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# Subcommittee on Neurological Disease of the Standing Committee on Health

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## EVIDENCE

## Tuesday, November 2, 2010

## Chair

**Mrs. Joy Smith**

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● (0850)

[*English*]

**The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)):** Good morning, everyone. Welcome to our committee. I'm very pleased to have you here today.

This meeting is pursuant to Standing Order 108(2), dealing with our study on neurological diseases.

Our witness from the Amyotrophic Lateral Sclerosis Society of Canada is David Cameron, the president and chief executive. Welcome, Mr. Cameron.

We also have Nigel Van Loan, a board member. Welcome, Nigel, I'm glad you're here.

We have François Gros-Louis, an assistant professor and a very astute researcher, I understand, with his own lab recently. Welcome, François.

We also have Sari Jormanainen. Welcome. I am so glad you are here this morning, Sari.

You will have ten minutes each for your presentations.

We will begin with Mr. Cameron, please.

**Mr. David Cameron (President and Chief Executive Officer, Amyotrophic Lateral Sclerosis Society of Canada):** Thank you.

Madam Chair and members of the committee, thank you very much for this opportunity to inform the subcommittee about ALS.

Before I get too far along, I just want to comment that I've been in Ottawa now about three times over the last four weeks. We were here on October 5, when we came here for our annual Hill day. We came here with three asks: for more funding for CIHR; consideration of compassionate care; and an ask around benefits for veterans with ALS.

I had the good fortune of meeting with Minister Blackburn on October 5, and we had a good discussion about benefits for veterans with ALS. I was invited back on October 15 to participate in a press conference with him, at which time he announced the granting of benefits to veterans with ALS, which is outstanding. My thanks to the Prime Minister for his personal intervention, and my thanks to Minister Blackburn for the initiative that was taken. It was very, very proactive. So that's one of the asks down.

During the October 5 Hill day, I had an invitation to attend a luncheon, where Mr. Ignatieff brought forward his platform with respect to compassionate care. We applaud that, and also hope and encourage all parties to put compassionate care into their platforms. So maybe that's another one partially down.

Now our ask is focused on getting more dollars for CIHR.

I've been president and CEO of ALS Canada for a little over seven years now, and I'm going to provide you with a little background on the organization. The Amyotrophic Lateral Sclerosis Society of Canada, ALS Canada, is 33 years old. It's a nationally incorporated health charity. It is composed of a volunteer board of 24 directors, most of whom are touched in some fashion. Those who are on the board will often seek their other friends and bring them onto the board. So it's a very passionate group. There are 10 provincially incorporated ALS societies, so in total there are 11 across the country. Each of those 10 has one representative on my board of directors, composed of the 24 individuals.

A little over 30 years ago the idea of creating a health charity called ALS Canada was conceived by a group of senior neurologists. Their rationale was simply that the disease had been around, it had been identified by Charcot back in the 1800s, and a cause and cure had still not yet been identified. So the group got together with the primary focus of research, and that has been the mandate for the past 33 years.

You heard a lot about research back on June 8, when we had the first opportunity to be here. You know that funding of research is our prime goal. In 2003 we were funding around $500,000 a year in research in partnership with CIHR and Muscular Dystrophy Canada, and now in 2010 our research investment in our budget is a little over $2 million. So there's been a great growth in the dollars made available.

About eight years ago the board of directors decided there was more that we could do beyond the research mandate, and we decided that we would start to address the quality of life issue, which has been the province and mandate of the provincial societies. Specifically what we do is to provide assistance to the ten provincial societies in their delivery of the support that is their purview. So we have resourced up with staff. We don't deliver, because that's in the purview of the provinces, but we assist.

We have a somewhat unique relationship as the 11 ALS societies. We have all agreed that moneys raised for research anywhere in the country, whether by ALS Canada or by any of the ten provincial societies, will flow to ALS Canada so that there is one central area of competency and we don't fragment the available dollars. I think that's somewhat unique in the health charity field.

On our support mandate, we have created resources for people with ALS and also for those individuals who want to know more about ALS. They may be friends or family who have come into this world they had never heard of before and are feeling lost. We have created a manual for the newly diagnosed individual, and we make that available through each of the ten provincial societies. It's also available through all 15 of the ALS clinics from coast to coast and is also available online. It's downloadable off our website.

We've developed a family physician's guide to ALS, because the family physician is often the first individual a patient comes to with symptoms. We've put it together in a CD-ROM. It's been revised, reviewed, and sanctioned by physicians, and we distribute it across the country to as many individuals as can. We make it available to physicians online, as well.

We have all the current information on ALS on our website as well as all the information on research. When individuals are newly diagnosed, and later along, they're anxious to know what's going on in research, and we are a prime source of that information.

About three or four years ago we made a decision to focus on the children of individuals who have ALS. What we were learning was that when there is a diagnosis, both of the individuals involved, the individual with ALS and the partner, focus very much on themselves. One leaves work; the other becomes a prime caregiver. Children are very often, not intentionally, moved to the side. They're sheltered from the information.

First off, we started an interactive website that has age-appropriate information for children so that, depending on where they are and what age they are, they can identify things that will give them a sense, in a non-intimidating fashion, of what ALS is. It's also available in booklets for the three different age groups.

This year, just in September, we initiated a youth retreat. We went to all of the provinces and identified individuals with ALS who had children, or children who had gone through an ALS experience, and invited them to the Toronto area for a retreat. We had about 17 individuals from about age 15 or 16 through to 22, and they came together for a weekend. The recurring comment we heard from the youth was that this was the first time they had been able to talk to people who knew what they are talking about. They didn't have to explain ALS. It was the first time they had been very comfortable just being able to talk about what was going on.

We hope to continue with that program. The youth went away energized and actually have turned into a bit of a social media group. They are getting the word on ALS out through their Twitter and Internet community.

ALS Canada is a small health charity. We have 11 staff to run the organization. Our annual budget is slightly under $4 million, $2 million of which goes into research. We don't look for and don't receive government funding. We do the fundraising ourselves. We have a donor base that wants to see solutions, and consequently they are very generous.

We are a founding member of Neurological Health Charities Canada, the NHCC. Again, we applaud the government for funding of $15 million for the national population health study in neurological diseases.

I think that is almost the ten minutes.

● (0855)

**The Chair:** It's almost the ten minutes, and you did very well.

**Mr. David Cameron:** Thank you very much.

**The Chair:** Thank you so much, Mr. Cameron.

We'll now go to board member Nigel Van Loan, please.

[*Translation*]

**Mr. Nigel Van Loan (Board Member, Amyotrophic Lateral Sclerosis Society of Canada):** Thank you Madam Chair and good morning. My name is Nigel Van Loan. I want to thank you for inviting me here today.

I am a member of the ALS Society of Canada. I used to be the President of the ALS Society of Ontario. Why? Because in November 1999, my wife Patricia developed ALS. Our life as we knew it changed dramatically the day of her diagnosis.

● (0900)

[*English*]

I became a caregiver on that day, taking on an ever-increasing role as supporter and provider of moral and physical assistance to a loved one. Please note that I didn't use the word “burden”: that term has no place in describing the relationship that grows and exists between an afflicted person and her or his caregivers.

If there can be any good news in our story, it is that ALS progressed relatively slowly in Patricia, so that we had more time than most to adjust and arrange for the appropriate assists and aids to be in place in time to be of use. Conversely, recently I was aiding a gentleman here in Ottawa stricken by ALS, and his disease progressed so quickly that support equipment was arriving just before his deteriorating condition demanded moving on to the next level. That's ALS for you: no two cases alike.

It was of unbelievable help that Patricia was a qualified social worker who had spent much of the last 15 years supporting and caring for people with ALS and Alzheimer's. She was an expert in navigating and utilizing the very parts of the health care system upon which we had now become dependent. Thank goodness, because there is nothing more obscure, obtuse, and indecipherable than our current support system for longer-term, terminal diseases such as ALS. The medical model pursues cure as the holy grail, but is very weak on care.

This past weekend I attended the Canadian Hospice Palliative Care Conference here in Ottawa and was relieved to find a growing body of evidence that inroads are being made, that the benefits of the ethos of palliative care are spreading, albeit slowly, to those suffering from life-threatening and life-ending diseases, not only just at end-of-life, but soon after diagnosis, which can be months or years before death.

On a related note, although I can grudgingly admit that there are tiny signs of progress, it still seems to be beyond our ability to realize that providing proper home care would lessen the overall costs of the medical system, freeing up acute care beds for those truly in need of such care. But thanks to Patricia's knowledge and guidance to me, often necessary, we were able to make our way through her seven years of progressive debilitation with a good degree of quality of life and a bearable level of financial strain. She was able, as she so devoutly wished, to die peacefully at home in March 2007.

I have just referred to the issue of financial strain. Allow me, please, to reiterate that the inexorable progression of ALS necessitates an ever-increasing reliance on medical and technical devices for mobility, for communication, for breathing support, for nutrition, for bathing, and for medically qualified assistance. This especially impacts on those who choose to stay at home for most if not all of their journey. This is the choice made by nearly all of those stricken with ALS. After all, who would want to spend the predicted two to five years in a hospital setting, and there are few if any other options.

In annex A to our submission, there is a breakout of typical costs that can accrue for these supports. Although it varies by province, I must assure you that a large part of these costs are not supported by government programs at any level. In Ontario, as an example, we currently state that about $140,000 is the average financial load directly placed upon a typical family. Therefore, ALS Ontario runs an excellent equipment loan program that we were able to make use of for a lot of Patricia's needs, but we were still out of pocket for almost $80,000, especially including the costs of home adaptations—bathroom and wheelchair access renovations, and for a wheelchair-accessible van. Granted, some tax credit was available at year-end for me, since I had a military superannuation for income, but early into Pat's journey I had given up my role of consultant and the income that this provided. And, of course, because of my self-employed status, employment insurance wasn't available to me, either from the outset or after the provision was introduced for a few weeks of insurance payouts for compassionate care.

Not surprisingly, therefore, I heartily endorse suggestions such as the recent Liberal family care plan calling for a longer period of employment insurance benefits and for the creation of a companion program that is not solely based on employment. This can be crucial to ensuring that families can survive. Since ALS can extend for years, it would be advantageous to allow partial weeks over a longer period rather than blocks of weeks at a time. I call upon all parties to address these issues in their own platforms and proposals addressing the needs of families and caregivers.

● (0905)

Madam Chair, please allow me to segue to a related issue of care and support for veterans suffering from ALS.

Earlier I made mention of providing guidance to a gentleman whose disease progressed quite rapidly. His name was Brian Dyck. As a result of his spirit and commitment, he became the face of ALS throughout the past year in the national capital region.

I was introduced to Brian shortly after his diagnosis about a year ago and I quickly discovered that prior to becoming a police constable he had been a military medic for over ten years, including service in Kuwait during the first Gulf War. Because I had been extensively involved with our contribution to that war, I had been following the developments in the U.S. regarding their recognition that there was a probabilistic connection between military service in that action and the later onset of ALS. In fact the U.S. government in their wisdom had concluded from extensive statistical evidence that even though the cause could not yet be ascertained, military service anywhere increases the chances of developing ALS.

As a result, they had introduced the policy of presumption, which ensures that any serviceman or veteran who develops ALS and their family will be provided with proper benefits and support. Therefore I advised Brian to apply for a veteran's pension on the individual claim track, while concurrently working with the staff of ALS Canada to move on the collective issue of setting in place a policy in Canada similar to that of the U.S.

As you now know, there has been considerable progress here with all current cases of ALS claims within the Veterans Affairs program being smartly moved along. Brian received word of the success of his claim just a week before his death last month, and no doubt was greatly relieved to realize that the support of his wife and his two-year-old daughter was now assured.

This notable progress was made possible by the Prime Minister, the Minister of Veterans Affairs, the staff of Veterans Affairs Canada, including the ombudsman, and by many members of all parties, whose compassionate recognition of the need came to the fore.

You have heard that we seek an increase in the funding of neurological research in Canada—primarily by adding to the overstrained budget of CIHR—not only with an immediate $350 million boost, but also with a multi-year commitment.

Allow me in my final comments to put one new twist on this call. In my opening remarks I implied that I became an active supporter of the ALS Society and related activities because my wife developed the disease. Many can empathize with this view—help research to find hope and a cure for your loved one. And yes, that was there. But I've been around science and technology long enough to recognize that we had only just started down that road, that it would be a long one and would consume some considerable time in arriving even at an understanding of what was going on in a person with ALS, and a longer time to arrive at the doorstep of possible cures.

But I will stick it out for as long as I can, because my wife was one of the seven or eight percent of ALS patients who have an inherited form of the disease through a defective gene passed from her mother, who along with her three siblings developed ALS.

There are now proven, through research, to be several genes that can—perhaps along with some sort of trigger incident—lead to ALS. My children therefore have a 50 percent chance of having that happen, and my grandchildren share that risk. So I selfishly want to see research proceed apace.

[*Translation*]

Madam Chair, neurological diseases have commonalities. We do our own work, but we also always read about what is happening for other diseases such as Huntingdon's, Parkinson's or Alzheimer's because certain drugs that are effective for some diseases might also be effective in treating ALS. That is why we are not asking for resources specifically for ALS, but for research in general.

Finally, we encourage support for caregivers by increasing the number of weeks of compassionate care benefits under the federal employment insurance program and creating a parallel program to that of compassionate care benefits that is not based on employment.

[*English*]

Thank you for your attention and for allowing me to testify on such a personally important matter.

**The Chair:** Thank you, Mr. Van Loan.

We'll now go to François Gros-Louis.

**Mr. François Gros-Louis (Assistant Professor; Amyotrophic Lateral Sclerosis Society of Canada):** Good morning.

My name is François Gros-Louis. I recently got an assistant professorship position at Université de Laval in Québec City.

First of all, I would like to thank all members of this committee for this opportunity to say a few words on ALS and on my research on this disease.

I will continue in French, but I will be happy to take any questions in either English or French.

[*Translation*]

My name is François Gros-Louis. I recently got an assistant professorship position at the Université Laval in Quebec City. Most of the research projects I have been involved in so far have been on ALS, which, as the previous speakers have mentioned, is an incurable neuro-degenerative disease. I did my doctoral degree at McGill University and it was mainly on the genetics of ALS. I then pursued my career by doing a post-doctoral internship at Dr. Jean-Pierre Julien's laboratory in Quebec City. At the time, I had received a number of offers from research labs in the United States and Europe, thanks in part to an initiative by ALS Canada, which, together with CIHR, the Canadian Institutes of Health Research, had set up a post-doctoral bursary program called the Tim E. Noël Fellowship in ALS Research. Having obtained that bursary, I decided to stay in Canada in order to devote my research to ALS and to the various patho-physiological mechanisms involved in this disease.

In Dr. Julien's lab we recently were the first to develop and demonstrate that a new therapeutic approach based on passive immunization through monoclonal antibodies that we have produced, could extend the survival of the animal models we were examining. It is still too soon to say whether the approach will effectively treat ALS patients. A number of points need to be clarified to properly understand all the biological determinants associated with this discovery and this potential treatment, but I believe that we have shown that it is important to continue to conduct fundamental and clinical research to identify, as we have done, not only new therapeutic approaches, but also the different causes of ALS and other neuro-degenerative diseases.

In most ALS cases, the causes are still unknown. Identifying the genetic and environmental risk factors associated with neuro-degenerative diseases and ALS is one of the first steps in properly understanding the biological aspects of these diseases. Understanding the different biological mechanisms will then allow us to develop, as we have done, new therapeutic approaches and to see if what we find in fundamental research can quickly be transposed to clinical research safely in order to treat patients.

I think this is an ideal time to invest in health research. Over the past few years, there have been a number of great discoveries including the human genome project, among others, and great technological advances that are becoming increasingly accessible to academic research labs. We now have the knowledge, technology and infrastructure because over the past few years, the government has made the necessary investment in research infrastructure through the Leaders Opportunity Fund or the CFI, the Canada Foundation for Innovation, for example. Now we just need research funding to keep these labs running effectively.

● (0910)

[*English*]

For most researchers, especially young investigators, it is really hard to get funding for innovative, crazy ideas we might have to pursue our research. We have good research infrastructure all across Canada. We now have access to new technologies, new molecular tools that were not previously available. So it is the perfect time to invest in health research to continue being world leaders in health research and neurological diseases in particular, as the Canadian population is growing old, and adult-onset diseases are increasing.

We are lacking the funding needed to appropriately carry out our research. Nobody would have thought until recently that immunization therapy in ALS would have led to beneficial effects. It was an innovative, crazy idea we had a few years ago, but it didn't get funding in the beginning. We had to wait a few years to get the necessary funding to continue our research. With more investment in health research we could have demonstrated earlier our immunization hypothesis in ALS.

Investing more funds in research also makes economic sense, not only for ALS research but across all neurological disciplines. Therapeutic targets can apply to a variety of neuro-degenerative diseases, and therapies developed for one disease can be applicable to others.

Investment in health research will not only pave the route for finding new therapeutic approaches, but will also keep high-paying research jobs in the country, which is critical in this economic climate. It will also maintain Canada's leadership role in health research excellence domestically and internationally, and keep pace with significant investment made by other countries, such as the United Kingdom, the U.S.A., Sweden, and Australia.

Thank you very much.

● (0915)

**The Chair:** Thank you very much. We appreciate your insight.

We'll now go to Sari Jormanainen for ten minutes.

**Ms. Sari Jormanainen (Amyotrophic Lateral Sclerosis Society of Canada):** Thank you. Good morning.

Madam Chair, members, I'm Sari Jormanainen. I'm 45 years old and living in Ottawa with my husband Paul and our two daughters, who are nine and twelve. I was diagnosed with ALS in April 2010. The diagnosis took quite some time to come out, and after a long process of uncertainty we received the news. It broke our hearts.

My daughters have been extremely passionate about the cause of ALS and they wish me to push forward the idea of research. They have organized bake sales and done the things that young girls can do, but we all know that's not going to be enough. There needs to be a long-term commitment to research to find a cure, and that's what they are looking for. That's the hope we have.

For me, that may be too late, but there will be others coming after me who will need that. The WHO actually is looking at Canada and estimating that by 2040, neuro-degenerative diseases—not only ALS but the wider group of diseases—would overtake cancer as the leading cause of death.

I think my children are very wise. They are looking at the future and looking at investments in something that will pay back later.

ALS is merciless. The progression in my case is clear. Within a year, I have progressed from a slight limp in my right foot into using a cane walker and now mainly a chair. ALS has also started taking effect in my arms, hands, and throat. There is fatigue and tiredness because of the disease.

It has forced me to say goodbyes to a lot of things in my life. At first I thought that would be temporary, that things could be fixed. That is not the case. I used to work as an analyst and senior strategic planner. I've said goodbye to work. I have said goodbye to my sports life and most of my hobbies.

I do need help at home already with everyday activities. Life in our house has changed drastically. We have mobility aids. We have bathroom aids. We have people coming to the house to help out. We have made changes to the house. Some of these aids come from the ALS Society's loan cupboard, which is of great help. Some have been paid by us and are partially covered by our insurance. Some big ticket items we pay out of pocket because there is nothing we can use to pay for them. Such things include porch lifts. That is essential for me to get out of the house and down to the street level. Work was involved with that. We bought a second-hand portable shower because eventually I will move downstairs to the main floor, and I need to be able to take showers on that floor.

This is only the beginning; we know that. There will be the hospital bed. There will be breathing devices and so forth. We will need a toilet on the main floor. We haven't even started thinking about the transportation needs for me in the future. Of course, this is all on top of the fact that I used to be an earning member of society. Now there is no salary income for me, and I'm afraid the disability pension will not make up for that.

The big question for us is that we are still at the beginning of this road, this journey, and we are trying to proactively look for ways of making sure that I can stay home, that I can be taken care of, and at the same time that our family can look forward to the future. That means we are trying to protect some sort of normalcy for our children and not deprive them, allowing them to excel at what they do at school and in their hobbies. They need to have future prospects.

● (0920)

What does this mean? It means practically that my husband, my caregiver, my love, takes a lot of the new responsibilities on his shoulders. Our daughters chip in, but they're young and cannot be expected to take care of me. Eventually, when ALS progresses to its advanced stages, I will be totally dependent on somebody else's help. That means that my primary caregiver needs to be around all the time. The big question is, how can we organize that?

My family clearly indicates they want me to stay at home. I want to stay at home. Most probably my husband will need to take time off from work. Still, we need to live on income from somewhere to do that. Community care can help, but is limited. We can't burden our friends and family with providing basic care, so we come to the big question of the EI benefits and how they are going to help us out.

As Nigel was saying earlier, the period of dependency can be relatively long, and in the case of ALS it often is. Therefore, the six weeks of EI benefits are not going to be enough for us. We are already dipping into our savings, and we're only at the beginning of the road.

I would also like to recognize the family care platform that the Liberal Party has put forward. At the same time, I would like to challenge all parties to come forward with improved platforms for compassionate care, particularly in view of these diseases becoming more common in our society. I think it makes economic sense to try to help people stay at home.

At this point I would like to thank you for listening to quite a personal story, and I would like to invite you to ask any questions later, if you wish to.

**The Chair:** Thank you so much, Sari.

We will begin our questioning with a first round of seven minutes for questions and answers. We will begin with Dr. Duncan.

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

Thank you, Ms. Jormanainen and Mr. Van Loan, for sharing something so personal.

I'm going to start with the financial side. Most people want to live at home; they want to be with their families. I think people need to understand the costs involved when families aren't supported. They're often forced to go into care. The cost of long-term care per year is about $200,000. A wheelchair is about $4,500. Power wheelchairs are $18,000 to $30,000.

I know that the provinces loan equipment. Ontario is loaning about 1,200 pieces of equipment, but the number of clients, as Ms. Jormanainen mentioned, is increasing by about 15%. The requests for equipment have increased by 67% since 2007, and the society does not receive government funding. I think 40% of ALS families live in poverty. You have the loss of two incomes, and spouses and children become the primary caregivers. Then you have home renovations.

My greatest concern is that we care for people and support the family. People living with ALS want to be heard. They want to be seen. They want to be contributing members of society, and their children need some sense of normalcy.

So what is the best way that we can support families to maintain their dignity and humanity?

● (0925)

**The Chair:** Who would like to respond to that?

Mr. Van Loan.

**Mr. Nigel Van Loan:** Thank you, Madam Chair.

I couldn't have said this better. Thank you very much.

You have all the latest numbers from ALS Ontario. I'm still the chairman of the support services committee, so I know these numbers by heart.

In truth, there is a phenomenal growth of demand for this equipment. I mentioned the ALS Ontario equipment pool earlier. There's over $2 million in capital value of equipment in our 14 depots that is shared. Even with that amount, it's not nearly enough, and therefore we're inundated with requests to buy more and more.

We just took on a donation from Veterans Affairs Canada. They are getting out of the equipment loan business and they provided all of their equipment to us. Even then, we had to go through and strip it down to those that were still usable. That won't nearly satisfy the need.

In my opinion, this whole thing has to be treated as a package for home care. That, as Sari said, and as I said earlier, is where the load is. People want to stay home. It is the least expensive option, versus acute care in a hospital. We need to make sure that home care budgets are adequate to the task of integrating the care, providing the equipment as and when required, and providing the medically qualified assistance at the time it is required.

In the case of my wife, she did not require any medically qualified assistance, right up to the final weeks of her life, because she never went for the breathing apparatus that requires 24-hour supervision. Others choose to go that route and they get into the place where they need around-the-clock care.

There was a gentleman, a deputy governor of the Bank of Canada, who suffered from this disease. Prior to his death, he estimated that the care the Bank of Canada provided for him totalled something in the order of $1.5 million—for around-the-clock care, to take him to the office to let him still work.

I'm not saying that's the required level for everyone. It is an expensive proposition, and we have to somehow get them coordinated into integrated home care. Unfortunately, it is largely a provincial matter.

I want to wave this plan because I helped develop it for this region of Ontario—the Champlain region. It's an integrated care pathway. That's how complicated it is to discuss all the issues required for the support of someone with ALS. If you had that sort of plan in hand across this country, you might well deliver the service when and where it's needed.

Thank you.

**The Chair:** Does anyone else want to make comment on this?

Mr. Cameron.

**Mr. David Cameron:** Very briefly, to add to what Nigel has said, there is an urgency with respect to this whole issue, and it affects a lot of the folks in this room. It's the baby boom generation.

The statistical onset of ALS is in the 55 years to 70 years age range. While it's being diagnosed in younger people, statistically the large size is in that age range. We all know the baby boom bubble is moving along, and consequently the statistical likelihood of more diagnoses of ALS is imminent.

● (0930)

**Ms. Kirsty Duncan:** I had the honour of being at ALS Ontario on Saturday, and they provided these figures. They've got a new campaign, and perhaps people can take a look at it. It's called “paralyzing poverty”, and it's worth taking a look at.

Ms. Jormanainen, the diagnosis is awful, and getting to a diagnosis is awful. What can be done to better support people through that diagnosis and afterwards?

**Ms. Sari Jormanainen:** It was very difficult to wait for the diagnosis. I have a wonderful family doctor, but he's never had an ALS patient, so he did not even really suspect ALS, and it wasn't until we got pretty far and got specialized doctors looking at my case that ALS even came into the picture. I would say that by the time of my diagnosis I had had some symptoms for about a year. Therefore, we knew that things were not right and we knew that something was going on. The children knew something was going on with mother.

It was very difficult to wait for that, and there was very little support during that time. Therefore, I very much support research that is being done—and I know there is some being done—in order to try to speed up that process, to find biomarkers or that sort of thing that could mark ALS or give a better indication of ALS.

Once the diagnosis was there, we were lucky, because we live in Ottawa and we have an ALS clinic here. It's a wonderful facility that supports the patient and the family. But of course their resources are limited as well. There is a regular follow-up to my condition and how it's developing.

**Ms. Kirsty Duncan:** Is there emotional support?

**Ms. Sari Jormanainen:** Yes, I'm getting there, because there are limitations that the clinic can't offer because of the number of patients. We have been lucky to access hospice services. It's only to talk about hospices as such, but I think “hospice” nowadays, as Nigel was saying, actually talks about palliative care, about issues that are coming up much earlier than before. We have in fact put our daughters in touch with a special family support person who is a psychologist and specialized in children and teenagers in this kind of situation. This is voluntary support. It's May Court. It's funded by us, citizens. We are seeing it as an important part of our team, because the girls will eventually start protecting their parents and not talking to us about the important difficult issues. They need those services outside. We are lucky because this is in our community, but I don't know how well such services are available elsewhere, for example, in areas where populations are more scattered.

It is difficult, and the one big piece is that ALS is changing all the time. Just now, when we have got used to this normal, a new normal, there will be a change and we have to readjust. And it means a readjustment for all of us in the family, and that is difficult.

● (0935)

**The Chair:** Thank you, Mrs. Jormanainen. We went way over time because it was important that we hear your answer, and I thank you for that.

Now we have Monsieur Malo.

[*Translation*]

**Mr. Luc Malo (Verchères—Les Patriotes, BQ):** I thank all our witnesses for being here this morning. I have a few questions I would like to ask about the various presentations given today. I would like some clarifications.

First, Mr. Cameron, you spoke to us about special support for afflicted veterans and their families. I am just wondering whether this illness is more prevalent among veterans than in the rest of the population.

[*English*]

**Mr. David Cameron:** We do not have Canadian data and we rely on the U.S. data. The integrity of the data that we might be able to pull out in Canada suffers from the fortunately small size of the community. But in the United States they originally saw anomalies after the first Gulf War and they saw a higher incidence of ALS in Gulf War veterans to the extent of something between 50% and 60% above the norm. They then did some further research outside the Gulf War and looked at military people in general, and looked at both combat and non-combat, going back as far as the Second World War. And again, the likelihood of ALS in the military community in the United States is somewhere around 50% higher than it is for you and me.

There are a lot of opinions and speculation about why that may be. The common one, of course, is that those involved in military service are exposed to environmental things that you and I are not. Maybe it's a predisposition and it's triggered by the environmental conditions. But the good news is that Veterans Affairs in the United States saw the relationship, and notwithstanding that there wasn't a cause-and-effect component, they went with this presumption and made that decision. And that has now been moved over, thankfully, to Veterans Affairs Canada.

[*Translation*]

**Mr. Luc Malo:** Are there studies being conducted to determine if there is a causal link or, more specifically, why the prevalence of this disease, as you mentioned, is 50% higher among veterans than in the rest of the population?

[*English*]

**Mr. David Cameron:** There are no studies of which I am aware in Canada, at this point, although we do have a clinical trials network in Canada. ALS Canada was part of the catalyst to bring it together. So there are 15 ALS clinics across Canada that are now just about ready to launch the third clinical trial in the last two and a half years. The folks on the research side at Veterans Affairs Canada are in contact with the folks in this clinical trials network in Canada, so there is a dialogue going on that I'm aware of that will explore what you're talking about at some point.

At this juncture, we don't know all the veterans who have ALS. Veterans Affairs Canada has indicated 37 or 39 open files at this point. There may be more who have not applied. And since this good news came out from Minister Blackburn, there's a heightened awareness among the military community and they're contacting my office and other ALS offices to find out more. So there will be a growing cohort in Canada, but it's still a small group in the scheme of a clinic trial.

As to whether or not there's anything going on in the U.S., I don't know. I can find out that information and pass it on to the clerk.

● (0940)

[*Translation*]

**Mr. Luc Malo:** Thank you very much.

According to the presentation, the cause of this disease is genetic in 7% of patients; some say that figure may be as high as 10%. Is the cause the same for the remaining 90%? Do we know what causes this illness? Are there different causes? I would like to get the discussion going with these questions.

**Mr. François Gros Louis:** It is true that up to 10% of patients have a genetic predisposition to the disease. The majority of patients have what is called sporadic ALS. We do not know what triggers ALS in these patients. Genes have been identified in what we call familial ALS, that is in cases where ALS is inherited. Some of these genes are also present in patients with sporadic ALS. Although rare, the same mutations are found in sporadic cases. The cause is unknown in most sporadic cases. According to my understanding of the illness, there is an interplay of the factors of genetic predisposition, aging and environmental aspects. The interplay of these three factors triggers the illness at a given point in the life of an individual.

**Mr. Luc Malo:** Do I have some time left, Madam Chair?

[*English*]

**The Chair:** Well, Monsieur Malo—

[*Translation*]

**Mr. Luc Malo:** Just as I thought, Madam Chair, my time was up.

[*English*]

**The Chair:** It's still on, but it will be off shortly.

Thank you so much.

We'll now go to Ms. Hughes.

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

I understand this illness is something that can be very stressful on the family, relatives, your friends. I'm just trying to get a little more information here.

[*Translation*]

My first question is for Mr. Gros-Louis. You mentioned, as did the other witnesses, that funding for research is very important. Could you tell us how much funding you require? Do you think that the current Conservative government has reduced funding? What effect has this had on you?

**Mr. François Gros Louis:** I am just at the beginning of my career and, therefore, it is difficult for me to talk about whether it was difficult to obtain research funding in the past. Over the years, there has been a reduction in research budgets, especially for the day-to-day operations of laboratories. However, there have been some greatly needed investments in infrastructure in order to modernize research laboratories. I believe it is time to reinvest in working capital. Operating grants are needed to improve the quality of the research conducted here.

**Mrs. Carol Hughes:** It is very difficult, at this time, to keep our scientists.

**Mr. François Gros Louis:** It is actually very difficult. For example, in Quebec—and this may be the case in the other provinces — young researchers are given a three-year contract. During that time, they must obtain research funds from CIHR or another granting body. If they do not, the contract is not renewed and they must look for employment in a non-academic area.

● (0945)

**Mrs. Carol Hughes:** Are universities frustrated with this process?

**Mr. François Gros Louis:** It is difficult to speak for the universities. However, it is definitely very frustrating for the young scientists. The next three years will be a rather stressful period, but I hope to have the opportunity to—

[*English*]

**Mrs. Carol Hughes:** You've mentioned the platform from the Liberals, and I certainly appreciate the fact that they've put this platform together. As I'm sure you know, the NDP certainly have been advocating.... Of course Tommy Douglas was the father of medicare, and his vision was to make sure Canadians would never need to dig into their pockets too much to be able to care for themselves. We have been advocating for decades now with respect to national home care and a national drug care program, so I'm wondering if you could comment on the fact that this has to be front and centre in order to ensure that people with neurological diseases such as ALS would be able to live their lives to the fullest and as comfortably as possible.

**Mr. Nigel Van Loan:** I certainly would agree, based on my earlier comments, that a national home care program would be highly desirable if it integrated all of the requirements so that someone suffering from this disease wasn't dealing with a multitude of agencies, which are difficult to identify in the first instance, and was able to have it presented as required and when required. So, yes, if that could be done on a national basis in this wonderful land of confederation and provinces, I'd be delighted to see it happen.

**Mrs. Carol Hughes:** I'm wondering if you could comment as well, because I'm not sure of the impact of the drugs on the national pharmacare or drug care program, how important that would be to the patients, knowing the fact that not everybody has a drug plan.

**Mr. David Cameron:** Perhaps I may comment first.

One of the additional unfortunate aspects of ALS is that there is little to no drug intervention therapy. There is one drug, Riluzole, that has efficacy with some patients. It needs to be used early in the diagnosis. It may delay symptoms for a brief period of time. Beyond that particular drug, there are no others. With ALS we encounter the dilemma that the pharmaceutical companies have of whether it's good business to be endeavouring to identify a molecule that will work for what is in the overall scheme of things something of an orphan disease. Consequently, there aren't many people who are going to take it. From a good corporate citizen point of view, it's the right thing to do. From a business perspective, they are challenged.

**Mrs. Carol Hughes:** The other question I have—and you may have the numbers for this—is with respect to orphan patients and how that impacts. I don't know if you've come across it. I know that in northern Ontario.... And I actually just became an orphan patient, so I'm wondering for someone who does not have a family physician what the impact is on those people who have neurological diseases such as ALS.

**Mr. David Cameron:** The challenge outside of the urban centres is very real. Actually, there are a couple of provinces now, supported by ALS Canada, who with the provincial society have identified mobile clinics. British Columbia is one, Alberta another, where they will get a team together, a neurologist, an OT and PT, they'll get in a van and go out into the hinterlands. They'll do that a couple of times a year. That addresses what you're describing in a small fashion, but not the big picture.

● (0950)

**Mrs. Carol Hughes:** Thank you.

**The Chair:** Thank you, Mr. Cameron.

With your indulgence, would the committee mind if I asked a question at this point?

**Some hon. members:** Agreed.

**The Chair:** Thank you. The Chair doesn't usually ask questions, but I am curious about something.

Talking about drugs, I would assume the drugs are very expensive. I know some provinces have some sort of program. You know, we can talk about a national drug strategy. It's not quite that easy, because it's shared between federal and provincial governments.

I'll give you an example. My husband takes drugs that cost $1,200 per prescription, but the province has a program whereby you can apply. Nothing has been mentioned about that, and I was wondering if you've done an analysis of which provinces have this in place to assist ALS patients. Is it some provinces that have it, or is it all of them? I don't know that. Does anyone know that?

Mr. Van Loan.

**Mr. Nigel Van Loan:** To say I know it would be slightly erroneous, because my knowledge is out of date. At one time when I had checked across the board, so to speak, I think you're precisely correct, some provinces had assistance, some didn't. Ontario, for instance, did not. All through my wife's disease...$643 a month for Rilutek, and that was solely on my dime. It was not on the formulary.

Mind you, for the Ontario formulary, it only applies to seniors, so it wouldn't apply to Sari, for instance, even if it were there. It may be there now and I haven't checked, I'm sorry.

**The Chair:** Mr. Cameron.

**Mr. David Cameron:** Just as a follow-up to that, it's been my experience with the company that makes Rilutek that if there is a need, they will address it.

**The Chair:** Okay. Is there any other information that you can give the committee in that regard? Because drugs can break a family, but it's my understanding that there are supports at the provincial level in most provinces.

I would ask maybe at some point in time that we analyze the different provinces and see what they have. Can you find that out?

**Ms. Karin Phillips (Committee Researcher):** I actually wrote a publication for the Library of Parliament.

**The Chair:** And can you answer that?

**Ms. Karin Phillips:** Most provinces.... I think there's one in the Maritimes—I can't remember which one, offhand; it might be New Brunswick. Anyway, I can provide that for the committee if they want to know.

**The Chair:** If we could get that information, that would be lovely. Thank you.

Now we will go to Mr. Brown.

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

Thank you for being with us again.

Certainly when I think of ALS I think of my good friend Derek Walton. I'd be remiss not to mention him. He's certainly sparked a lot of interest from the community I come from in Barrie, where he skydives every year to raise funds for Sunnybrook's research. I'm sure there are volunteers like Derek across the country. That's one of the special things about your association, to see how people facing adversity sacrifice so much for research and to move the yardstick forward, and hopefully our committee can be helpful in that as well.

There were a few things mentioned I took interest in. It was mentioned that you had some previous partnerships with a muscular dystrophy.... What type of work did you do with MD? I know the firefighters across Canada do a lot of research with MD, and I didn't realize there maybe were some overlapping areas. What commonalities are there?

**Mr. David Cameron:** This partnership began in 1999 and it was a tripartite relationship among Muscular Dystrophy Canada, ALS Canada, and CIHR central, at that point in time. Each of the three parties agreed to put in $550,000 a year. So there was $1.65 million available in what's called the neurological research partnership, or NRP, for short. It's still in place ten years later.

We use CIHR to do the peer review, and each of the three parties pays the money out directly to whichever researcher is successful. In the early days of the partnership there wasn't enough ALS research out there. There wasn't enough scientifically meritorious research in neurological diseases to spend all the money. That's changed. The NRP became the only game in town for the research community in neurological diseases in the early 2000s. We got to the point where, yes, we were not only spending the money, but there were quite a number of highly ranked research grants that couldn't be funded because we ran out of those dollars.

So probably somewhere between three and four three-to-five-year grants in neurological disease research are granted every year.

I don't know, François, whether you've had an NRP grant, but an awful lot of the ALS researchers in Canada have.

● (0955)

**Mr. Patrick Brown:** Everyone asked the Alzheimer Society where Canada was in a global context. They mentioned that France and the U.K. were obviously doing some very interesting work. Is there anything we're not doing in Canada that we should be in terms of research? Are there any other countries that Canada should look to partnerships with? Are there any interesting research projects being done abroad that are promising? I know with Alzheimer's that Canada actually formed a research partnership with a few European countries to look at areas of commonalities. In terms of ALS, is there anything like that? Are there any countries that are putting a real focus on it that Canada could look towards?

**Mr. David Cameron:** One of the things that I find with the ALS research community internationally is a tremendous collaboration, a collaborative spirit. All of the senior researchers know one another; they all go to the same research conferences right around the world, and there is a sharing of information. We have had a number of collaborations between the ALS Society of Canada and our American counterpart. There have been some clinical trial collaborations between the clinical trials network here and the one in the United States. We have some collaborations with our U.K. counterpart as well.

To my knowledge, there is no work that's going on outside of Canada and North America that the ALS researchers in Canada are either not aware of or not involved in. What we find is that the ALS researchers tend to have an area of focus, and they will collaborate with their counterparts who have a similar focus in other countries, and share their information quite gladly.

**Mr. Patrick Brown:** François, you mentioned that one of the things researchers do is they have these crazy ideas, wild ideas, and they like to chase every possibility, and that's exciting.

Can you tell us a little bit—I think it would be educational for us —about what types of research projects you are not able to do because of the more limited scope of research funding in Canada? I realize that if we're ever going to make breakthroughs, it really is looking for that needle in the haystack, and we're going to need a lot of different hands searching for that needle. What type of work are you doing? What type of work do you envision that we should be doing?

**Mr. François Gros-Louis:** Fundamental research on ALS all across Canada is really a cost-effective type of research. To transition to clinics, I think it costs a lot of money. What you find in fundamental research is that it is very expensive to be able to transpose it to clinics. There's a good initiative by ALS Canada, called the Canadian ALS Clinical Trials and Research Network, which tries to bring together all clinics across Canada, because to have access to a large pool of patients in only one province or only one ALS centre.... Canada is a huge country, so it's difficult to manage all the ALS research together. I think ALS Canada found a way to do it, but it's really costly. We need that type of thing.

● (1000)

**Mr. Patrick Brown:** David.

**Mr. David Cameron:** You heard François say that trying to get a grant for a wild idea is not likely to happen. At this point, CIHR is granting about 19% to 20% of the applications, so you've got all that group of around 80% that are simply not being granted.

**Mr. Patrick Brown:** Is that in the ALS field?

**Mr. David Cameron:** No, that's right across the board.

**Mr. Patrick Brown:** In general.

And are the ratios similar in ALS?

**Mr. David Cameron:** Yes.

That's why we have expanded our program, to the point where we're investing over $2 million a year in research.

**Mr. Patrick Brown:** Do you believe that most of those 80% that aren't currently being funded have merit, or are there some that just don't make sense?

**Mr. David Cameron:** The way the system works is that when the review is done they have to be above a certain level. So some of those 80% would fall below, but an awful lot are above the level, and there's simply no money up there.

We put together a program a couple of years ago that we called discovery grants. There's $100,000 for one year for that kind of wild idea that you would never get funded anywhere, particularly if you're a young researcher and you've got a new idea. It's that kind of thing that maybe we're going to hit on one of these. So we're investing about $200,000 a year looking for two of these wild ideas and maybe something will come to fruition.

**Mr. Patrick Brown:** Just to put this in context, you're investing $200,000 a year, and what do you think the monetary value is of 80% of the grants that aren't being funded? How many opportunities are we leaving on the table? Do we have any idea?

**Mr. David Cameron:** It's hundreds of millions of dollars. A grant for three to five years is in the $600,000 to $700,000 range, maybe. So extrapolate that out over all of the fields.

One thing I just want to make clear on this subject of CIHR. Nigel was talking about $350 million. We're not asking for ALS, we're asking for CIHR to have the funding, because when the discovery happens, it will assist everybody.

**The Chair:** Thank you, Mr. Cameron.

We'll now go to Dr. Duncan. And we're going now into our second round, five minutes each for questions and answers. I've been a little lenient on the time because as I've listened to your testimony I thought we needed that. But that doesn't mean to say I'm going to do it this round.

Dr. Duncan.

**Ms. Kirsty Duncan:** Thank you, Madam Chair.

I'd like to draw to the attention of the committee that the European Brain Council is advocating that 2013 be declared the “year of the brain”. This would line up well with the national population health study of neurological conditions, ending March 2013. Canada will also be hosting the World Parkinson Congress in October 2013. We'll have 4,000 researchers coming. Maybe the committee could recommend that Canada also declare 2013 the “year of the brain”.

I will now pick up on ALS and veterans. This is something I've been doing a lot of thinking about. Perhaps, Mr. Cameron, I can ask you if it would be worth our identifying and contacting veterans with ALS—including those whose claims for ALS were previously denied—through either direct mailings or other outreach programs.

I think we absolutely need a national ALS registry, which I believe you're working on, because we have to identify veterans with the disease regardless of when they served. We need to track their health status. It's probably best to do this through an initial telephone interview, covering their health and military service, and perhaps twice-yearly interviews thereafter, and ensuring research regarding the different types of treatment in order to better support veterans with ALS.

I wonder if you could comment on that, please.

**The Chair:** Mr. Cameron.

**Mr. David Cameron:** First of all, let me say that it's my understanding that Veterans Affairs Canada has already taken the initiative to go out to all of those veterans who have been turned down. And actually, just a couple of days ago we received a comment from somebody in B.C. who wrote to the local ALS Society, saying, “Guess what I just got in the mail—a retroactive cheque”. They have no idea how it ultimately happened, but it doesn't matter. It's on the table.

It certainly makes good sense to be proactive in communicating to the veterans community that there has been a change in the policy from almost a universal denial—and then having to go through the appeal process when you have a lot on your plate—to the circumstance now where they're being looked at and being granted.

There is a lack of awareness. It's a big country. Not everybody is following that news. So in some fashion, getting the message out, we are doing what we can, and it's on our website.... The Veterans Affairs documentation will be on our website shortly. But anything that can be done through Veterans Affairs or any other government agency to get the message out there....

A registry, you're right. We are working on an ALS registry, and we expect it's going to start up in the new year. The infrastructure is now in place, subject of course to privacy rules. There is no reason at all that veterans with ALS shouldn't be part and parcel of that.

● (1005)

**Ms. Kirsty Duncan:** How do you feel about tracking our vets, an initial telephone interview looking at health and military service—and perhaps twice-yearly interviews afterwards—and looking at specific research regarding types of treatment in order to better support vets?

**Mr. David Cameron:** That makes good sense. It also enables the opportunity to perhaps identify the contributing or triggering factor that has initiated the ALS. If there's a commonality—for example, environmental—the more information we have, the more statistical data out of Veterans Affairs, the better off we will be.

**The Chair:** Thank you, Mr. Cameron.

**Mr. Nigel Van Loan:** May I just add one comment to that, Madam Chairman?

**The Chair:** Please go ahead.

**Mr. Nigel Van Loan:** We as a society are working very closely with Veterans Affairs in Charlottetown with the appropriate people, both research and medical, to make sure that our knowledge is shared with them in terms of how they might progress the care and support of veterans.

**The Chair:** Thank you, Mr. Van Loan.

We'll now go to Mr. Brown.

**Mr. Patrick Brown:** I'd like to follow up on some of the questions I'd asked before.

The $350 million: what would that do in terms of the percentage of research not being reached? Would that mean that it's 25/75, or would that dramatically change the scope of things?

**Mr. David Cameron:** I think it would make a dramatic difference, simply because if you divide the $600,000 or $700,000 into the $350 million, it will generate a significantly larger body of research and knowledge. I know that we have finite dollars....

I haven't done the analysis that would respond directly to that question.

**Mr. Patrick Brown:** Down the road, if it's possible to do that, it would be interesting to know what it means. When we're looking at making pitches and presenting ideas within our various caucuses, I think it would be very interesting to know how much more research should be done and what that means for organizations like yours.

There's another thing I wanted to ask about. This is the neurological disorders subcommittee, and the reason we're looking at each of these subsets is that we believe there are a lot of commonalities and that it's important for us to understand that better. What do you view are the commonalities between the major neurological disorders? When you invest in research in one, how does it benefit our understanding of the brain in general?

**Mr. François Gros-Louis:** Neurological diseases involve neurons, and there are different types of neurons. We think that for all neurodegenerative diseases—for example, ALS, Alzheimer's, Huntington's—the same kinds of degenerative pathways are involved but different neurons are involved.

In ALS, it's motor neurons that are degenerating. In Alzheimer's, it's memory cells that patients are losing. In Huntington's, the neurons are of a different type. In multiple sclerosis, it's myelin that's degenerating. But we think the pathways are kind of similar.

One example is the immunization therapy we're developing with ALS. This approach was also used with Alzheimer's disease, where they went into a clinical trial with a vaccine for Alzheimer's. The clinical trial was stopped because some of the patients developed adverse effects. That's why, before going into a clinical trial with immunization in ALS, we will look carefully at what happened during the Alzheimer's disease trial and not repeat the same problem they had.

● (1010)

**Mr. Patrick Brown:** Do you find there's a lot of sharing of knowledge amongst the various neurological groups? Is that happening in Canada?

**Mr. François Gros-Louis:** Yes, it's happening in Canada, for sure. During the national meetings of the Canadian neuroscience society—they organize a meeting every year—there is a lot of sharing of information.

**Mr. Patrick Brown:** There is something else I'm interested in. A year ago I lost my grandmother to Alzheimer's. I remember asking the doctor at the time about Alzheimer's. I was surprised at how much we didn't know about it and how little understanding there was of the brain when it came to Alzheimer's.

I guess that's my concern with neurological disorders: what basis are we starting from? For instance, I went to the CIBC Run for the Cure, and they talked about the tremendous progress in breast cancer research, comparing the life spans and the survival percentages. What basis are we starting at here? What have we learned in the last 20 years? What progress are we making, and what opportunities are there for progress? Have we had successes? Are we optimistic about successes?

I know those are general questions, but....

**Mr. François Gros-Louis:** Yes, we are really optimistic. It's very difficult to study neurological diseases. It's difficult to get brain biopsies. Nobody wants to give them, so we are developing animal models, cellular models, to study those diseases.

The technology is there. We have various animal models that help us a lot to study the biology of the disease. Over the past years we have begun to understand which biological defects lead to those diseases.

**The Chair:** Thank you very much.

Monsieur Malo.

[*Translation*]

**Mr. Luc Malo:** Thank you, Madam Chair.

I will continue along those lines. In reply to a question posed by Ms. Hughes, Mr. Gros-Louis said that it is important for him and young researchers to generate interest in the research they are conducting. I would like to provide you with an opportunity to explain the research you are involved in, and to explain why it is pertinent, interesting and promising. Therefore, I am simply asking you to expand on what you told my colleague, Patrick Brown, and explain to us why passive immunization, based on various models used to treat Alzheimer's, may be promising in the case of amyotrophic lateral sclerosis.

**Mr. François Gros Louis:** The passive immunization that we are developing is based on the administration of monoclonal antibodies, antibodies specific to a protein called SOD1. A small number of patients possess mutations of this gene. It is believed that administering these antibodies to patients will eliminate the protein's toxic effect.

As we know, the majority of ALS cases are sporadic. Recent, unpublished studies have shown that sporadic patients can acquire malformations of this protein even if there is no mutation in the SOD1 gene. Environmental toxins can cause misfolding of the protein's tertiary structure and create toxicity. The treatment we are developing could be used with patients who do not have a genetic mutation, which represents the vast majority of people suffering from ALS.

● (1015)

**Mr. Luc Malo:** This scientific procedure that you have developed is just one being studied internationally. Is the community of researchers studying ALS focusing, for the time being, only on this alternative, or is other research on other advances being conducted elsewhere in the world? Are researchers from all over the world talking to one another in order to come to a better understanding of ALS?

**Mr. François Gros Louis:** Yes, there are a number of collaborations with various research groups around the world. For example, with regard to immunization, there is currently a collaboration with a Boston group with a view to humanizing the antibodies identified. Antibodies have been developed in mice. Going directly to clinical trials with patients would be a bad idea because they would develop rather adverse immune reactions. Thus, we have to humanize these antibodies. Some groups in the United States have specialized in this technology. We are actively working with them to carry out this research. There are also other proteins involved, not just the SOD1 protein I mentioned. Other genetic mutations have been identified, other abnormal proteins have been found in ALS patients. A great deal of research is currently being conducted on this subject.

**Mr. Luc Malo:** Have you established a timetable? For example, earlier you said that clinical trials are not being carried out in order to avoid repeating the mistakes or encountering the problems observed with Alzheimer's. Nevertheless, do you know approximately when this will take place?

**Mr. François Gros Louis:** It is very difficult to say. I am not directly involved in the clinical translation. The post-doctoral supervisor looks after that aspect. It is very difficult to establish a precise timetable.

**Mr. Luc Malo:** Are there specific obstacles that have already been identified?

**Mr. François Gros Louis:** Yes, first patients have to be recruited. It may be very difficult to get them to agree to participate in the research project. It is a new technique and some patients may have concerns. Furthermore, the antibodies may have no effect or the effect may be moderated. There is also the issue of antibody delivery, of how to inject the antibodies. Will intravenous injection have to be done via intrathecal injection directly into the nervous system in order to be effective? We do not presently have the answer to such questions.

[*English*]

**The Chair:** Thank you, Monsieur Malo.

[*Translation*]

**Mr. Luc Malo:** I have one last question, Madam Chair. And then I will turn the remaining time over to you.

[*English*]

**The Chair:** Of course. Go ahead.

[*Translation*]

**Mr. Luc Malo:** Thank you very much.

One or more genes that cause this disease have been identified. Have they been identified in children? Mr. Van Loan, you said that one of your fears is that your children or grandchildren may carry such a gene. Are we already starting to see that this is detrimental for children or grandchildren who may be carrying this disease?

● (1020)

[*English*]

**Mr. Nigel Van Loan:** Thank you.

If my children or my grandchildren carried these genes, there is a blood test that would identify that. However, that is a minefield into which I do not advocate they go at this time. We do not have protection for them against future insurance problems, in that case. There's a host of issues to be dealt with ethically and legally in this area.

**The Chair:** Thank you, Monsieur Malo. That's an unusually short time for you.

There is the possibility that we will run out of time, Mrs. Hughes. You're sort of down at the end of the list, so Mr. Brown will graciously let you take his place. You can ask some questions now. Then we'll wrap up at 10:30.

Thank you, Mrs. Hughes.

**Mrs. Carol Hughes:** Thank you. I greatly appreciate your generosity of time here. Never mind that he wants something, I'm sure.

**Voices:** Oh, oh!

**Mrs. Carol Hughes:** I have a couple of comments. The first is about when it's genetic, and being able to get insurance. Some insurance coverage must be extremely difficult to get. It puts those people in precarious situations, so I can understand the comment you made with regard to youth.

There was some talk across the table about employment insurance, compassionate care, and palliative care. I sit on the palliative care and compassionate care committee. I know there are some difficulties there as well.

Do you have any suggestions as to what should be brought forward, aside from EI changes? Even with EI changes, I don't think you could get it for a very long period of time. Let's face it: this is an illness that you could need assistance with for three to five years, or maybe longer.

On compassionate care, is there something the federal government could do? I know tax credits are there, but that doesn't usually help someone with their wages for the year. Is there something else that people have in mind?

**Ms. Sari Jormanainen:** I think Nigel actually brought out already a few points that I would also highlight.

I think the EI benefits are very important, but also flexibility in that system to allow, for example in my case, my husband to maybe start with a day off work and then increase that time as the need arises.

I also very much agree with Nigel's point on bringing the different operators together. Here I'm talking about the ALS clinic that is doing a great job and the ALS Society that is doing a great job. The community care has limited resources but is an important player, and increasingly important when the disease progresses. And then there is the family doctor who often needs support to be actively involved and to deliver the care that is needed.

In Ottawa, the city does have palliative care teams. We're lucky in that way, and later on our family will have access to that. But again, it's another factor, another team that needs to come in to support us at home.

And then there is the whole emotional aspect. I still feel that we are lucky to have access to service, but many families do not. I do actually acknowledge the work that the ALS Society has done in this regard, because those were exactly the brochures that we showed to our children. There was no way of keeping them in the dark when things were moving on.

So I do think that there's this sort of coming together. We know about the Champlain district work that has been done to bring these bits and pieces together. It's exemplary, but I think that needs to also show in the field and I think that remains a challenge.

● (1025)

**Mrs. Carol Hughes:** I don't know if there's any more....

**Mr. Nigel Van Loan:** May I add to that, Madam Chair?

At the palliative care meeting I attended, I made reference to a feeling that we're finally getting this spread out, this ethos of palliative care, and that's what it is. It's not a technique. It's not something that is different from just the whole ethical way in which you approach patients.

If there's anything that can be done at the national level, federally, it is the encouragement of the national bodies that accredit medical people such as nurses, such as social workers, such as doctors, to ensure that their curricula bring this ethos to bear in their training.

**Mrs. Carol Hughes:** If I have a little bit of time, I would just sent it back to Mr. Brown.

**The Chair:** Actually, four seconds, but he gets a lot in four seconds. So do you have a question, Mr. Brown?

**Mr. Patrick Brown:** That's fine.

**The Chair:** Okay. I would give you more than that.

Thank you very much. We want to thank you for coming today.

I'll just read out our mandate for our website:

> On the 26th of March, 2009, the committee passed a motion establishing the Subcommittee on Neurological Diseases. The subcommittee has agreed to conduct a study that will focus on five diseases, including autism spectrum disorder, ALS, multiple sclerosis, Alzheimer's disease, and Parkinson's disease. Written submissions regarding neurological diseases and disorders will also be considered.

So that is the mandate for our website.

I know that we do have another committee coming in in a few minutes, but I know that some of our people just want to have a private couple of words with you. This will give you an opportunity to do that.

Mr. Van Loan, could you please table your report so we can distribute that to all the committee members?

**Mr. Nigel Van Loan:** I'm not sure. Do you refer to this? It's unfortunately a draft version. I will make connection with your clerk to deliver both a French and an English copy to her of the final version.

**The Chair:** Oh, that would be so nice. Yes, thank you. Thank you.

You see how anxious everybody is? They didn't forget the report. We've been listening very attentively because this is a very serious issue and we're so pleased and honoured that you share your stories with us and your knowledge and you're keeping up with absolutely everything.

Mr. Cameron, it was so good to hear some of the acknowledgement you've noticed and we sure wish you well in your research. It's extremely important.

We will dismiss for now, and thank you again.

The meeting is adjourned.

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