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Tuesday, June 8, 2010

Chair

Mrs. Joy Smith

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● (1100)

[*English*]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): I'll ask everyone to take their seats now so that we can get started.

I want to welcome the witnesses today. This is the Subcommittee on Neurological Disease of the Standing Committee on Health. Pursuant to Standing Order 108(2), the study on neurological diseases will begin today.

In this particular area, we have with us Denise Figlewicz, vice-president of research with the ALS Society of Canada; we have Felicia Travis Valo; and we have Melanie York, who is a board member of the ALS Society of Canada.

Welcome. I'm very glad you could join us.

We also have Dr. Alex Parker, assistant professor from the Université de Montréal research centre. We're very pleased to have you here.

We'll have five-minute presentations, and we'll begin with Ms. Figlewicz.

[*Translation*]

Dr. Denise Figlewicz (Vice-President, Research, Amyotrophic Lateral Sclerosis (ALS) Society of Canada): Good morning. My name is Denise Figlewicz. I am Vice-President, Research, at the Amyotrophic Lateral Sclerosis Society of Canada.

Thank you for having invited me today to make a presentation to you.

[*English*]

Good morning, everyone.

I want to thank you very much for this opportunity to say a few words this morning about ALS and the ALS Society of Canada.

Amyotrophic lateral sclerosis is an adult-onset neurodegenerative disease. It's rapidly progressive and ultimately fatal. Specific groups of nerve cells that control the voluntary contraction of muscles are lost. As the nerve cells die and the disease progresses, individuals lose the use of their hands and arms, their legs, speaking, swallowing, and breathing.

Our sense of urgency with respect to the question of diagnosis, care, and development and identification of treatments for ALS is heightened by the population change. We're looking at the aging of the baby boom generation, because the age of highest risk for ALS will very soon overlap with the age of the baby boom generation. What we consider a serious health problem now is about to increase significantly.

The primary mandate of ALS Canada is to fund research to identify disease mechanisms and putative new therapies for ALS. As vice-president of research for ALS Canada, I identify research needs and create and implement grant programs, knowing that the identification of treatments for ALS will come from research discoveries. I have to say that recent history will support me in saying that discovery of treatments related to research is directly proportional to the amount of money that is invested in the research itself.

ALS Canada invests in our senior scientists. Our flagship grant program is one that is carried out in partnership with the Canadian Institutes of Health Research and Muscular Dystrophy Canada. Last year, the Neuromuscular Research Partnership funded $2.74 million in operating grants for senior scientists.

We also provide discovery grants to encourage novel approaches to research in ALS or to bring researchers from other fields into the field of ALS research. We have pre- and post-doctoral fellowships to encourage the development of the next generation of scientists in research in ALS and other neurological diseases.

In 2009, we initiated the first clinical research fellowship. This is a special program in which an individual who is board certified in either neurology or physiatry is given two years of salary support to work in an ALS clinical centre. That situation will allow them to learn about the special needs of patients as well as to learn how to carry out clinical research. The goal of the program is to increase the number of expert ALS clinicians and clinician researchers throughout Canada.

We also provide travel stipends to encourage our scientists at all levels to travel to international meetings to meet their international colleagues and to present their work.

My total research budget for this year is $2.033 million.

The subcommittee has asked for an update on research related to diagnostics for ALS. Unfortunately, I have to say that the diagnosis of ALS remains an area in which research is badly needed. There are no biomarkers for ALS of sufficient specificity or sensitivity. Thus the diagnosis for ALS remains a diagnosis of exclusion. What this means is that an individual is followed over time by their clinician as other related syndromes are ruled out. A patient can wait as much as 18 months for access to care and resources specifically related to ALS. We are seeking out research opportunities right now to help while basic research is under way identifying treatments.

When I began my job in 2006, the message that I heard from both ALS clinicians and ALS patient groups was one of frustration, not just at the lack of treatments available, but also at the lack of opportunities to participate in research studies or clinical trials. In a direct response to this, ALS Canada has aided the incorporation of a clinical research and trials consortium at 15 ALS centres across the country, from Vancouver through to Halifax.

We underwrote the incorporation of this group and we also provided the funding for their very first clinical trial. In January 2009, a clinical trial was begun. This came to an end last fall.

● (1105)

A great achievement as part of this was that our CALS, the Canadian ALS clinical trials consortium, worked with probably the best ALS consortium in the world out of the northeast of the U.S. called NEALS. As a result of the very good collaborative bonds that were built at that time, CALS and NEALS are currently already engaged in the next clinical trial together.

We believe this type of clinical trials network represents a model for a turnkey package that could be readily modified for application to other diseases for which clinical trials in Canada are rare or non-existent. However, ALS—

The Chair: Ms. Figlewicz, your time is coming to a close. I've given you an extra minute. I just want to make you aware that you need to wrap up pretty soon.

There will be time for questions and answers. Thanks.

Dr. Denise Figlewicz: All right. In fact, I am almost finished.

The Chair: Oh, good.

Dr. Denise Figlewicz: I just wanted to say that ALS Canada cannot continue to support clinical trials. The support of clinical trials is undoubtedly an arena of national concern, not one that can be undertaken by provincial health systems.

Thank you very much for your attention.

The Chair: Thank you. There will be an opportunity for you to say more when people ask you questions.

Ms. Valo.

Ms. Felicia Travis Valo (Amyotrophic Lateral Sclerosis (ALS) Society of Canada): Good morning, esteemed members of the committee. Thank you very much for this opportunity.

I am here before you today because my husband, Sidney Valo, lost his heroic battle with ALS in December 2008.

[*Translation*]

Our life, as we had known it, came to an abrupt end the day of his diagnosis. Instead of pursuing his own interests, Sid devoted himself to raising public awareness and to gathering funds, which is so necessary for ALS, and he was thus able to collect nearly $300,000, despite the fact that he was progressively losing his ability to walk, to eat and to speak.

[*English*]

It is also because of my husband's legacy and commitment to the ALS community that I am here today in the hope that you may gain a better understanding of the devastating toll of this disease.

Sid and I were made painfully aware that ALS has no known cause and no cure or effective treatments. While we were grappling with this reality, we had to quickly sell our home, relocate to an apartment that could be made accessible, set our financial affairs in order, and prepare our children for the worst.

As the disease progressed, Sid became physically paralyzed and totally dependent on full-time care, while remaining cognitively intact and acutely aware of his demise. Not infrequently, he was emotionally tormented at the pain and stress his fatal illness was causing his family. To that point, two of our children took longer to complete their university degrees. We also lost a source of income when I had to give up my psychology practice of 20 years.

After he died, I was diagnosed with post-traumatic stress disorder, and it is only in the last six months that I've been able to resume my work on a full-time basis.

I also made a conscious decision to relinquish my role as wife in some respects and to assume the one of primary caregiver. While this was physically and emotionally taxing in ways I could not have anticipated, I came to realize there were many less fortunate people than me who were doing this with far fewer financial, logistical, and technical supports.

The equipment and personnel required, such as specialized caregivers, are considerable and the costs can be staggering and can leave families in financial ruin. While resources and equipment and tools exist, these aren't always readily available, and for those less savvy in navigating the system, it's easy to see how overwhelmed and demoralized family members can become.

Many individuals with ALS are often unable to be fully cared for at home, sometimes because the primary caregiver is also the primary breadwinner, and other times because the family, simply put, burns out. This has psychological consequences that can leave the families divided and shattered. Despite the many supports we had, I often felt on the brink of collapse.

These are but a few of the compelling reasons that we desperately need to revamp Canada's compassionate care policy—

● (1110)

The Chair: Could you slow down just a little bit for the translators.

Ms. Felicia Travis Valo: Oh, I'm sorry, I'm trying to keep within my time limit.

These are but a few of the compelling reasons that we desperately need to revamp Canada's compassionate care policy to build in greater flexibility for EI. For example, it would be advantageous to allow partial weeks over a longer period, rather than blocks of weeks at a time.

The creation of a companion program to the compassionate care benefit not solely based on employment would also be crucial to ensuring that families can survive.

[*Translation*]

ALS patients deserve to have hope, and this is only possible with the advancement of research, increased clinical trial opportunities and better support for the family, more particularly the caregivers. Treatments for this horrible illness are desperately needed. This is why we are asking for your help and support.

[*English*]

Thank you very much for this opportunity.

The Chair: Thank you.

Ms. York.

Ms. Melanie York (Board Member, Amyotrophic Lateral Sclerosis (ALS) Society of Canada): Ladies and gentlemen, thank you very much for inviting me to come to this meeting to be a witness.

My name is Melanie York. I am 56 years old and I am living and dying with ALS. Prior to my diagnosis in September 2008, I was fully active and passionately engaged in life. I was an award-winning television producer at YTV. Always full of adventure, I was an avid traveller who loved to scuba dive, hike, and motorcycle, and on my quieter days, paint, read, and cook.

All of that joy in life is now gone. My arms and legs do not function. I have become totally dependent on others for my care and the simplest of needs. I cannot feed myself or hug my family, and I am so vulnerable that I cannot be left alone. ALS constantly challenges me to be courageous in the face of this devastating disease. At night I pray that I will wake up the next morning without further loss of function. I live daily with exhaustion, depression, and raging frustration. While my body is being stolen from me, my mind, spirit, and heart have to watch. Perhaps that is why ALS is akin to being buried alive.

Adding to the physical and emotional hardships of this illness are huge financial burdens. In 2009 I spent close to $60,000 from my savings on costs directly related to ALS, which included electric chair lifts, full-time care, alternative treatments, and home modifications. ALS moves at locomotive speed, and subsequently, six months later, I am now forced to move again, into a home that can satisfy all my long-term needs, necessitating my partner and I to incur hundreds of thousands of dollars of debt. All ALS patients face incredible financial challenges, giving rise to the phrase “ALS is the bankruptcy disease”.

I am kept alive by a caring team of people, including family, friends, salaried caregivers, and my partner, who has reduced his workload to care for me. Though I visit a Toronto ALS clinic and have only limited access to a multidisciplinary team, it is my caregivers who support and care for me 24/7.

Education for support people is sorely lacking, and burnout is inevitable. I believe that the role of the caregiver needs to be fully acknowledged and redefined when dealing with chronic illness. To that point, I suggest that the federal government expand its policy on compassionate care to better reflect the needs of those who are chronically ill and those who care for them. The current policy of six weeks off in a six-month period is totally inadequate. We need to be more flexible and responsive to the realities of caring for those we love, allowing for partial weeks over a longer period of time rather than just blocks of weeks. Another viable suggestion could be a period of 26 weeks, accessed over a 52-week period.

There is no question that the training and mobilization of caregivers is essential—absolutely essential—to those living with ALS and other neurological diseases.

I have joined the board of ALS Canada because I have always had a strong voice. Now is the time for me to use that voice, as ALS will take that soon too. The clock is ticking very fast. A cure for ALS depends on research, and research depends on money.

Thank you very much.

● (1115)

The Chair: You are certainly very courageous people.

Mr. Parker.

[*Translation*]

Dr. Alex Parker (Assistant Professor, Research Centre of the University of Montreal Hospital Centre (CRCHUM), Department of pathology and Cell Biology, Université de Montréal): Welcome everyone. My name is Alex Parker. I am a researcher at the University of Montreal. I did my doctorate at the University of British Columbia, and then I did my post-doctorate in Paris, France. Allow me to continue in English.

[*English*]

For most of my career I've been studying Huntington's disease, but my interest lies generally in neurodegeneration.

We made some important discoveries during my time in France, and we hope there will ultimately be benefits to patients. But another aspect to be considered is that the fruits of that research lie primarily in France and the United States, as they were the sources of the funding. This is something that I think Canada misses out on a lot of the time.

Recently, thanks to ALS Canada, I've been recruited to study ALS. This is directly due to an initiative from ALS Canada known as the Bernice Ramsay discovery grants. It is an initiative to fund high-risk research or attract researchers with different techniques to the field. I thought our approach would be applicable, so I applied. This type of funding doesn't really exist at the federal level. It is a lifeline for groups like mine, because I'm a relatively new researcher. This funding directly is like a lifeline to the lab, allowing me to set up and get going. It's been very beneficial so far.

I'm not saying all of the federal funding is inadequate. Some aspects are very good. For example, my salary is funded by the CIHR as a new investigator; infrastructure from the Canadian Foundation for Innovation was fantastic; and the new initiatives for funding student scholarships are also good. But we are missing one aspect, and that is operating funding to basically run the lab. We have projects ready to go. I could run three projects tomorrow, but I just don't have the money to get them going. This could be a situation where if we wait too long on some of these things, other people will move ahead, and some of the commercial aspects will go elsewhere.

So I believe that an increase in neuroscience funding is crucial. Why do I think this? It's because, as Denise touched on earlier, Canadians are living longer than ever, and the number one risk factor for all neurodegenerative diseases is aging. Just because people are living longer doesn't mean they are necessarily living healthier. You'll see an increased occurrence of many neurological diseases, including ALS, as people live longer.

We need to not just increase Canadians' lifespans, but increase their health spans also and maintain a healthy and productive population. What we're asking for are basically resources to eliminate suffering—that's an obvious benefit—but also to strengthen our scientific efforts. These will hopefully have benefits for the patients and families, but there will also be economic, societal, and productivity benefits.

At this point, working in a lab, I would say that two-thirds of the pieces are in place: infrastructure and support for training studentships. But we basically need the resources to round it out and do the experiments. I'll leave it at that.

Thank you very much.

● (1120)

The Chair: Thank you very much for your presentations this morning. It must have been very hard for you to come here today to tell us about the challenges you have. But the reason we have you here is because you have a group of people around this committee who are more than interested, who feel very compelled to listen to the challenges and try to move forward to do something to help.

We'll go into our first round of questions and answers. We're going to begin with Dr. Duncan.

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

Thank you all for coming, and for your courage and strength in coming here. I think you've touched all of us and we're overwhelmed.

Felicia, what are the five things that would have helped your family? You talked about compassionate care, but tell us everything that would have helped your family relieve the suffering.

Ms. Felicia Travis Valo: I think initially a more comprehensive team at the hospital Sid first went to, to be diagnosed. It was a bit disjointed, the efforts to diagnose him. And we ultimately went to the States because we couldn't get it done here properly. So that would be one thing.

Once we came back with the diagnosis—which, by the way, was made instantaneously once we went down to the States, whereas here it was a nine-month ordeal of going down different paths, with different possible diagnoses... Once we came back, unfortunately, the ALS clinic was not as well equipped as it needed to be to offer service. The personnel there, as well-intentioned as they are, are stretched to the max. There's a need for clinical coordinators. There's a need for more support groups. There's a need for a more comprehensive team. So I think that would be the second thing.

There's a need for better information packages, so that when a person is diagnosed you get material that takes you step by step in a better way than is currently being provided.

Four, a cure. Treatments. Hope. We often felt that there was no real need to go to hospital. It was a very unsatisfying experience. Again, as I say, as well-intentioned as everyone was there, there really wasn't much to offer. We ultimately went to the States for clinical trials because there were none here. Now, fortunately, that's changed. But unfortunately, by the time the clinical trials came to Toronto, my husband's disease was so advanced that he couldn't participate. But he was very instrumental in bringing clinical trials to Toronto.

And I think more awareness. We felt very alone in this disease. It's often called the orphan disease. Here we are, it's June, ALS Awareness Month, and very few people know that it is. I think we would have felt better supported if there was a more concerted effort on the awareness front.

Ms. Kirsty Duncan: Thanks, Felicia.

I really want to echo what our chair said. This committee exists because I think we're all frustrated with the lack of treatment, a cure, and we know there are things available overseas that we'd like to get here.

Melanie, are there any supports that would...?

● (1125)

Ms. Melanie York: There are a couple of things I want to say.

There is an incredible lack of integration between your regular GP and your neurologist. I feel as though I live in, sometimes, two separate places. There's very little awareness among GPs of ALS. There are no coordinated treatments, really, between your GP and your neurologist.

I find that I have to depend on my own intuition most of the time as to what to do. I'm not saying it's a lack of caring. It's a lack of what's available. It's a fear of stepping out of the box in terms of treatment. Even though I spent $10,000 last year on alternative treatment and was told, “Well, you know, there's no proof, no proof, no proof”, I have nothing to lose. I don't know if it helped. It helped me mentally and it helped me emotionally, because the worst thing is to feel that you can do nothing for yourself.

I went on a clinical trial. It took me eight months to get results from it. By that time, I lost more and more function. The reality of how you can get into a clinical trial, get the information, and the speed at which your body is continuing to decay don't match up.

Every trial has its own specifications in terms of when you can get in. I'm also part of a statistic for study. Sometimes I feel, am I a statistic? Am I a patient?

I have ALS; I am not ALS. It's very important for me to tell you that, because I have devoted most of my energy to keeping my mind as balanced as I can, to keeping my spirits strong, to contributing and to being here. That is all I can do for myself. Otherwise I open my hands to everybody else and at a certain point you feel spun around and around, and you have to stop because the insanity is too much.

I think—we've mentioned this—there is also a need for spiritual care. The medical model as it exists now has a strong emphasis on the clinical and diagnostic, but somewhere we need to mobilize people's ability to heal themselves. I'm not saying a cure; I'm saying to bring themselves to the best place possible within themselves to deal with this. You have to live alongside this illness. How do you do it if you have no access to that kind of support, help, or guidance?

If I could put anything forward, it would be—not just for ALS—the need for compassionate spiritual care. I'm not even talking about God, but whatever it is to that person will so help mobilize strength and the ability to live with this and to contribute.

As you can see, I'm quite devastated by this, but I refuse to give up and stop being myself. Nobody is going to take that from me until I no longer have it.

The Chair: Thank you. You certainly are an inspiration to a lot of people, Ms. York. What you say is very insightful and very helpful, because you're the face of ALS. Verbalizing it helps a lot of people who are in that situation.

We now go to Monsieur Malo.

[*Translation*]

Mr. Luc Malo (Verchères—Les Patriotes, BQ): Thank you, Madam Chair.

Ms. Travis Valo, Ms. Duncan asked you to name five things that you would like to have. I think that the most moving one in your response was a treatment leading to a cure. I remember that when Ms. Duncan pleaded for the creation of this sub-committee, one of the main elements, if not the principal one, motivating her to invite us to look into this issue was the fact that this sub-committee would be able to hear researchers from all over the world who would be able to tell us where we are at in the area of research towards finding treatments capable of leading to a cure.

Given that you did not do so in your presentation, Mr. Parker, I would like you to give us an overview of where ALS research is at on the road to finding a treatment that could lead to a cure.

● (1130)

Dr. Alex Parker: The most important aspect is that we need time. However, it is not possible to ask the government to give us time to carry out research work. In the absence of being provided with time, we are asking for financial resources. It is as simple as that.

In Montreal, for example, there is a broad group that is presently studying ALS and that has found two or three genes involved in the disease. The model is now being applied to animals. Studies have begun with a view to finding drugs and determining those genes that are involved in the disease. This is a long and costly process.

We really need money in order to do this work. For us, it is simple. It is not an academic exercise. This is a serious disease. For researchers, it is simply a matter of money.

Mr. Luc Malo: Based on what I know about the state of the advancement of research internationally, all that researchers have succeeded in discovering are a few genes that might be responsible for the disease. That is it.

Dr. Alex Parker: Yes, for the time being. That is the first stage. Afterwards, what do we do? At present, we have no idea of the way these genes work. This takes time. We need laboratories, obviously, post-doctoral students, technicians, etc. A good project can take maybe two or three years, and the costs are relative.

In my view, we are on the right path. We have identified two or three genes and we are now working on determining the role of those genes. We will then be able to find the effective drug in the system. Afterwards, we will move on to the critical trial stage. That is how it works.

Mr. Luc Malo: Would you like to add something, Madam Figlewicz?

Dr. Denise Figlewicz: I would like to say two things.

First of all, it must be stated that neurological diseases share some points in common. Every researcher goes about his or her work, but constantly follows the evolution of the research work being done on other diseases such as Huntington's, Parkinson's and Alzheimer's. Indeed, certain drugs that are effective in the case of certain diseases can also be effective in the treatment of ALS. This is why we are not asking for resources for ALS specifically, but for research. The effective treatment might be found a little bit outside of our own field of research.

Secondly, Alex talked about the creation of model systems for the in-lab discovery of treatments. What is also lacking is a budget to transition effective in-lab treatments all the way to the treatment of human patients. Between the two, there is a big black hole.

It is very difficult, because a researcher is not specialized in the application of research to humans. We are specialized in critical research, but there are not many resources available for the development of a treatment between the laboratory and the clinics. The situation is the same for all diseases.

Dr. Alex Parker: I previously worked in the United States on Huntington's, for which a system exists. Let us say that we are successful in finding new drugs that are effective in the model system, be it with a fly, a worm or a mouse. We then move on to clinical trials. There is a system in place for Huntington's disease, but there is still nothing for ALS.

In fact, the present problem is that, even if I discover something that works very well with another model, what am I going to do if I do not have the money to carry out a test on a mouse? Clinical trials are assuredly too costly. I cannot pay for everything.

● (1135)

[*English*]

The Chair: Thank you, Dr. Parker.

We're going to go on. With the committee's permission, may I ask a question? Is that okay?

Some hon. members: Agreed.

The Chair: There was one thing you said, that two or three genes could potentially lead to the cause of ALS. Then, Ms. Figlewicz, you said there could be a linkage between the neurological diseases.

Dr. Parker, I think you could answer this: do you think if research was done with these genes there could be a possible linkage, say, to Parkinson's? And why do you think that?

Dr. Alex Parker: Yes, I think so. From my lab, I know the recent genes we've identified in ALS affect toxicity in our models for Huntington's disease and also our model for Alzheimer's disease. There's a definite crossover. I don't know about Parkinson's because we don't have that in our lab.

It's somewhat surprising, but maybe not. The point is well taken that anything we find in one of these diseases, for the most part, will have a good chance in functioning across other late onset neurogenetic diseases as well.

The Chair: That's very interesting. Thank you, Dr. Parker, for your answer.

We'll now go to Ms. Hughes.

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

I greatly appreciate your time here today. I think it's imperative that we hear from as many groups as we can on the neurological illnesses.

[*Translation*]

I do not know if it is Ms. York or Ms. Travis Valo who made the comment about drug trials. I am wondering how many clinical trials are being done at present in Canada and where. Is it a Baycrest Hospital in Toronto, or elsewhere?

[*English*]

Ms. Felicia Travis Valo: It's Sunnybrook Hospital. They've had one clinical trial, and that entailed the use of lithium. I think it was going to be—and please correct me if I'm wrong—an 18-month study. It was stopped midway through because it was found to be totally inefficacious.

I think there is a trial under way shortly...

Ms. Melanie York: Ceftriaxone.

Ms. Felicia Travis Valo: Ceftriaxone, yes.

Ms. Melanie York: To follow up on this point, I was on the lithium trial. This was based on a study in Italy. Unfortunately, I think it had a lot of holes in it.

I think everybody is desperate to grab on to something hopeful. I began the study around February 2008. They stopped it in September after six months, and then it took me six months to find out whether I was on the lithium or the placebo. In the end they found that people who had been on the lithium had trended a little more downward. That put so much fear into me. You put your life in the way of...you don't know.

I'm sorry, I need a drink.

Mrs. Carol Hughes: Thank you very much.

I can understand the difficulties for the family members, for those who are around us to support us. I have a sister who has Alzheimer's. She's 57 years old and she was diagnosed at age 50. I understand the frustration with regard to the supports out there.

You did talk about support networks, and I think we need to dwell on that a little more. It's obvious you do get the runaround, that it's extremely difficult to obtain any information or sometimes the direct information as to where you actually need to go for the support. Obviously there is some indication that we need better documents out there. It seems that whether it's research or this documentation or support networks, one of the key factors is the funding.

I'm trying to get some sense as to the main agency where you get all that information, because obviously the ALS Society is very limited as well.

● (1140)

Ms. Melanie York: I get bits and pieces from the hospital, from the integrated clinic; otherwise I would say I make myself knowledgeable.

Mrs. Carol Hughes: Is there anyone in particular who is able to assist you with respect to direction as to programming, for example, where you can get the programming for your house—the March of Dimes or anything like that? Is it frustrating? I'm sure it must be frustrating to have to go to a variety of different agencies for different assistance.

Ms. Melanie York: I would think there is not a collective reality around services. I don't want to say there are no services—there are—but I don't feel they are coordinated and presented in a thorough and needed way.

I don't know if that was your experience.

Ms. Felicia Travis Valo: Definitely.

Ms. Melanie York: You have to be smart and you have to ask questions. That's true in life anywhere. You have to be your own advocate, even with ALS, and there is only so much energy and so much room you have, but the reality is, I would say, you have to go after your own treatment and your own sense of taking care of yourself. You really have to manage and find your way through that system.

There is a lot of stuff online, and there are doctors in the States, but I just feel that we haven't coordinated everything. The communication, I feel, is not strong. Most of the communication is so depressing—seriously, not that I'm a bundle of joy here. It is so depressing that you don't get a sense that there is a forward movement of advocacy for real change. You feel lost in the system and you don't feel there is a real forward-thinking movement and approach to shift this to a new place.

Mrs. Carol Hughes: Could I just ask, Mr. Parker, are there a certain number of universities in Canada looking at trying to do some research on that? How many dollars are we talking about that you would consider a boost right now?

Dr. Alex Parker: Not for awareness, obviously, but for the actual research itself...? How much? Any increase is great; I'm not going to say anything bad about that. We are asking for an across-the-board increase of 1%, and that would benefit all research itself. How much would it be just for the neurological diseases? I suppose an extra....

With an average CIHR grant, for example, if you're lucky, you can get about $300,000 over five years. That's a lot; that would set up a new lab like the one I have for a long time. But those are so hard to come by.

On the amount of funding you get, it's kind of the same. It's just that the number awarded is very low. So if it could be bumped up even a percentage point, that would make a big difference. What happens now is you have an idea and you have to go around to smaller, different agencies and hopefully package enough research to go for the big one, and then if you get it you can finish a project and hopefully find something interesting. That is hard to do.

Right now I have a small amount of funding from the CIHR. I'm very grateful for the support from ALS Canada, and I have funding from Switzerland. As a new person, it has been hard to get into the big grants from the CIHR.

I don't know. Just an increase...I can't give you a dollar amount because I don't have a budget.

● (1145)

The Chair: Thank you, Dr. Parker.

We'll now go to Mr. Brown.

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

Thank you for all the testimony. It has certainly been very interesting.

Felicia, you mentioned that here we are in ALS Awareness Month and there doesn't seem to be that much focus on ALS. Just as a silver lining, we have our annual walk in Barrie this Saturday, and we're expecting a huge turnout.

The last time I met you was with Derek Walton, whom we call Braveheart in Barrie. He is in a wheelchair but still manages to skydive to raise money for ALS and the work that's being done at Sunnybrook. Our community certainly embraced him, and there has been tremendous exposure and awareness for ALS, I believe, in Barrie, and I'm sure in lots of small towns across Canada there are similar people like Derek who are raising awareness. I can only hope that is going to continue to grow.

I want to ask a few questions with regard to opportunities that we may not be engaging. It has been clear what the need is in terms of care giving, and I appreciate how that was referenced. That is certainly good advice that we should put in our report. But concerning research and clinical trials, what are we missing the boat on by having, as you mentioned, a very low amount? What clinical research, what research, are we not doing?

Alex or Denise, is there any light you can shed for the committee? If there were greater investments in research, what would we be doing right now?

Dr. Denise Figlewicz: Our clinical trials network is running a trial on ceftriaxone, and a few of the centres are running a second trial. Some of our clinicians work as part of American groups also, so there's an advantage there. We could carry out more trials, because there are things on the launch pad waiting to be tried. For example, I was at the American Academy of Neurology conference in April, and in the session they were talking about the progression of clinical trials from phase one, which is just safety, through phase three, which is the full-blown proper clinical trial. And there are a number of candidates sort of waiting their turn.

Mr. Patrick Brown: Do you have any information on those candidates and what's waiting on the launch pad right now?

Dr. Denise Figlewicz: There are drugs that act on different mechanisms. One of them is supposedly going to act on intercellular protein aggregates, which has something in common with a number of neurodegenerative disorders. So it's a compound that works on that. That's from a small biotech company. There is something from another small biotech company that is working on the main system of cell death in motor neurons, which has been identified in the lab.

There are a few problems. Small biotech companies can only go so far because of their commercial reality. If something isn't snapped up by a large biotech company and individual clinical trial centres don't have funding—which they don't—this is the stuff that sort of sits by the wayside.

Mr. Patrick Brown: You used the term “commercial reality”. Can you define that?

Dr. Denise Figlewicz: Yes. ALS is unfortunately not an attractive candidate to large pharmaceutical companies because the number of individuals with ALS is rather small. Technically speaking, by the international definition, ALS is considered to be a rare disease. So a biotech company looks for a compound that will be marketed to a large group of people, or to a group of people who will live and take the compound for 20 to 40 years. That makes a good market.

ALS is not a good market. We try to convince biotech companies that one benefit is the tremendous publicity they would get for any compound they came up with that was of benefit. That's something you can't buy. We all know the consequences to the biotech companies of negative publicity.

The fact of the matter is it's very hard to attract a biotech company to invest in the development of drugs for some of the neurological disorders.

● (1150)

Mr. Patrick Brown: What can the government do to help get around that hurdle of the commercial reality? You'd hate to see hope in research stifled because of the bottom line that a multinational drug company may have. What role can government play to help with a rare disorder issue?

We actually had an interesting discussion about this last week, but I'd be interested to hear your take.

Dr. Denise Figlewicz: I can think of two things. One is what Alex was referring to, which exists in the U.S. for the sort of nurturing of compounds from the lab to clinical trials. I've heard someone speak on this. There are actual pathways where you sort of shepherd a compound through. The amount of money involved in that is a million dollars—it's up there. But the same amount of money...

Dr. Alex Parker: It's very effective.

Dr. Denise Figlewicz: It really is the shepherding of a promising compound straight through all the different steps needed to bring it to a clinical trial.

Mr. Patrick Brown: You mentioned a million dollars to help shepherd it. Where does that come from?

Dr. Denise Figlewicz: I think it's approximately the amount of money they talk about for the entire process. That's going from a university laboratory up to a biotech company. You need to have a lot of pre-clinical trials, safety, and clearance in the United States with the FDA. It has its own agenda about things that need to be done before a compound can actually be given to a human as part of a clinical study. I could get accurate figures on this, if the committee would like, from the American model.

Mr. Patrick Brown: Absolutely. That would be very interesting

Dr. Denise Figlewicz: On a second alternative, I heard somebody from England speak a couple of months ago. They have the same concern we have about the gap between what you find from research and moving it along to a treatment that's accessible to patients. What they may be doing in the U.K. is a different approach, where the government is sort of walking in as a matchmaker between the universities and the biotech companies.

I can't give you an answer on dollars for that, but I can give you an idea that the government is prepared to play the role of bringing together the researchers and the drug companies. But I really can't give you a dollar figure for what that involvement would cost.

Mr. Patrick Brown: The other thing I just wanted to mention is that I understand there's some interesting research being done by Dr. Jean-Pierre Julien at Laval University and Dr. Chris McGibbon at the University of New Brunswick. If the ALS side is getting information about the work, I know I'd be fascinated and I'm sure the committee would be fascinated. If it could be submitted to the clerk, we'd greatly appreciate it, if you have that information as it develops.

Dr. Denise Figlewicz: I think you may be referring to the immunization study.

Dr. Alex Parker: Probably.

Dr. Denise Figlewicz: That's right. This is Dr. Jean-Pierre Julien's work. In fact, the idea for what he's doing is based on something that was tried for Alzheimer's disease, which was to try to immunize individuals against a protein or a fragment of a protein, which triggers an inflammatory response. Dr. Julien is doing this with the superoxide dismutase protein that's been implicated directly in familial ALS and probably indirectly in the rest of ALS cases. I know they are doing this in animal models right now.

Dr. Alex Parker: Yes, that's right.

Dr. Denise Figlewicz: I don't know when this is going to be ready to be moved to clinical trial, but they're going step by step, because the problem is that you worry about creating an anti-immune reaction against something that you start with to be helpful. What they're worried about is curing one thing and causing a secondary phenomenon that can be really deleterious to the nervous system.

Progress is good.

The Chair: Thank you so much.

Now we'll give Dr. Duncan the last question.

You have just a little under five minutes, Dr. Duncan.

Ms. Kirsty Duncan: Thank you, Madam Chair.

I'm going to pick up on Mr. Brown's comments.

If you could write your wish list to the government, what would you like to see regarding ALS research in terms of investment, the number of researchers we currently have, the number we need, and the distance people have to travel for treatment? Write your wish list.

Dr. Denise Figlewicz: Our ask in terms of research funding has been to follow the recommendations of the Kirby report and bring the CIHR funding level to be 1% of health spending in Canada. That's the financial wish.

● (1155)

Ms. Kirsty Duncan: Currently, how many treatment centres are there? I think you said 15 across the country. What is the average distance people are travelling?

I think Felicia mentioned it's not always what people need, and people are travelling to the United States or overseas. What more can we do?

Ms. Melanie York: I just want to throw something in.

I think within Canada there are many people who don't live within the treatment centre areas. If there's any way we can come up with mobile units with interdisciplinary teams that can travel, I think that would be a brilliant step in the right direction. You have to remember that people are isolated, they have limited funds, and whatever they have, they're using for themselves. If there's that sense of care and connectivity that you can have in mobile units going around, or volunteer doctors... I'm not sure, but there needs to be something to address outlying communities or people who live even 50 kilometres away. It's just too far and too hard for people to travel, so they don't get the care regularly that they need. They do not.

Ms. Kirsty Duncan: The last question is this, again picking up from Mr. Brown. What are the potential therapies for ALS that are currently being investigated, and what, if any, new treatments are being given to ALS patients right now here in Canada?

Dr. Denise Figlewicz: I think the therapies are those we mentioned. I have to say that if you do not regard the geographic issue, which I'm not playing down—it's a very serious one—our clinicians are actually completely in tune with international groups. I don't think we would be concerned any more that there's something being tried elsewhere that could not be tried in Canada.

The problem is one of limitations of funding for the clinical centres, because if we could be running things in parallel, that would be a wonderful thing. Right now, financially, it's not possible.

I'm sorry, what was the second half?

Ms. Kirsty Duncan: What treatments are being offered to people right now?

Ms. Melanie York: The only approved drug is called Riluzole, or Rilutek. The efficacy for it is an extension of three months of life. Whether or not that is reality, I don't know. I'm taking it, but that is all that is currently offered to me.

The Chair: Thank you, Ms. York.

Today I have to say that each one of you makes a huge difference in this country. For you to come here and tell this committee what it's like—it's on the record in Hansard—so many people will know what you're saying today, and that makes a difference. Each one of us is a leader in this country, and each one of us is committed to doing everything we can to assist you.

You are an inspiration—I really want you to know that—to all of us, not only to people with ALS, but to those with other diseases as well. You do break ground and you do make a difference for other people around you. Unfortunately, some of us have to be pioneers, and that makes things challenging. There is definitely a very important purpose in what we're doing here today.

I want to thank you very much for coming. I want to thank the committee for their commitment and dedication.

There are further subcommittee meetings you need to know about on neurological diseases. We will be here on the 15th with multiple sclerosis and with ALS again on the 22nd.

Thank you, everybody.

The committee is dismissed.

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