's disease. They're not perfect models of Alzheimer's disease, but they do replicate some of the conditions. They're actually mice that have had injected into them the human gene for familial Alzheimer's disease, and they end up with a sort of a mouse Alzheimer's disease. Before we can try any drug clinically, it has to be shown to work on the animal model. So this, in a sense, addresses what you're saying. What has happened is they've produced, on the basis of good solid scientific reasoning, a drug that ought to work, for example, in stopping the production of this suspect protein. It worked on the animals fine, and they took it to the humans and it didn't work. This has happened about four or five times with very exciting prospects. As soon as they went from the animal to the human, they failed.

Here we have a reason for having the basic scientists and the clinical people work together. I'm a basic researcher, although I understand the clinical side of it as well, and it's hard to see why it worked on the animals and it didn't work on the humans. We have some good ideas now, but they're not ideas that have been generated very much as a consequence of collaboration between clinical and basic. We do actually need to foster that. I don't know exactly in what form it can be promoted, but the idea that we must get them together should be very much promoted. In fact it would be nice if there were certain initiatives that would be allowed only if basic and clinical researchers worked together. We don't have that.

● (0935)

Ms. Kirsty Duncan: Thank you, Dr. Diamond.

Mr. Mann and Dr. Lester, I'd like to hear from you about increasing awareness and education to reduce stigma. What recommendations would you make to this committee around awareness and education to reduce stigma?

Dr. Robert Lester: Let me just start, because as I indicated to you, I'm a physician. I totally missed my wife's diagnosis, and it was only caught because I developed a very temporary neurological problem that brought me to the attention of a neurologist; he then recognized, as I was coming out of my problem, that I was going to be okay, but he was worried about my wife.

So I think that's a very important question. I was just thinking about it as I was on the plane, while they were de-icing it. There are the sorts of things that happened when the stroke strategy was introduced, and they had those very visual types of things on television—you know, with the pounding. I think that is really a very visible way that people can understand what is happening. What are the early signs of dementia? What is dementia versus normal aging? How do you tell them apart? I think that's a really important thing.

As part of that, I think there's also this whole education piece and this whole issue of the stigma. People are afraid to talk about it, either people with early dementia—it is an exception—or caregivers who are embarrassed about the fact that their loved one has developed dementia. I think somehow dealing with the stigma is really going to be an important issue.

I think the next thing is the whole issue of the primary care provider and equipping that primary care provider with the tools for the early diagnosis intervention. As far as I know from talking to my colleagues, there is no one single tool that most family doctors can apply in order to begin to even suspect dementia, nor is there any way in the system that family doctors are rewarded for spending the time to diagnose dementia. Somehow I think looking at the whole fee schedule is probably beyond this committee, but I think it's an important issue, because right now doctors, including me when I was practising, are rewarded for volume, not for quality and not for outcomes. I think somehow changing how doctors get rewarded...so that primary care physicians actually spend the appropriate amount of time to diagnose dementia and are rewarded commensurate with that time.

Those would be my early thoughts on that.

Ms. Kirsty Duncan: Thank you.

The Chair: Thank you so much. It was very interesting.

We'll now go to Ms. Hughes.

[*Translation*]

Mrs. Carol Hughes: I'm going to be putting my questions to you in French, so I will let you get ready to listen to the interpretation.

Madam Chair, I hope the few minutes it takes to set up will not be deducted from my time.

[*English*]

The Chair: I'll just start your time again until they get ready, so you'll have your full time, Ms. Hughes.

Does everyone have their earpieces in?

Dr. Robert Lester: I can't figure it out.

The Chair: I will have the clerk come and assist you. We do that just to challenge everybody when they come to committee. It took me only a year and a half to figure it out.

● (0940)

[*Translation*]

Mrs. Carol Hughes: Is everyone ready?

[*English*]

The Chair: All right, Ms. Hughes, we'll start you over again.

[*Translation*]

Mrs. Carol Hughes: Thank you. I apologize, but sometimes we have to use French to give the interpreters an opportunity to showcase their skills.

First of all, thank you very much for your presentations.

Mr. Diamond, I found your presentation extremely interesting. I think it's one of the best that has ever been made to this committee.

I sympathize with your plights, Mr. Mann and Mr. Lester. My sister is 57 years old and she was diagnosed at 50 years of age. We knew that she was having some problems before then, but the diagnosis was not confirmed until she was 50 years old. We do not know how much time she has left. The fact of the matter is that it is extremely difficult for those who receive this diagnosis to get some support. Clearly, this is a problem, just as it is a problem understanding what a person with Alzheimer's is going through.

You talked about many things, Mr. Lester. Some are saying that the problem lies with the provincial government, that the provinces are responsible, but I believe that everyone, provincial and federal members of Parliament alike, have a role to play in ensuring that these people get the support they need and that they are treated well when they are institutionalized.

Most people feel frustrated. You are correct when you say that many people perhaps feel ashamed to be suffering from Alzheimer's. They try to hide it from everyone around them.

It's even harder for the caregivers. You pinpointed the problem. While the federal government claims to offer support to those who care for family members or a friend, the only type of support available to them is employment insurance compassionate care benefits. Unless I'm mistaken, caregivers are entitled to receive such benefits only for six weeks. Six weeks isn't much when you're dealing with an illness like this.

A tax credit is also available, but it isn't enough, in my opinion. Tax credits are not really useful because they involve small amounts. Family members who are unable to care for a brother, sister or parent at home face a major problem.

What steps should be taken to help caregivers of Alzheimer sufferers? Anyone?

[*English*]

Ms. Deborah Benczkowski: One of the things that's important is some kind of income security. As you said, many people who are caring for their loved one with dementia are out of the workforce. They may have already retired and tax credits don't really help them. EI benefits don't help them either, and they're short term anyway.

With the Health Charities Coalition of Canada, one of the things we talked to parliamentarians about last fall was the need for a guaranteed income security payment that could be available to families providing that kind of care. We have to remember that those families are keeping that person out of more expensive long-term care options, or nursing care options, usually until the end of life. So there is a savings to the system. We have information about that in our *Rising Tide* document, which describes some of the strategies we could employ to help people keep their loved ones at home.

Aging in place, maintaining people in their own homes for a longer period of time, is also effective. People's ability to maintain their activities of daily living is usually strengthened by being in their home environment, being where they're comfortable. A move to any kind of a facility can often precipitate a swift decline in someone's functioning.

● (0945)

The Chair: Dr. Diamond, I think you wanted to say a few words.

Dr. Jack Diamond: I just wanted to add that I think it was last year a paper came out in which they investigated the effect on the health of caregivers of a one-day respite each week. There was a significant amelioration of the physical and mental conditions, many of them medical, as a consequence of having this one-day break.

Ms. Deborah Benczkowski: A well-known researcher, Dr. Mary Mittelman, out of New York, has done a study on caregivers and providing support to them. Her study found that even with a moderate, six-week caregiver intervention support program, where caregivers learn about how to better provide care and deal with their own stress, transfers to a care facility could be delayed by nearly two years. That's an enormous cost savings if someone can be maintained at home. It was an additional 536 days or something like that.

Mrs. Carol Hughes: Ms. MacDonald.

Ms. Shannon MacDonald: Although I know we're talking primarily about Alzheimer's disease, I'd like to mention that the issues and the examples illustrated through the Alzheimer's lens are relevant across the spectrum of neurological conditions. This relates particularly to caregiving. There are mothers caring for children with severe neurological and physical disabilities as a result of their neuro-developmental condition. So the issues we raise in one discussion have direct applicability across the spectrum of neurological conditions.

The Chair: Ms. MacDonald, we're out of time. I'm sorry.

Mr. Brown.

Mr. Patrick Brown (Barrie, CPC): Thank you, Madam Chair, and my thanks to all of you for the comments here today. Shannon, welcome back. I know you've been our most avid participant at the back of the room during these hearings.

I have a few questions. With respect to Alzheimer's research, Canada is engaged in partnerships with the U.K., Germany, and France, and we are looking at potential partnerships in China and the U.S. What evidence of that are you seeing...? Is there any reason for optimism with these types of partnerships? Do you see any practical benefits for these collective working arrangements with other countries?

Ms. Deborah Benczkowski: The Alzheimer Society is working quite closely with Canadian Institutes of Health Research, the Institute of Aging in particular, on the ICRSAD, which is the international collaborative research strategy for Alzheimer's disease. I think that's the one you're speaking about.

It is just in its fledgling days, and I know there have not been significant dollars put against it. But there have been wonderful collaborations set up with the countries you've spoken about. The Alzheimer Society of Canada has been supportive of this partnership and is working together with CIHR to promote it further.

Have we seen any evidence? I don't know if I can answer that question specifically. I think Dr. Beaudet, who was here earlier today, would probably be a better person to ask. I think you heard from Dr. Rémi Quirion last week, who was leading that particular collaboration.

With regard to the question that Dr. Diamond answered a few minutes ago, these large international collaborative studies where people are working together across the spectrum of research in many different countries are going to be the answer—they are going to find the cause and cure for Alzheimer's disease. I feel very strongly that we need to support those collaborations.

● (0950)

Mr. Patrick Brown: Looking at commitments made by other countries, where does Canada stand in terms of investments—particularly into Alzheimer's—on a per capita level? Do you have any information on what other G-8 countries are doing in terms of investment in research?

Ms. Deborah Benczkowski: In terms of the other G-8 countries, Canada is behind the pack in terms of having any kind of a strategy to tackle the problems associated with Alzheimer's disease.

We know that the majority of G-8 countries, excluding the U.S. but including countries like South Korea, which has a very robust dementia strategy recently profiled in an amazing article in the *The New York Times*, if you had an opportunity to read that.... Canada is certainly lagging behind, both in our contribution to research and in the fact that we don't have a concerted government strategy to address the rising tide that's coming at us.

Mr. Patrick Brown: I thought I read a statistic somewhere that if you looked at the per capita investments in Germany and the U.K. and France, they were something like $75 or $100 per citizen. In Canada it was more in the $20 to $25 range.

Do you have any information that could be passed on to the committee from the Alzheimer Society on those types of contrasts? I think that would be helpful to look at when we look at the types of investments we want to see in Canada.

Ms. Deborah Benczkowski: Alzheimer's Disease International, which is the international organizing body for associations and societies around the world, released a world Alzheimer report in September. I believe there is information in that report about that, and I could forward that on to you.

Mr. Patrick Brown: Okay. Thank you.

I have a question for Shannon. I realize that your role with the neurological charities is a new initiative. I think it was a year or two ago that it was embarked upon. I have two questions. One, how is the study going in terms of the $15 million investment to have that study of the rates of neurological disorders in Canada? Are there any initial signs that we're seeing about the growing prevalence of neurological disorders in Canada?

Secondly, a few of the witnesses we've heard in previous weeks have talked about some of the fascinating overlaps that we see in neurological disorders, where investments in one disease have resulted in new information being found on a different neurological disorder. Can you maybe expand for the committee why we can learn so much about these different diseases by investments in any of them?

Ms. Shannon MacDonald: To answer your first question, the study is going well, but it's a large study and there are lots of people involved. We took the time at the onset of the study to engage the community of stakeholders to determine the priority areas of study, and 3,000 Canadians across the country contributed to that understanding. Then we brought together two workshops of scientists—about 60 scientists from across the country—to have the same conversation.

We knew when we framed this study a year ago that we were addressing the right issues. Fifteen million dollars is a lot of money, but it's not enough. So we wanted to be very careful and know that we were spending the money in the most effective way.

We have a study that's framed around understanding more about the prevalence and incidence, the actual state and prevalence, of these conditions in Canada; understanding the impact to individuals, families, and society as a whole; understanding health services and what's available and what's needed; better understanding risk factors for onset and also for progression, because there are secondary prevention issues that don't get dealt with very well either; and really understanding and be able to paint a very robust picture of neurological conditions in Canada so that it will inform our policy and decision-making.

The status of the study is that we have some surveys out in the field. Statistics Canada has survey projects under way as part of the study. We have nine research teams, which are large pan-Canadian teams across Canada that are now funded. Funds are flowing and contribution agreements are signed, I'm happy to report. Their work is getting under way.

We have a progress meeting scheduled for March 1 and 2 where all of those teams will come together and do what Dr. Beaudet was talking about this morning, which was the open sharing of information even though you're still in the middle of your project. The foundation of this study is that people will share throughout.

I don't have any findings to report to you, but one of the happy consequences of this study is that what we have seen from that very first meeting of scientists—which we actually convened before the study was announced—is a level of collaboration and collegial information sharing and knowledge exchange that has never existed within the neurosciences in Canada before, particularly among researchers who do clinical and population-based research. We experienced many situations where colleagues were actually down the hall from each other, but because one works on epilepsy and one works on MS, they had never actually met each other.

That has been a tremendous benefit of this study. We now have teams. We have expert advisory groups in each of those areas of the study that I mentioned, all working....

So the vast majority of Canadian researchers working in the neurosciences are in some way connected to this study, perhaps because they are contributing on one specific piece of information about the condition they work with or perhaps because they are a PI or a co-PI on a very large project.

I wish I had more to report to you in terms of findings, but certainly we are seeing very positive offshoots of the study, and we will look forward to March 1 and 2, when we have our first progress meeting.

● (0955)

Mr. Patrick Brown: One thing that I've asked before around this —

The Chair: Sorry, Mr. Brown, your time is up.

We'll go to our second round of five-minute questions and answers.

Sorry about that, Mr. Brown. I just wanted to hear what you had to say at the end, so we went quite a bit over.

We'll start with Dr. Duncan for five minutes.

Ms. Kirsty Duncan: Thank you, Madam Chair.

I'm not sure who would like to answer this. Could you let the committee know whether a disease registry exists for Alzheimer's disease and related dementia here in Canada, as well as for other neurological conditions? What is the status and what is required?

The Chair: Who would like to take that on? Shannon?

Ms. Shannon MacDonald: I know a little bit about this because we do have a registry component in the national population health study. In Canada, generally, registries have not been pulled together in a coordinated strategic fashion. Generally, you have a particular clinician or investigator or small group that is particularly interested, so registries pop up regionally. The work is under way now, and some of the work of the study is to both develop an inventory of those registries and also fund some demonstrations around developing best practices for building and expanding neurological registries in Canada, and also demonstrating the expansion of a particular registry from a regional focus to a more national perspective.

There's actually a call out right now, which was just released, for that work in particular. But generally speaking, registries for neurological conditions tend to be built in isolation and generally around more rare conditions. Although Alzheimer's is rare in the neurological community, it is actually one of the most prevalent conditions. Registries tend to be built around more rare conditions, such as cerebral palsy, I would suggest, or some of the neuromuscular disorders.

Ms. Kirsty Duncan: This committee passed a motion to make 2030 the year of the brain, and we hope this will go up to the health committee. Could you talk to why that would be...?

Sorry, it's 2013.

Ms. Shannon MacDonald: I will not be here in 2030.

Voices: Oh, oh!

Ms. Kirsty Duncan: I'm really tired. You know what I mean—2013.

Why would that be important in terms of galvanizing awareness, education, and research?

Ms. Shannon MacDonald: It's an exciting target because it gives us all something to move forward to collectively. It's important for the subcommittee to also know that the EU has funded a study very similar to the national population health study that's happening in Canada right now, and it's actually on the same timeline.

So in 2013 that study will also wrap up and the findings will be released. The EU is also moving toward declaring 2013 the year of the brain. That in and of itself is quite interesting in terms of collaboration. But there are also a number of exciting neurological events planned for Canada in 2013, in addition to the conclusion of the national population health study, which will involve quite a large-scale consensus development conference.

We also have the World Parkinson Congress coming to Canada for the very first time. It will be in Montreal in the fall. I actually put out a quick note to try to gather information from all of our members about what's happening, and there's a tremendous wealth of activity that will be happening in Canada. It's a wonderful opportunity to build on, on what's already happening and what's already planned.

Ms. Kirsty Duncan: Mr. Mann, I'd like to hear from you.

You talk about stigma and how to reduce it. I'd like to hear why this is so important.

Mr. Jim Mann: I shared the stage a year or two ago with a few people. There was a couple on the stage. One was a person with Alzheimer's and the other was his caregiver wife. They were relatively new to the city where they were living, having moved from back east, and didn't really have a lot of friends. They chose to tell people—friends and neighbours—in the city that he had suffered from TIAs, small strokes, rather than admit he had Alzheimer's. My jaw hit the stage. I was quite distressed. That to me is the stigma you talk about.

I say in my presentations that you address the stigma by addressing the stereotype. As long as the man on the street—I hate the phrase—thinks of Alzheimer's as being in the very elderly and in the final stages, society in general will not rally behind it, if you will. There's that sense of finality, whereas if you have a younger person out there saying, “I have the disease and there is life after diagnosis”, and that whole story, the stereotype changes. The feeling in society changes. The stigma is reduced, in my mind.

● (1000)

The Chair: Thank you, Mr. Mann.

We'll go to Mr. Brown.

Mr. Patrick Brown: There's one question I have asked before, and was just getting to before we had to change the order of the questioning: what's being left off the table when we look at research funding? I've asked this of all the different groups that have been before us.

One complaint we've heard in general is that we only really get to 20% of the excellent research, and there just isn't investment available for 80% of the research we'd like to do as a country. Is that something you find specifically in Alzheimer's research as well? We've certainly heard that with MS, Parkinson's, and ALS. Are there any examples of exciting research that we haven't been able to undertake in an interesting field related to Alzheimer's because there just wasn't available room within the CIHR, despite it being an excellent research project?

Dr. Jack Diamond: You're absolutely right that 20% is the usual figure we cite of the amount we can actually fund, and the 80% we want to fund goes unfunded.

Contributing to this, if I may interject this point, we talk about curing disease. If you cured Alzheimer's disease—if you had a magic potion and went to a patient and cured the disease—you wouldn't see any difference in the patient. What is lost is lost. You would stop the disease from going any further. You would stop the disease in the brain, but the dementia, lack of cognitive abilities, or ability to look after activities of daily life would remain where they were. So one whole area of research we're now realizing has really been neglected is how to reverse the process.

Now, this isn't a pipe dream. Alzheimer's happens because all the connections start to disappear in the brain. We know how to restore connections in the brain. It's a whole exciting new area of research. I'm not sure, but we may have one lab in Canada that's actually pursuing this. Yet it's necessary, if we're going to cure the patient as well as the disease, that we recover lost functions. There's hardly any track record of people in this area in Canada, because we haven't funded that kind of research. That's the sort of thing we're missing out on.

Ms. Deborah Benczkowski: If I could just comment, at the Alzheimer Society of Canada we fund two streams of research. Of our research, 50% of our funding goes toward biomedical, so that's cause and cure, but 50% of our research funds also go to quality of life research. So how do we help people who are living with the disease—and their caregivers? How do we help them to maintain their quality of life? It's on the social and psychological side of research, and that's extremely important.

We run a research competition every fall, and we just closed off our competition. We had almost 50% more applications for research funding than we had last year. I really believe that has to do with a lot of the recent visibility that we've had in terms of the disease, the *Rising Tide* report that has come forward, and a lot of the education and awareness that has gone on. But we have only 10% more funding to apply towards our program this year.

So as good news as it is, there are so many researchers out there who want to do research in this area. They have great ideas, most of them will be peer reviewed—and Jack is the one who leads that program for us—and they will be within the fundable range. But the problem is now we will just wind up disappointing more researchers because we don't have the funds to fund them.

● (1005)

Mr. Patrick Brown: One stat I found especially alarming was when we asked how much time among researchers is spent on the actual application. One response I heard one week was 50%; another week I heard a person say 80% of the time was spent simply filling out applications. I found that alarming. Why would we want to have intellectual talent like that spending time in the red tape process, in the process of showing what they want to do, and not actually investing that in the lab?

Is that something you find in Alzheimer's research too? Is there a disproportionate amount of time spent on simply filling out applications?

Dr. Jack Diamond: I'll address this.

We took a chance here in the Alzheimer Society. CIHR, which is obviously the main funding body in the country, has a certain format and style of how you have to apply and how it's discussed and all the rest of it. Now, driven by necessity, when I was looking to get people on to our panels, most of the people I wanted were already on CIHR panels, so I had to make our process more attractive and make it easier for them to do.

We have actually—our society alone—hugely cut down some of this process. I would say we've cut it down to a quarter or a fifth of what CIHR, which is a traditional national body in most countries, demands, and we get away with it. There are no CIHR people here right now, but I feel like saying to them, why do you give your reviewers such a tough time—the reviewers I'm talking about now—and the applicants when it isn't necessary? I personally don't believe it's necessary, and our program runs efficiently and well without having this lengthy, tedious need that CIHR imposes.

We had three people successively who were on our panels from the States, and they all said how marvellous they thought our Alzheimer Society program was in this regard. So it can be done. We do it, but I think CIHR does not.

Mr. Patrick Brown: What type of stuff is required from a researcher that may not be necessary that you have removed from your application process?

Dr. Jack Diamond: Well, here's one right off. The most wonderful summary of any research project is that provided by the applicant. CIHR requires that people describe in summary what the application is about, but it's already there. All they have to do is print it off and send it round to the panels, and that's what we do. So they have a summary. They don't have to do it themselves. How can they improve upon the applicant's summary? That's one thing we do.

The other is that we don't require such a long description in words. We do invite them to talk about it when the panel meets, from their own notes, but they don't have to provide it in detail beforehand. These are two specific items that we do that help our reviewers and applicants.

Also, our application has only five pages; CIHR's has 20 pages. Many agencies in the States are going to a five-page application. It's difficult at first to write a five-page application when you're used to being able to spell out everything in 20, but that's what we do.

The Chair: Thank you, Dr. Diamond.

We'll now go to Dr. Duncan.

Ms. Kirsty Duncan: Thank you, Madam Chair.

Something that hasn't come up in this committee is brain banks. I'm wondering if you can address what brain banks currently exist in Canada, their importance, what data should be collected, and any recommendations you would like to make to this committee about brain banks, please.

● (1010)

Ms. Deborah Benczkowski: We do have one brain bank in Canada. I'm saying this because I was recently at a collaborative meeting with a number of researchers from across Canada and CIHR—and I'm going on my memory of that meeting. My understanding is that we do have one brain bank. I believe it's in the Maritimes. Part of the conversation at that meeting was around the idea that it's not critically important to have brain banks in Canada because there's so much collaboration now.

The Chair: May I interrupt to ask you something? You've made the statement about this brain bank. You don't know for certain.

Ms. Deborah Benczkowski: I don't know for certain, but I heard this at a meeting I was at. It will need to be double-checked.

The Chair: We will double-check that. Thank you.

Ms. Deborah Benczkowski: I heard at a meeting that there is only one brain bank in Canada.

Dr. Jack Diamond: I agree. I think it's in the Maritimes.

You did ask what was required of a brain bank. It's not just a question of people. We often receive letters from people offering to donate their brain. To work efficiently, a brain bank has to have a complete and accurate clinical picture of what that patient had been through, the whole history and final diagnosis—everything has to be there for it to be useful. It's not adequate just to have the brain; we need those notes, and that isn't always as easily obtainable as you might think.

Ms. Shannon MacDonald: I would like to comment...and the only reason I know this is I spent a lot of time with a neuropathologist one day when we were originally scoping out the national population study. There are actually many brain banks in Canada, several big ones. The problem is, much like what I spoke about in terms of registries, they're not linked. They're not part of a system. The one in Halifax doesn't necessarily talk to the one in Regina. They often tend to be connected to a particular researcher, clinician, or team.

The other piece is that a funding model isn't currently in place to support a system of brain banks. So there isn't information sharing between them. They're perhaps not collecting or using information in the same ways so that there can be knowledge exchange. And like researchers, they—it's another type of research. So they are in a similar position where they are working very hard to identify sources of funding.

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

If we wanted to make it more holistic, so that they talk to one another, what recommendations would you make to this committee? That's going to require infrastructure, funding....

Ms. Shannon MacDonald: I go back to the recommendation we've made around the national brain strategy overall, which is that we've come a long way, but a tremendous number of conversations need to be initiated and facilitated. I would suggest that a brain bank conversation is one of those things that's part of a research strategy, part of a national research approach to neuroscience in Canada, and there probably hasn't been the convening of a conversation of neuropathologists and people who can tell us the benefit of having brain banks. What can we learn through brain banks? To some of us the idea is quite gory, but to others it's the stuff life is made of because it's a wonderful source of information and potential new findings. I would suggest that like everything in our proposal for a brain strategy, we need to begin a process of consultation, of convening some of those conversations, so we know what the really important issues are and come up with some ideas of how to move forward.

The Chair: Thank you.

Ms. Benczkowski, you started to comment on the brain bank effectiveness and we were interrupted. Would you further your thoughts on that? It goes along with what Dr. Duncan is asking.

Ms. Deborah Benczkowski: At the meeting I was at recently—and I apologize if I had the wrong information—they were talking about Alzheimer brain banks. Maybe that's the distinction. One of the comments I heard from a number of the researchers who were in the room—and these were all Alzheimer's researchers—was that some things are not worth building a huge infrastructure around when there are so many collaborations available around the world, particularly the number of brain banks across North America that Canadian scientists have been able to take advantage of. That was the conversation I heard. I'm not taking a position on this. I'm just saying that was a conversation I heard at a meeting of Canadian scientists just a few weeks ago.

● (1015)

The Chair: Dr. Duncan, I'll give you one more minute.

Ms. Kirsty Duncan: Thank you.

I appreciate all your comments.

I'm going to ask a hard question here, if it's okay, but I think we have to ask it. We have heard over and over—and I'm a very strong supporter of a national brain strategy, as you all know—that the Alzheimer Society has also called for a pan-Canadian dementia strategy.

What would be the main components of that, and how do we combine that within a national brain strategy?

Ms. Deborah Benczkowski: All of our components for a dementia strategy are included in the components for a national brain strategy, because we work very closely with NHCC.

It was really a question of timing when we wrote the *Rising Tide* report and we were involved in pulling together the recommendations. We were probably first out of the gate, so we're now at the point where we're totally supportive of the brain strategy. We feel that all of the issues we have put forward in *Rising Tide* are all addressed in the brain strategy. That's why we're behind that 100%.

The Chair: We will go to Mr. Brown.

Mr. Patrick Brown: Thank you.

Thank you for all the comments so far.

I want to expand a little bit more upon the question I was asking last time about the research process, because that's something that is solely federal, and a lot of the things we deal with overlap different jurisdictions. Jack's comments were certainly interesting on the difficulties.

Shannon, have you noticed that with other neurological disorders, too? Is this a common thread that you've found among the variety of groups that Neurological Health Charities Canada represent?

Ms. Shannon MacDonald: Do you mean the difficulty in funding research?

Mr. Patrick Brown: One is the lack of research dollars, but two is the process of filling out the applications.

Ms. Shannon MacDonald: Yes, there is definitely a need for a very solid peer-reviewed research process, so that we know that good work is being funded and the work that's being funded has the feasibility of delivering results. So the scrutiny and the review process is important, but that's not to say that it can't be improved upon.

Certainly, I know that the majority of NHCC members do fund research and they do run peer-reviewed processes. I'm not aware of the detail of those processes, but the Alzheimer Society of Canada would be one of those organizations. I would suggest that most are operating in a very similar fashion. All would meet, in my opinion, CIHR's expectations around what a quality review process includes.

Certainly, when you get to the issue about funds, there is no question that every organization.... This committee has been incredibly helpful in raising the profile and awareness of neurological conditions, and as profile and awareness is raised, so too is interest in the field. As we continue, one of the things that the neurological charities do very well is to fund emerging investigators, investigators who perhaps don't have enough behind them yet to qualify for a CIHR grant. We want to keep them in Canada. We want to keep them excited about the field. They need to be funded by somebody, and the health charities play a very important role in, as Jack talked about, the training programs. So yes, there is always really good science left on the table. Most organizations would say they probably leave no less than 50% of really good fundable projects on the table.

Mr. Patrick Brown: Another question to you, Jack.

I know in your 2008 report on Alzheimer's disease you projected that by 2031 there would be 750,000 Canadians with Alzheimer's disease or dementia. Why are we seeing a growing rate of Alzheimer's disease in Canada? Are there any indicators that would suggest that there are any causes for that in society? Why are there more Canadians—

Dr. Jack Diamond: The usual explanation we give for this, which I think applies across—

Mr. Patrick Brown: Aside from population growth.

Dr. Jack Diamond: It applies across the world, actually. There are two things. People are living longer, and this, I have to say, applies especially to men. At one time, twice as many women got Alzheimer's as men. The reason for that traditionally was that women lived longer than men. Well, men are catching up now, they're living longer, and while they're living longer, they are more lengthily exposed to the risk factors.

It was earlier said that we don't know what causes Alzheimer's, and in a sense that's true, but in a sense it isn't true. We do know what causes Alzheimer's. It's when the combined effects of the risk factors overwhelm the capacity of the brain to repair itself. It's as simple as that. What they do, of course, is very complicated. But it's all the risk factors, and of course the longer you live the longer you're exposed to those risk factors. Some are environmental; some are personal, like high blood pressure, high cholesterol, diabetes or obesity, chronic stress, chronic depression. These are all risk factors, and the longer you're exposed to them, of course, the more effective they're going to be.

The combination of the two, increased risk factors and increased duration of life, are actually adding to the numbers. Of course, the baby boomers right now have enormously boosted the numbers. But even without the baby boomers, we are still seeing an increase in diagnosed cases.

● (1020)

Mr. Patrick Brown: A few years ago I was asked to present a government grant to a seniors' home in Barrie. It was at IOOF, and it was a grant to have all the seniors there take painting classes. It was a New Horizons grant, and it said that mental stimulation is a means of delaying the onset of Alzheimer's. I know the seniors there loved it.

Is that the type of thing we should be looking at? Should we be looking at more opportunities to work within seniors' homes in Canada?

Dr. Jack Diamond: You've lit upon actually the most important thing we have going right now.

If you don't want to get Alzheimer's, ladies and gentlemen, there are four things you should address immediately. One is regularly maintained exercise—just modest exercise, not a four-minute mile; an hour's gardening or an hour's housework is the same as an hour in the gym. Another is using your head by exercising your brain and involving yourself in activities. Another one is socialization, not isolating yourself but interacting. The final one is a healthy lifestyle, especially with diets and things like that. These have all been shown to significantly reduce the numbers, or advance, let's say, the time at which you get the condition, if you're going to get it, and they slow it down in people who already have it. No drug we have yet achieves that.

The Chair: Thank you very much, Mr. Brown.

Thank you, Dr. Diamond.

Ms. Hughes, I'm going to skip to you now because I want you to have an opportunity to ask some questions.

Mrs. Carol Hughes: Thank you.

You mentioned baby boomers. Certainly, I think we are going to be seeing an increase in the early onset of Alzheimer's because of the number of baby boomers who are coming up the ranks here. I think my sister was a prime example of that. My sister was very active and she did lots of reading. Sometimes we still shake our heads and ask, what's going on here?

I think there are a lot of people out there who may have it and don't know they have it. Dr. Lester and Mr. Mann certainly have indicated that, with respect to when it actually started, when the onset actually began.

And I think this would be part of the national strategy—how better to educate people to look for the signs, so that maybe some of the medication that is out there that would prevent or stop the progression.... I wonder if Dr. Lester and Dr. Diamond would like to comment on that.

Dr. Robert Lester: As I said earlier, I think that education of both the public and the primary care health providers would be extremely important in preventing or early detection of the disease and therefore early intervention. As I said, if you can intervene earlier, you can probably slow the progress. So I think the strategy around education is really a relatively inexpensive way of addressing some of the early problems that people with dementia have.

I will just give you an example with my own case. My son lives in Scottsdale, Arizona. Early on, he said to me, “There's something wrong with mom, because she can't find her way home when she goes out on the street.” I said, “All the houses here look the same. They're all brown adobe houses. What's the problem?” Given that I was living with her, I didn't see it, but my children who were not seeing her on a regular basis did see it.

I think this whole concept of education is extremely important, and it goes back to the whole issue of removing the stigma, which allows people to come forth.

I know, for example, that when my wife was diagnosed, friends of 60 years disappeared. They totally disappeared. Family disappeared. Colleagues disappeared. No one visits my wife except me and my daughter—virtually no one. I think if someone has cancer or someone has heart disease, that doesn't occur. People continue to participate. People just don't know what do when someone develops dementia. They don't know how to react. I think this whole concept of what it is, how you deal with it, how people identify it early, is really critical to the strategy, from my perspective.

● (1025)

Dr. Jack Diamond: I can just add to that.

Remember I told you about the hallmarks of Alzheimer's disease, the plaques and the tangles. They begin decades before the dementia. People who are 30 and 40 who are doomed to get Alzheimer's already are developing these changes in the brain. Right now there is a strategy going on in most countries, including Canada—which is just being pulled together by Dr. Serge Gauthier—to investigate the proposals that have been made for early diagnosis. Ridiculous as it sounds, this includes pre-symptomatic diagnosis. We actually have the tools, if we wanted to use them, that could detect the signs of impending Alzheimer's before you actually have conditions that Dr. Lester was just referring to. But they are not necessarily going to be approved.

They are potentially expensive. One of them, the spinal tap, is invasive and potentially dangerous. If we could do all of those things without any discomfort, then we could actually pick up people, and they could start to address the possibility that they're going to get Alzheimer's even before they have any symptoms at all.

Mrs. Carol Hughes: With the increase in Alzheimer's and the fact that I think just every home doesn't have the capacity or the ability to really provide the services needed and the stimulation needed for these people, it's becoming more of a warehousing issue. Especially with the baby boomers and the early onset, the programs are just not in place. I don't think this is a responsibility province to province. I think as a whole, when you're looking at early onset, we have to look at programming on the national level, to say this is what we need to do to assist them in being able to stay productive while they're in long-term care facilities or while they're being cared for by a caregiver—and I was one of those caregivers, by the way.

I'm just wondering, as to the strategy and the role of the federal government, what would you like us to hear a little bit more today that may have been missed or that hasn't been emphasized enough?

Ms. Shannon MacDonald: There are key tables that these issues could be raised at, so that the levels of government could be working together to start to address some of these things that perhaps are delivered by a province or a territory but that we want to be universally available across the country. So I would strongly encourage the Government of Canada to take a leadership role and take these issues to FPT tables, particularly around health.

Every provincial and territorial government across the country wants to keep its citizens productive. They recognize the economic benefits of keeping people at home for as long as possible. There isn't a track to run on right now, and some leadership around bringing the issues forward at the policy table, where real conversations can happen about solutions, I believe would be one of the single most important things that could come out of this work.

Dr. Jack Diamond: This applies not only to Alzheimer's disease. There are other diseases. We know of one gene that makes you susceptible to Alzheimer's. It's a simple test, but you couldn't just go to a hospital and get it. Your doctor might be able to get if for you if he thought there were reasons why he would like to be sure that you are or are not on the way to getting Alzheimer's. It's called the ApoE4 test. This is a question that really hasn't been discussed as openly as it should.

I believe in the States, if you go into a hospital, they routinely test for this gene—but they don't tell the patient, it's buried in the records—because it might help the clinician make a diagnosis subsequently.

● (1030)

The Chair: Just be very brief, please, Ms. Benczkowski, and then we're going to stop.

Ms. Deborah Benczkowski: I'll say just two things. Recently, in meetings I've had in Ottawa with members of Parliament, the Alzheimer Society has received two messages, one being that any issues around the creation of a strategy will not be looked on very favourably, that the push for having strategies is really not something the government will support. That is one message I heard.

The second message I heard is that any kind of work at the federal-provincial-territorial table should really come up through the provincial ministers, not from the federal minister.

So I would suggest that that's a real opportunity for this subcommittee to come forward with a clear recommendation.

I agree with what Shannon said in terms of the federal government having a real role in taking leadership on developing a brain strategy and addressing these issues.

The Chair: Thank you so very much.

I want to thank the panel for coming today and giving us your very insightful information.

This committee, I believe, is a very unique committee. People are very committed. You understand that at the committee everybody has their wish list. If you wanted to pay astronomical tax dollars, we could put everything into health care. But the strategy around neurological disorders is something this committee wanted brought to the forefront, to do what we could to address it. It is, I think as never before, an emerging health issue that's really never been addressed the way we need it to be.

But I have to tell you quite honestly that if you brought people in talking about cancer—talking about anything else—they would come with the same zeal and the same demands, and probably the same picture. What makes this different is that this is something, in our view, that we've never really had in front of a committee. And I give credit to all my colleagues who have taken up the torch and really want to get this examined, as we all do.

I think all of us have had someone in our lives or someone who has touched our lives.... This is not foreign to us because we are members of Parliament, as Ms. Hughes has so eloquently attested to. So the understanding about caregiving and about this research is of paramount importance for us to hear and to put forward.

Thank you so much for joining us today.

I will adjourn now until our next meeting.

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