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## **Subcommittee on Neurological Disease of the Standing Committee on Health**

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**EVIDENCE**

**Tuesday, November 30, 2010**

—  
**Chair**

**Mrs. Joy Smith**



## Subcommittee on Neurological Disease of the Standing Committee on Health

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•(0850)

[English]

**The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)):**  
Welcome to our subcommittee.

I'm Joy Smith, the chair of the subcommittee.

It does feel like a full-fledged committee. We've done so much work on neurological disorders, and it's been a very serious topic with the members of the subcommittee.

This morning, pursuant to Standing Order 108(2), we are continuing our study on neurological disorders.

We are going to be starting with individuals. We have Dr. Song, from the Canada Research Chair in Alzheimer's Disease. We have Dr. Serge Gauthier. From the Canadian Institutes of Health Research, we have Dr. Rémi Quirion, executive director. From Canada's Research-Based Pharmaceutical Companies, we have Mark Ferdinand, vice-president of policy. From NeuroScience Canada, we have Inez Jabalpurwala, president.

Welcome to all of you.

We will start with you, Dr. Song. You have five minutes for your presentation.

**Dr. Weihong Song (Canada Research Chair in Alzheimer's Disease, Jack Brown and Family Professorship, University of British Columbia, As an Individual):** Thanks.

Honourable Chair, honourable members of the subcommittee on neurological disease, my name is Weihong Song. I am the Canada research chair in Alzheimer's disease, and a Jack Brown and Family professor at UBC.

It's my great honour to meet with you today to discuss the developments in research related to Alzheimer's disease and to present my suggestions and recommendations related to the federal role in supporting Alzheimer's disease research.

Alzheimer's disease is the most common neurodegenerative disorder leading to dementia. It costs Canadians \$15 billion a year right now and it is estimated to be \$153 billion by 2038. Every 71 seconds someone develops Alzheimer's. One in eleven Canadians over the age of 65 currently has Alzheimer's disease or a related dementia. It is the fourth-leading cause of death for people aged 65 and over.

This is a heartbreaking illness and burdens many families. One in six Canadians has someone with Alzheimer's disease in their family. My own family, actually, has been affected by this disease too. My

father died from Alzheimer's disease seven years ago and now my mother suffers from stroke and dementia.

As you can see, this has affected me deeply, not only as a clinician and basic researcher professionally but also personally as a son of Alzheimer patients, to experience what it is like to be someone whose family is affected by it.

Canada has many outstanding world-leading Alzheimer research scientists and has an excellent track record in Alzheimer research. Canadian researchers made great contributions in discovering novel genes and their mutations causing Alzheimer's disease, in establishing unique animal model systems, in studying early diagnosis biomarkers and neuro-imaging, as well as in leading Alzheimer disease drug trials and development.

My own interest in Alzheimer's disease began 20 years ago, when I was a chief psychiatrist in China and published my first Alzheimer research paper reporting clinical analysis of the disease. Previously, at Harvard Medical School, we discovered a role of gene mutations in the familial Alzheimer's disease.

Since I moved to UBC nine years ago, my laboratory at UBC has become one of the world's leading Alzheimer research labs. We recently discovered how low oxygen supply to brains, such as in stroke and other cerebral vascular diseases, leads to Alzheimer's disease development. Our pre-clinical study showed that an anti-epileptic drug, VPA, could prevent and treat Alzheimer's disease.

Researchers have made great strides for the past 25 years; however, at present there is no effective way to prevent and cure this disease. The major reason for this is that we do not know the real causes for the majority of the Alzheimer's disease patients, and the pathological mechanism leading to the disease remains elusive. Therefore, we have not had a good tool for early diagnosis and valid targets yet to be further uncovered for drug development.

Although there are many breakthroughs, the Alzheimer research in Canada is extremely underfunded by the federal government. The benefits of federal funding in Alzheimer's research are extraordinary. By delaying the onset of the disease by two years, we will reduce the cumulative costs by a quarter—\$219 billion—by the year 2038. By delaying the onset of the disease by five years, we will reduce the cost by half—almost \$400 billion over the next 30 years.

The need for federal action is urgent. Following are my suggestions and recommendations.

First, increase the federal funding for Alzheimer's disease targeted for clinical and basic research. It is especially critical to increase funding to basic studies on the risk factors and causes, underlying mechanisms, biomarkers identification and validation, and novel drug target discovery. My recommendation is for \$50 million per year for the initial five years, for open competitions through the CIHR.

Second is federal support to build three to five research centres of excellence on Alzheimer's disease across Canada. The centres will serve as a basis for cutting-edge research and new knowledge generation, and a training base for graduate students and post-doctoral fellows, as well as recruiting and retaining the best scientists working on Alzheimer's disease in Canada. My recommendation is for \$3 million to \$5 million per year for an initial five years for each centre.

● (0855)

Third, increase federal support for awareness, knowledge translation, and patient care through national and local Alzheimer societies and organizations. Such supports should also be accessible in multiple languages and by minority ethnic groups.

Fourth is federal support for private donations on Alzheimer's disease. Such support will greatly encourage philanthropic efforts and partnership of the private and business sectors. My recommendation is to have matching funds available to the institutions and organizations receiving private donations that focus on Alzheimer's disease research.

My coming to Canada and my lab's success in Alzheimer's research can be greatly attributed to generous donations from the Jack Brown family and the David Townsend family. They have donated close to \$10 million to me for UBC. The donations have allowed me to establish a state-of-the-art research lab at UBC with cutting-edge techniques and the ability to recruit talented peoples worldwide for the past nine years and have made significant impacts on our research to identify a novel molecular mechanism leading to this disease and a possible new treatment for Alzheimer's disease.

My final recommendation concerns federal support of international partnerships and collaboration on Alzheimer's disease research. International collaborations will greatly enhance our research ability with complementary resources and expertise from other countries. My recommendation is to support a joint Canada-China centre for translational medical research in Down syndrome and Alzheimer's disease. The centre will be a network of research teams of clinician scientists and investigators, based in Vancouver and Chongqing with team members from other top institutions across Canada and China. The international collaboration centre will focus on translational research and have joint quality personnel training, early diagnosis markers, drug development, health policy, and clinical service. It has received strong support from UBC, Chongqing Medical University, and the Townsend family donations.

My recommendation is for \$5 million per year for five years for the partnership.

Thank you very much, respectfully.

**The Chair:** Thank you, Dr. Song.

We'll now go to Dr. Quirion, executive director, from the Canadian Institutes of Health Research....

I'm sorry, Dr. Gauthier, you were on the list next. Maybe I should go to you first.

● (0900)

**Dr. Serge Gauthier (As an Individual):** Thank you, Madam.

[*Translation*]

Members of the Subcommittee on Neurological Disease of the Standing Committee on Health, I am going to speak to you today as a clinician-scientist. My recommendations will pertain both to research and the needs of patients and their families. I have provided you with a copy of my document.

For the past 20 years now in Canada, there has been important progress in the area of patient management. There have been three consensual conferences that brought together the main stakeholders, i.e. the physicians from the various disciplines, and the members of the Alzheimer Society of Canada. The meetings concerned dementia, which is one stage of Alzheimer's disease. If there is another meeting next year, it will not be about dementia, but rather about Alzheimer's disease as a whole. We now feel that we can diagnose the disease before the dementia stage, which opens the door to primary prevention among those who are at risk, and to secondary prevention among people who have premonitory symptoms.

My first recommendation is to encourage research on prevention through targeted initiatives by the institutes, which Dr. Quirion is going to address, and the participation of the Alzheimer Society of Canada, whose representatives you will be meeting next week. There could for instance be a registry of Canadians who would be interested in participating in research on prevention, which would help us to undertake projects at a lower cost, while having a greater number of participants.

Secondly, the development of medication that could help to prevent the disease depends on the Patent Act that is currently in effect. Between the development of these molecules that could help in prevention and their phase III clinical trials, from seven to ten years can elapse. And so the patents that are currently available will practically have expired by then.

At a symposium we took part in in 2007, the Americans mentioned this problem regarding the Patent Act. In Canada and in the United States, if the length of patents that is currently authorized remains the same, this act is going to limit the participation of the pharmaceutical industry in the development of new molecules that require very long trials.

My third recommendation is to consider the possibility of amending the Patent Act or its regulations in order to encourage research on molecules that could help in prevention.

We already have medication available in Canada to treat the symptoms of Alzheimer's disease, medication that has been rigorously assessed by Health Canada. Unfortunately, Canadians' access to this medication varies by province because of the coverage in effect in each province. Although the decision to reimburse medication is one that is made by provincial governments, I think that there is social unfairness in Canada due to the fact that medication that is already recognized as effective is not available to everyone everywhere.

For that reason, you could consider the possibility of bringing in a national charter on the rights of patients to have access to recognized treatments. My fourth recommendation is to eliminate differences among the various parts of Canada with regard to access to established treatments. That recommendation however may go beyond the topic of Alzheimer's disease.

My last point, and not the least, concerns the social and individual costs generated by the disease, which Dr. Song referred to. These costs increase as the patient approaches the dementia stage, be it moderate or severe. This has been demonstrated in Canadian studies. There are already tax credits for the diseased individual offered by both levels of government, on the order of \$6,000 a year.

For caregivers, for instance the son or daughter of the patient who sometimes stops working for two or three years in order to assist his or her parent, the applicable tax credit is very low. It is on the order of \$1,000 per year. You here at the federal level are the only ones who could consider increasing tax credits for caregivers, and also perhaps for the patients in order to help people to keep their relatives at home as long as possible.

Thank you.

• (0905)

[English]

**The Chair:** Thank you so much, Dr. Gauthier. We appreciate your presentation.

Now we have Dr. Rémi Quirion from the Canadian Institutes of Health Research.

[Translation]

**Dr. Rémi Quirion (Executive Director, International Collaborative Research Strategy for Alzheimer's Disease, Canadian Institutes of Health Research):** Madam Chair, members of the committee, good morning.

[English]

It's a pleasure, on behalf of CIHR and president Alain Beaudet, to be here with you to briefly summarize some of the recent funding activity and decisions of the Canadian Institutes of Health Research on research into Alzheimer's disease and related dementia.

To add to what Dr. Song and Dr. Gauthier said, I will give just a few words first on Alzheimer's disease.

Alzheimer's disease kills. There is no cure for Alzheimer's disease. The treatments we have are not truly effective, and miracles do not occur. Sometimes when you have cancer you have a remission, you have instant recovery. We don't understand it, but it happens. That does not happen with Alzheimer's disease. When you are diagnosed

as suffering from Alzheimer's disease, you will die from it seven to 10 years later. It's a long journey, during which your loved ones see you and your personality disappear in front of their eyes. Even if you are still physically fit, it's a hard and long journey for the patient and for all the loved ones. Today, half a million Canadians live with Alzheimer's disease. It's the seventh-leading cause of death in Canada, and these numbers are increasing daily. Dr. Song mentioned there's a new case every 71 seconds.

Economically it costs society billions of dollars a year, and socially it's probably even more staggering in cost. In our view the solution is research. It offers hope for a better tomorrow and a better outcome. We are most fortunate that Canadian scientists and clinicians are recognized as being world leaders in the field of Alzheimer's disease research.

Research in Alzheimer's disease is a priority for CIHR. We are investing more than \$30 million per year in our regular program, such as investigator-initiated grants, salary awards, and targeted team grants. CIHR, via its institute of aging, is the main funder—to the tune of \$30 million—of a very ambitious Canadian longitudinal study on aging. It's a program that will follow a cohort of Canadians 45 and older over the next 20 years. Data from the cohort should prove most useful in informing us on successful aging—why some people age well, and why others do not age so well and develop Alzheimer's disease. We also support the Canadian Dementia Knowledge Translation Network, which aims to ensure that best practices are used in the treatment of persons suffering from Alzheimer's disease and related dementia.

This is clearly not enough, considering the size of the challenge. Accordingly, CIHR decided to make research on Alzheimer's disease one of its main priorities, with an additional investment of \$25 million. This money is used to develop what is known as the international collaborative research strategy for Alzheimer's disease, with the aim of accelerating discovery by partnering with the Alzheimer Society of Canada and the very best teams throughout the world. Partnership is key, and in Canada we have an excellent but small community, so we need to partner worldwide to come up a solution.

The focus of our initiative is on prevention, early diagnosis, and early treatment of Alzheimer's disease. We believe that is where our investment will have the greatest impact and lead to the development of a truly effective treatment and even, hopefully, the prevention of some forms of Alzheimer's disease.

To date we have established partnerships with funders and scientists in France, in partnership with Quebec; a network including the U.K., Germany, Italy, Ireland, Belgium; China; and the United States. We are also hoping to develop a network of experts platform, such as genomics, epigenetics imaging, animal model, brain banking, clinical trial neuropsychology, and services in research and population health. We hope to develop that network of experts platform throughout Canada in the coming year. This will allow our Canadian experts to be able to partner at the international level with colleagues throughout the world.

But again, this is not enough compared to other countries that have made massive investments in the field of Alzheimer's disease research. These include the United States of America, Germany, the United Kingdom, France, and now many others.

● (0910)

So we need a large increase in funding in future years. We are confident that with increased support, our experts will deliver and discover ways to combat this formidable enemy known as Alzheimer's disease.

I have one recommendation for the committee today: that a significant targeted budget be provided to CIHR to fully implement our international strategy for research on Alzheimer's disease.

Thank you very much.

**The Chair:** Thank you very much. We appreciate your presentation this morning, Doctor.

Mr. Ferdinand, would you present now, please.

**Mr. Mark Ferdinand (Vice-President, Policy, Canada's Research-Based Pharmaceutical Companies (Rx & D)):** Thank you, Madam Chair.

Good morning to everyone.

My name is Mark Ferdinand. I am the vice-president of policy and research at Canada's Research-Based Pharmaceutical Companies, otherwise known as Rx & D.

I have two modest goals to share with you today: first, to present to you the findings of our latest report—entitled “The Rx&D International Report on Access to Medicines”, otherwise known as the IRAM report—to really illustrate the differences that exist between Canadians' access to mental health drugs, including drugs related to Alzheimer's and Parkinson's; and second, to provide you with some recommendations that we hope would also allow us to incentivize further private sector research, generally related to pharmaceutical research, but specifically in the area that Dr. Gauthier spoke of a little bit earlier.

[*Translation*]

You all know very well that neurological and mental illnesses indirectly affect all Canadian men and women, whether those afflicted are acquaintances, members of the family, friends or colleagues.

Today, half a million Canadians are living with Alzheimer's disease or suffering from dementia. In the course of one generation, that figure could double and there could be one million affected people throughout the country.

We are well aware of the reality patients and their families must grapple with on a daily basis. That is precisely what motivates our industry to do what it does.

[*English*]

Canadians expect the best, and we think we have the best health care system in the world. However, findings from our most recent international report on access to medicines, undertaken by Wyatt Health Management—this time it's the fourth annual report—raise questions about the quality of Canada's health care system, in particular demonstrating that despite recent advances in care, Canada still lags far behind other developed countries in terms of access to new medicines.

Our IRAM report examines the public reimbursement of new innovative medicines and patient access to those medicines not only within Canadian public drug plans but 28 other OECD countries, including Scotland.

Our report findings illustrate the pressing need to provide appropriate choice and care for patients, particularly in the area of mental health and neurological diseases.

During my talk this morning, I will not actually be talking about early diagnosis and prevention, and the research that certainly could be done in that space. We believe there is still some room for improvement in that space, but I will be talking to you specifically about the treatment options that exist out there in the world today.

It's a wake-up call, really, for our country's leaders and for Canadians to understand how public health plans are performing vis-à-vis patient needs when we look at how Canada's health care system and treatment experience compare with access to life-saving medicines and quality of care for patients in other countries.

The overall findings of our report show that Canadians who rely solely on public health plans or public drug plans—senior citizens, low-income individuals, families—do not have the same access to new medicines as citizens in 28 other OECD countries, plus Scotland.

[*Translation*]

Surprisingly, these people do not benefit from the progress that has been made in medicine over the past five or six years.

[*English*]

**The Chair:** Excuse me, Mr. Ferdinand. Could you slow down just a little bit for our translators?

Thank you.

[*Translation*]

**Mr. Mark Ferdinand:** Very well.

Canada ranks 26th out of the 29 OECD countries for public health plan reimbursement of medicines. Canadians expect better and deserve better.

The results of the Rx&D International Report on Access to Medication, the RIAM, put the emphasis on diseases that are of specific concern to this subcommittee. If we focus on access to medication for the treatment of mental and neurological diseases, the situation in Canada is even more worrisome. For neurological diseases, the international average for public health plan reimbursement of medicines is 88%. The patient access to the same medicines for Canadians is 28%. Canada ranks 26th out of the 29 OECD countries.

• (0915)

[English]

I would be happy to address specific data for Parkinson's and Alzheimer's drugs during the question and answer session.

In addition, an assessment of new drug launches over the last 20-year period places Canada second to last among leading economic nations behind Germany, Italy, France, the U.S., and the U.K. Not only are the drugs that are available and approved for use in Canada not available at the same rate as they are in other countries, but we also see that there are fewer drug launches in Canada compared to other leading countries.

What does this mean for Canadians? Doctors and health care professionals do not have the ability to offer patients in Canada the benefits of new medicines that reflect the latest research and new drug developments. And they don't have access to therapeutic choice, which may be very important for individuals who may not respond to the first drug that may be prescribed to them.

The impact of this steady erosion is reduced patient access to medicines and vaccines, concerns about the quality of care for patients and their families, and significant cost repercussions for the health care system, which is striving, as we know, to be more cost-effective and responsive to patient needs.

Specifically with regard to recommendations, first, we believe that Canada needs a more globally competitive intellectual property system and regime. We believe the implementation of effective right of appeal for innovators within Canada's patent regulations would be a step in the right direction.

We would also say that it would also be worthwhile, as Dr. Gauthier pointed out, to consider whether there are other amendments that could be made to the patent system to incentivize research and development in the private sector within Canada.

Second, Canada has been and continues to be a leader in clinical research in the world. However, that position is slipping. In order to further incentivize further private sector R and D in Canada, we believe that Canada can expand the definition of the current SRED tax credit to better capture all aspects of clinical research and clinical trials. We believe this is urgent. When clinical trials are done elsewhere, Canadians generally speaking have to wait longer to experience the benefits of new drugs and therapies that could otherwise be used in clinical practice here.

Third, a more predictable funding mechanism for vaccines should be added to public immunization programs, in general. As many of you may have seen in the last couple of weeks, we have seen at least some promising news in the world of research on a vaccine for

Alzheimer's disease. We're at very early days, and certainly, right now, there is no private sector R and D being invested in that research from the pharmaceutical companies. But this is the type of research that we believe can be done not only in North America but certainly in Canada, given the expertise that is here.

Finally, as we all know, regulatory policy can also support patients' access to new medicines. That would be done through making Health Canada's regulatory review of drugs more efficient. What we need to do is break down existing and significant barriers to timely access to new medicines. When we compare Canada's review times to other countries', we know that they are doing much better than they were in the past. We are currently taking, on average, 390 days to review new medicines. But this is still longer than what we see in the States, which averages about 350 days for approvals, and almost 100 days longer than it takes in Europe.

In conclusion, caring for patients with Alzheimer's is like caring for a child who will never grow up. The patient is not independent, nor is the caregiver.

Our industry strives to reduce the burden on families and the health care system while improving the lives of these patients. We remain committed to working in partnership with all levels of government, stakeholders, and health care professionals to find ways to make innovative therapies available to doctors and patients, as other countries have done, to improve access for patients, and to provide better health care generally.

Thank you very much. I welcome your questions a little bit later.

**The Chair:** Thank you very much, Mr. Ferdinand.

Now we'll go to Ms. Jabalpurwala.

**Ms. Inez Jabalpurwala (President, NeuroScience Canada):** Thank you, Madam Chair.

Thank you, committee members. I very much appreciate this opportunity to speak before you.

The brain is the most vital and complex organ of the human body. Brain disorders carry both economic and human costs that are greater than those for cancer and cardiovascular disease combined.

While some brain diseases respond to treatment, there are no cures at the present time. People with a brain disorder may live for a very long time, and with some conditions, they may slowly degenerate and lose function before dying.

When we link direct costs and costs associated with disability, we reach an economic burden that is in the order of \$60 billion, and this is a conservative estimate, based on a 38% cost relative to the total cost of disease. Of course we've heard numbers about the growing Alzheimer's impact and related dementias, and of course the numbers are going to significantly escalate in the coming years.

For the past 10 years I have been the president of a neuroscience research funding organization that has brought science, business leadership, and academia together. During this period I worked closely with the Honourable Michael H. Wilson, who was our past chair and is now the honorary chair, and who has been a long-time advocate for the neurosciences. The current chair, Rupert Duchesne, is the CEO of Groupe Aeroplan Inc., but he started his career in neuropsychopharmacology. Both Michael and Rupert have been personally and directly touched by a brain disorder in their lives, so this is a very personal and meaningful mission for them.

The goal of NeuroScience Canada has been to maximize our current investment in research but also to make future investments more efficient and, most importantly, more focused on outcomes that will link directly to patients. NeuroScience Canada, with that in mind, provided the impetus and the rationale to form Neurological Health Charities Canada. That has been the grouping that has brought together the voluntary health organizations. It's significant to note that the U.S. has been quite envious of this accomplishment, because in fact to bring together all of these disease groupings around one common voice has been a significant challenge, and we are the first to have been able to accomplish this.

Over the past 10 years I have learned a great deal about both research funding and the science, and there are two themes that have emerged for me: our current state of funding, and where the science is going. For me, the main undercurrent of these two and how they're linked together is based on how we're funding and based on where the science is going; do we have an alignment, or do we need to fundamentally change the model upon which we are currently basing our decisions for funding science?

To look at the current status of funding, Canada has benefited because of government and private donors, who have put a significant amount into funding infrastructure and salaries to attract and retain our top faculty. This is seen through the Canada Foundation for Innovation, the Canada research chairs, Genome Canada, as well as private donors, such as what Dr. Song mentioned as being pivotal to his research.

Canada is a leader in the field of neuroscience, as all of my colleagues have mentioned. Many of the most important discoveries around the brain have been made by Canadian researchers or a Canadian lab. But we also excel at collaboration. We have a culture where we share knowledge and we share information. This is quite different from the way research is traditionally done in the U.S.; even though much better funded, it's a highly competitive and much more individualistic model. So we have something in Canada that is really quite special, and it's very appropriate for the brain, where there is a complexity that requires us to collaborate.

We also are known for our ability to maximize every dollar that we do provide to research. Although we hear that our funding is relatively low compared to the U.S., we are still able to achieve breakthroughs. So we should be very proud of the output of Canadians.

We have the capacity and the excellence. What's missing is the third leg of the stool, and that is the operating grants. Operating grants are what enable our researchers to run their labs and provide

training environments to doctoral students and post-doctoral fellows. This is where we fall behind.

In 2009-10, the CIHR provided \$179 million in operating grants across the neurosciences, and that includes mental health, addiction, and the sensory organs. The voluntary organizations, the ones grouped under Neurological Health Charities, combined were only able to disburse \$20 million a year.

Now, that is a symbol of the public's response to the importance of funding brain research and their lack of understanding about the impact. The total is about \$200 million.

That, when contrasted with the conservative \$60 billion investment, we can see is really disproportionate.

● (0920)

Turning to the science now, 90% of what we know about the brain was discovered in the last 15 to 20 years. This was spurred by the 1990s, which were declared the Decade of the Brain, in which there was an explosion of brain research around the world. That led to basic discoveries about how the brain works. What we discovered was that we moved from looking at the parts of the brain to really understanding how the systems in the brain function and how the brain as a whole is one system.

We realize that there are three possible underlying causes to the range of brain disorders: cells die and particular types of cell groups or particular regions of the brain might result in a particular disorder; connections between cells don't function so they can't communicate with each other; or there are problems with the whole circuitry of the brain linked to a chemical or molecular imbalance, and this is the case for the vast majority of psychiatric conditions.

This also broke down these two silos of neurological and psychiatric conditions so that we have to stop thinking about the brain and the mind and start thinking about one mechanism in which there are linkages. We should also note there are many conditions, Alzheimer's being one key example, in which there are both neurological and psychiatric components, so we no longer have this barrier.

How have we been funding research? Traditionally we focused on individual grants to support researchers in specific disciplines or around specific diseases. This has produced important new knowledge about how the brain works, but recent experience indicates that we can actually fund in a way that will accelerate our ability to translate this knowledge into patients and treatment.

A series of pilot studies undertaken by NeuroScience Canada provided five grants that were multidisciplinary, multi-institutional, and focused on common mechanisms, and we saw dramatic results in terms of achieving breakthroughs. This program, which was called the brain repair program, was celebrated around the world by leading researchers. It partnered with the CIHR and worked with all of the communities, including the voluntary health organizations. We developed something that we feel is really very special, which led to our ability to more rapidly reach breakthroughs and to translate these into applications for how we are going to diagnose, treat, and cure brain disorders. So we see that there is a link between the funding and where the science is going.

What have I learned from all this, and what are my key conclusions? First of all, in order to maximize the return on our investments in infrastructure and salary, we need to do more on the operating grant side. We need to congratulate the government and private donors for building this infrastructure, which has given us the capacity, and now we need to make sure that these labs and these researchers are fully operating.

Second, we need to focus our research investment on the brain as one complex system and not just as a collection of diseases, and on investigating commonalities from which a single breakthrough has the potential for therapies and cures for multiple illnesses.

Dr. Song gave an excellent example of how an anti-epileptic drug was being used for Alzheimer's, so if that research had not been done in an area that one would think had no relation to Alzheimer's, we wouldn't have had what is a significant breakthrough. We have to stop thinking in terms of diseases and start looking overall at how we can have a multiple effect.

We need to better coordinate our existing efforts so that we can spur discovery and create resources that the whole field can share, through such things as creating technology platforms or bringing technology and people together so that we have something that everybody in the community can use and benefit from. We need to involve the public, patients, families, caregivers, and ultimately all Canadians who will be touched by brain disorder. Doing so will better link patients to outcomes and will also ensure that government investment is recognized and is used to stimulate private dollars, because we need to do more, as the general public, in terms of how much we are investing in research.

What does this mean finally? It means exciting the public around one unifying vision for the brain and engaging all of the key players: science, business and philanthropic leadership, and the voluntary sector. This is the thinking behind the national brain strategy that has been tabled to this committee.

We need to fund collaborative, multidisciplinary research with common themes that link the brain disorders to this big vision for the brain and reinforce the brain as one system. This does not mean that we stop funding the pipeline. The pipeline is important, and the individual grants are important, but we need to focus our efforts on the next big breakthroughs, and those are going to come about with these larger grants.

Finally, we need to create a public-private partnership to provide not just more government funding but strategic funding with a

private component, a bottom-up consultative process, not a top-down one. This is the research pillar of the national brain strategy, and that was developed by the Canadian Association for Neuroscience working with the voluntary health organizations through Neurological Health Charities.

● (0925)

I believe the result will be a more efficient and effective use of public funding and a leverage effect that stimulates private investment in brain research. I believe the public will applaud a government partnership with the private sector for matched funding as a demonstration of their working closely with the voluntary sector organizations that represent patients, families, and caregivers; with the research community; and with business and philanthropic leaders.

We have a chance, right now, to do something spectacular for the brain. Canada has all the components needed: the way we do science, the way we collaborate, the infrastructure and salaries we've developed, and the model we have put in place.

Let's be a leader in this and let's do something really remarkable.

● (0930)

**The Chair:** With the permission of the committee, I'd like to ask a couple of questions prior to our starting. Then we'll go into our rounds.

Is that okay? All right.

I have a couple of questions for you. What is NeuroScience Canada? Is it an NGO?

**Ms. Inez Jabalpurwala:** It is. We are a member of Neurological Health Charities as an organization, but we represent all of the brain disorders.

**The Chair:** You're an NGO, though. That's what you are.

What is your background? Are you a scientist or a doctor?

**Ms. Inez Jabalpurwala:** No, I'm not a scientist. I was brought on board because one of our purposes was to not have what might be perceived as a bias of science. It was to use the science advisory committee to provide advice but lead an actual program that looks at how we can better do science.

**The Chair:** Okay, thank you.

You made a statement in your presentation that brain disorders carry an economic burden that is greater than cancer and cardiovascular disease combined. Where are your figures for that?

**Ms. Inez Jabalpurwala:** That's based on several studies. We have that documented in the material I have circulated. We looked at what Health Canada had done in terms of evaluating the economic burden. It never had a category for brain disorders, so we put together this category based on the different diseases. Then we looked at what the World Health Organization has done in this area—

**The Chair:** You said "economic burden". What is your dollar number?

**Ms. Inez Jabalpurwala:** It is \$60 billion.

**The Chair:** So \$60 billion for brain. And that was based on...?

**Ms. Inez Jabalpurwala:** That was based on 38% of the total burden of disease. That brings together both direct costs and costs linked to disability.

**The Chair:** Thank you.

Dr. Duncan, you have seven minutes for questions and answers.

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

Thank you to all of you for coming. You've presented so much material, I'm not sure where to go this morning.

Could you table, for the committee, all existing Alzheimer's and dementia networks in Canada and internationally? If that could be broadened to cover neurological, that would be terrific. Could you also table with the committee the investments by Germany, the U.K., the U.S., and other countries so that we can see that direct comparison, please?

Mr. Ferdinand, you mentioned that Canadians don't have access to the latest drugs or choices, or we wait longer. You said that you could give us the specifics for Alzheimer's and Parkinson's disease. I was wondering if you could do that now, please.

**Mr. Mark Ferdinand:** Thank you, Dr. Duncan.

I'd be happy to table with the committee actual graphs and further information so that it's clearer, but I would just say that we were able to identify, based on our international report on access to medicines, 150 drugs, 33 of which were cancer drugs. That was our study. In that grouping, there were 29 drugs that treat neuropsychiatric disorders: addiction, mental health, Alzheimer's, pain, Parkinson's, and the list goes on.

I'd be happy to provide to the committee a listing of all those drugs, as well, so that you can see their status of reimbursement in Canada, under the public drug plans, and in the other countries.

**The Chair:** Mr. Ferdinand, would you mind tabling those with my clerk? We'll see that they're distributed to all committee members.

**Mr. Mark Ferdinand:** We'll do that. It will be clearer, I think, to see the information in that form.

**Ms. Kirsty Duncan:** Thank you.

I'd like to ask all of you, if you could write your wish list to this committee, in terms of research, what would be your top recommendations? Write your wish list.

Dr. Quirion, would you like to start?

**Dr. Rémi Quirion:** If you want me to start on a wish list, my wish list is quite long.

• (0935)

**Ms. Kirsty Duncan:** We'd like to hear it.

**Dr. Rémi Quirion:** I think, in a sense, I'm in agreement with what others have mentioned, and that's to create a very strong network of Canadian experts, to have core centres in the country that will be expert in clinical research related to Alzheimer's disease and

dementia; an animal model; brain banking, because brain banks are very useful for us to look at and see what's wrong in an Alzheimer brain; health services research, such as how we organize services in the country and access to care for persons suffering from dementia.

Basically, this set of centres and core will be tremendous, will stimulate collaboration between experts of all kinds in the country, but also allow us to partner much more effectively at the international level. By teaming together, we'll be able to solve the problem.

**Ms. Kirsty Duncan:** Like a network of centres of excellence?

**Dr. Rémi Quirion:** Yes. It would be a bit like in the United States, where they have now 28 of these Alzheimer's disease centres. Each of them is funded to the level of about \$8 million to \$10 million a year. We don't necessarily ask for that in Canada, but each of these centres should have at least a budget of about \$2 million to \$3 million per year. I think, considering the excellence of the teams of experts in the country, we could probably support five or six networks that will be top-level internationally.

**Ms. Kirsty Duncan:** And what would each centre look like?

**Dr. Rémi Quirion:** Basically, some of them will be a bit more virtual. Others, such as where Weihong Song is, could be physical. At McGill, it could be physical because we have a node of people who are able to look at Alzheimer's disease from different perspectives. But in other places, like here in Ottawa, there'll be a few people that are experts in Alzheimer's disease, not enough to have a centre, a physical centre here, but they will be associated with the centre in Toronto or with some other centre in the country.

That's why a network of centres, where you have five or six core, is quite effective. Then people collaborate, and all the data, all the knowledge, and all the technology is available to everyone.

**Ms. Kirsty Duncan:** So that's part of your wish list: a network of centres of excellence. What else do you want on that wish list?

**Dr. Rémi Quirion:** There are three other things that are also, of course, very important. We need to have a training ground to train the next generation of scientists and clinicians in the field of brain research, and in this case Alzheimer's disease. That is very important.

Weihong here is very young, but Serge and I are getting a bit older. So we have to make sure that the next generation of scientists is there and will be able to replace us in the future. And excellence is key. It's not just to train these guys, but they need to be at the very best international level. These types of networking centres that I was talking about will help very much in terms of training the next generation of scientists. So that would be number two.

And number three would be to make sure, as Inez said, that we have money, that we have dollars to run the experiments and do the research.

**Ms. Kirsty Duncan:** In terms of operating grants, what kind of dollars are we looking at?

**Dr. Rémi Quirion:** Well, in Canada at the moment, at the Canadian Institutes of Health Research, the average grant is about \$120,000 per year. And usually this is for five years. Most of the grants are five-year grants.

**Ms. Kirsty Duncan:** And what is needed?

**Dr. Rémi Quirion:** If we compare it with the U.S., the model is a bit different, but there it would be twice as much as that. That gives you the figure.

I think if we were able to go to what we call an individual grant, at \$200,000 per year for five years—so a block grant of \$1 million for an investigator—that would be much more competitive than where we are now in comparison with the United States, with Germany, and with the United Kingdom.

That would be a significant increase in support, direct support, to a lab or to a team of scientists.

**Ms. Kirsty Duncan:** Thank you.

And would others like to add to the wish list?

Dr. Song.

**Dr. Weihong Song:** I mentioned my wish list in my presentation, Dr. Duncan, and it would very much echo what Dr. Rémi Quirion just said. In Canada we have very excellent experts across the country, but we do have a cluster of experts in certain places. To be viewed as a centre of excellence would be a great addition to our researchers.

When Rémi talked about the second part of wish list, actually, I think that centre, with a training base, would be embedded in that. When I moved to Canada from Harvard nine years ago, of huge benefit was the Canada research chairs program. Obviously we have the ability to run the lab, hire the graduate students, or hire the post-docs, but right now...is really not that good, so....

● (0940)

**The Chair:** Thank you, Dr. Song.

We'll now go to Monsieur Malo.

[*Translation*]

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

Good morning, Dr. Gauthier. Welcome to all of you.

I want to understand your second recommendation on the changes you would like us to make to the Patent Act regarding pharmaceuticals. I understand from your recommendation that where research on prevention is concerned, more time is needed to study the effectiveness of a molecule. Under the current Patent Act, the protection could expire before the medication was marketed or studied in clinical trials.

Have I understood your recommendation correctly? Could it be applied to something else besides Alzheimer's disease?

**Dr. Serge Gauthier:** I will begin answering, and my colleague may have something to add.

For Alzheimer's disease, symptomatic treatments in use currently are administered for six months to two years on the average, and clinical trials to demonstrate their effectiveness last six months. In that case the approval and trial period under the current Patent Act is appropriate.

To prevent Alzheimer's disease among certain high-risk populations, we may have to use new molecules that modify amyloid or other protein deposits in the brain. The trial period will then be from five to seven years for the crucial phase III studies. For preventive treatment of younger patients where we would like to see very early intervention, trial periods could last for 10 years. So in those cases, we see that the trial period would be much longer than usual with regard to the current patent protection.

[*English*]

**The Chair:** Would anybody else like to comment?

Monsieur Malo.

[*Translation*]

**Mr. Luc Malo:** I understand you quite well.

Mr. Ferdinand, you were talking about the development of vaccines. Is this to prevent the disease, as Dr. Gauthier was suggesting, or is it—

**Mr. Mark Ferdinand:** Indeed, because in my opinion, we are just beginning to evaluate the research that is being done, in the universities in particular, here and elsewhere, on the prevention of certain mental illnesses. So as we are just in the preliminary stages of the development of vaccines which we hope will be very effective, we have to encourage this type of research. It is entirely new. We must thus encourage this research, and if we have expertise here in Canada in this area being studied by the subcommittee, perhaps we should not only encourage our researchers, but also seek to obtain funds from external sources.

If there are, elsewhere in the world, pharmaceutical firms, lenders or investors who want to invest in vaccines and prevention research, we have to create an environment that will attract these funds. Over \$100 billion is invested in life sciences globally, and in Canada we attract about 2% of those investments. I think that given all of the excellence the other witnesses spoke to earlier, we can attract much more than 2% of those funds here to Canada.

**Mr. Luc Malo:** How much, approximately?

● (0945)

**Mr. Mark Ferdinand:** It depends, because all sorts of factors influence investments.

**Mr. Luc Malo:** Which ones?

**Mr. Mark Ferdinand:** For instance, patent laws may have an influence. In the private sector if you want patent protection, a certain market exclusivity that rewards the investments that the private company makes in research, that can attract funds. For instance, the United States quite recently passed a patent extension, particularly to encourage research on biologic medication.

The same sort of incentive measure could be used not only for biologic medication, but also perhaps for vaccines. Research on vaccines takes much longer than research to develop medication.

**Mr. Luc Malo:** What I understand from your comments is that the development of vaccines is at a very preliminary stage.

**Mr. Mark Ferdinand:** Yes. At least that is the case for vaccines against Alzheimer's disease. There have not been any successes in the past few years, in spite of the large amount of research that is being done in this field. Since the 1990s and the beginning of the last decade there has of course been research on vaccines against Alzheimer's. A great deal has been learned, but no effective medications have been developed that would be approved by the FDA or Health Canada. There is still work to be done.

**Mr. Luc Malo:** If I understand correctly, Doctor Gauthier, you are working on finding tools to prevent the disease, or that is what you hope to focus on in your research.

**Dr. Serge Gauthier:** Yes. I think that we have reached a certain plateau currently with regard to molecules that can attenuate symptoms at the dementia stage. However, we may be luckier with new models or new molecules. Also, as the lady was saying, we may develop an original approach that may derive from observation in the context of another disease, which could apply to many other cerebral pathologies.

We need to invest in prevention at this time. We have a whole cohort of baby boomers, and I am one of them, who are aware of the risks and who may be willing to invest some of their own funds. To add something to the reply given to Ms. Duncan earlier, I would say that if we could get the public fired up about the prevention of neurological diseases, we might be able to obtain private investment to add to the funds available from the federal level.

**Mr. Luc Malo:** Very well.

Thank you very much, Madam Chair.

[English]

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

I want to welcome Mr. Marston to the committee.

You have seven minutes for questions and answers, Mr. Marston.

**Mr. Wayne Marston (Hamilton East—Stoney Creek, NDP):** It's interesting to take a seat about a minute before you have to ask seven minutes' worth of questions, but thank you, Madam Chair, I appreciate your welcome.

I see there's a recommendation from Mr. Gauthier regarding an increase in the tax credit for patients with chronic debilitating illnesses. Tax breaks don't put much money into people's pockets unless they already have money and resources.

We have some supports under employment insurance. Would an expansion of the program under employment insurance be more helpful?

**Dr. Serge Gauthier:** Most of the Alzheimer's patients are already retired and about 75 years of age, so they would have to pay income tax to get some money back with the tax credit. Perhaps the new generation of baby boomers, as they move into the ages when many of them unfortunately will have dementia, will have enough income to take advantage of such a program. But for the children who are caregivers and still working, your suggestion is a very appropriate one to explore.

**Mr. Wayne Marston:** Most of us know more people with MS than with AD in my generation. I'm a boomer as well—although it's

hard to tell. Recently there has been anguish around the magic bullet they'd thought they had found for MS.

Is there anything on the horizon investigatively that would lead us to the same kind of situation, where there might be something to push back Alzheimer's once it starts?

**Dr. Serge Gauthier:** Actually, the starting point has changed. We no longer wait for dementia to say that someone has Alzheimer's disease. The new biomarkers include spinal fluid examination—we need a spinal fluid lab in Canada, so add it to the wish list, please—and PET imaging, which is imaging of the brain with different tracers.

If we can make a diagnosis of Alzheimer's before there is dementia, we can gain about two years, on average. Those two years before dementia is our window, we think, to study the disease where the brain is still able to recuperate. Some of the connections could be rebuilt. It bridges what the young lady was saying here about brain repair systems.

That's what we're hoping. It would take three years, I would say, to establish whether this prevention in the pre-dementia stage was actually working. Some of the drugs that have failed in the later stages might work earlier. There are new molecules being tested in animal models right now.

• (0950)

**Mr. Wayne Marston:** I'm sorry I missed the part of the presentation that spoke to that, because prevention is always the better model in anything we come up against from a health standpoint.

When you talk about this advance screening, how do you choose the persons to screen? There must be some evidence or family history. How do you make that choice?

**Dr. Serge Gauthier:** You're right on the mark: family history is probably the key factor. There may be some blood test to support your family history as a risk. There was a discovery made in Canada about a gene that malfunctions in 15% of the population. It's a variation of a gene that allows your brain to carry cholesterol efficiently in and out, and to build connections as you grow up as a child and maintain those connections as you age. So there are ways to identify people at risk from family history, some genetic tests.

Some new brain scans—fMRI—would also allow detection of people with some brain connection abnormalities even before they have symptoms. This is technology available now. So we're building momentum in the next year at McGill, and hopefully elsewhere across the country, for prevention in people at the highest risk, where the risk is justifying the means for prevention.

But in parallel to that, for the population as a whole, at lower risk, there are other interventions that resemble heart and stroke prevention that are already in place, such as controlling your blood pressure, having red wine, men staying married. There's a host of other prevention measures that can be diffused through knowledge transfer for the people at the lower level of risk.

**Mr. Wayne Marston:** I wouldn't have expected the "staying married" part.

My wife and I are fine, thank you very much.

**The Chair:** Excuse me: we're editing here.

**Voices:** Oh, oh!

**Mr. Wayne Marston:** You talked about cholesterol. Is there evidence that cholesterol at high levels impedes the function of the brain, or even leads to this?

**Dr. Serge Gauthier:** It's part of a number of vascular risk factors, which include high blood pressure, especially at your age—40 to 60. In mid-life, high blood pressure is a known risk factor for dementia in general and Alzheimer in particular. That's preventive with technologies already available. That also includes diabetes, which is on the rise in our continent; high cholesterol, which we're starting to control in mid-life now, with appropriate medications, with exercise and diet; smoking is a factor we're controlling. So cholesterol should be seen as part of a number of vascular risk factors on which we do have some control.

**Mr. Wayne Marston:** I'll keep taking my Crestor, thank you.

Thank you very much, Chair.

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

We'll now go to Mr. Brown.

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

Thank you for all the presentations here today.

Certainly this is a fascinating topic. I know my family, like most families, has been touched by Alzheimer's. I remember seeing my grandmother two years ago pass away of dementia. I remember that the doctor told us seven years before that it's one of the worst ways to die, and it really is, because it is so insidious. I hope that with the work we're doing we're making progress. There's an exciting remedy here about the \$30 million invested through CIHR, and the list of other ideas of what we could be doing.

I have a few questions that I'm curious about. We had the Alzheimer Society on the Hill two years ago when they presented the "Rising Tide" report about the economic consequences associated with Alzheimer's and dementia. Could you share a little bit of information on that and how real those numbers are? Do you agree with the assessment? At the time, Scott Dudgeon was their CEO, who shared with MPs that this was going to be a multi-billion dollar cost to the Canadian health care system.

**Dr. Rémi Quirion:** The Alzheimer Society of Canada is part of the coalition that Inez talked about, and it is a partner with us. We are working very closely with them in developing the international strategy that I talked about. The numbers they have are real. We all mentioned them, so it's billions of dollars. Of course, the number of

Canadians suffering from dementia is also increasing very rapidly, so it's the rising tide. Now we are calling our report "Turning the Tide".

So we need to find ways to slow down the progression of the disease and to reduce the number of Canadians suffering from that disease. One way is prevention, as Serge was discussing, controlling your blood pressure, exercise, good diet, and so on. There is a pharmaceutical approach as well.

● (0955)

**Mr. Patrick Brown:** One thing I've always been perplexed by, and I remember when I asked questions about this years ago I was surprised by it, is how little we really knew about the brain. It was a very frustrating process. I've heard people say that mental activity certainly helps avoid the onset. Then I think of people like Ronald Reagan and Margaret Thatcher, who have had incredibly stimulating lives. You hear about physical activity, but then you hear in the NFL there are higher rates of Alzheimer's and dementia than anywhere else, and they have incredible levels of physical activity.

How certain are we that those are means to delay onset? When you see examples like that, it certainly causes confusion.

**Dr. Rémi Quirion:** Yes, football players and those in other types of sports have a lot of head injuries, and we know that head injuries are a factor in the development of Alzheimer's-type dementia. So the head injury part is not a good thing for boxers or for football players and so on.

When we talk about physical activity or red wine, it also always depends on your background, your genetic background, how you're made, and also the lifestyle you have. This is on average. Basically we are studying 500 people, and we say, on average, higher education or more physical exercise is better for you. But that does not mean that university professors like me will not get Alzheimer's or that the Prime Minister of Canada will not get Alzheimer's. It's an average that we are talking about.

There's another thing that is probably important for members to know. Alzheimer's disease in the end will probably turn out to be a bit of a spectrum of disorder, a bit like cancer. There will be subtypes of the disease.

Maybe a better example would be hypertension. If you have high blood pressure, for some of us the treatment is to dilate the vessel—a vasodilator—for others it's the kidneys, and for others it's the heart. So probably with Alzheimer's disease, in a few years' time when we have better drugs, a group of patients will get one type of drug because it's one protein in the brain, the amyloid protein, that's key. For others, it may be another type of drug.

At the moment, we don't understand enough of the disease process to start to disentangle all that into subgroups. So that's also important to remember.

**Mr. Patrick Brown:** A few weeks ago we heard from a constituent of mine from Barrie, Greg McGinnis. He told us that the current drug plan didn't cover his basic needs in terms of Parkinson's.

Do you have any comments, Mark? You're so involved with the pharmaceutical industry in Canada. What does your research suggest? Are there lots of people with Alzheimer's who have that same challenge, where their drug plans in Canada don't cover basic requirements?

**Mr. Mark Ferdinand:** We only have a few drugs that treat Alzheimer's that have been approved for use within Canada within the last six or seven years. We generally see this all across mental health drugs, including drugs for Alzheimer's. So we don't have, let's say, a basket of ten to look at. We're looking at maybe one or two. But when we look at those one or two drugs to treat Alzheimer's, unfortunately, what we see is that most other countries in the OECD—the other 28 countries—provide some form of public coverage for those drugs.

**Mr. Patrick Brown:** What types of drugs are those?

**Mr. Mark Ferdinand:** I'll provide you with a list of the drugs. Some of the lists are extensive. The challenge is that in Canada, across the country, we basically do not see a form of public coverage for those same drugs. What we tend to see is that the drugs will have been reviewed by the common drug review and then, generally speaking, across most public plans, not reimbursed.

I mentioned 28% as being the average coverage that we see for these types of drugs here in Canada, whereas we're seeing in excess of 80% to 90% coverage in the other OECD countries for the drugs that will have been approved for use here.

So we're not seeing the same level of sophistication, maybe, in providing access to drugs in Canada's public plans as we see elsewhere in the OECD.

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

We'll now go to our second round of five minutes. I've been very liberal with the timing, as you've probably guessed by now.

We'll go with Dr. Duncan.

**Ms. Kirsty Duncan:** Thanks, Madam Chair.

I'm wondering if you're able to provide specific examples of how access to treatment varies through Canada.

Yes, Dr. Gauthier.

• (1000)

**Dr. Serge Gauthier:** That's quite easy, because for Alzheimer's disease right now, there are only two kinds of medicine. One kind, which we've had for 10 years, increases the brain levels of a transmitter called acetylcholine. It was approved in Quebec and Ontario within a year or two, but there was a lag time for the Maritimes by about five years and a lag time for B.C. by about seven years. Now it's across the country.

The second class of drug comes from Germany and Austria, and this medicine is reimbursed only in Quebec, despite evidence building up that not only does this single drug work on another brain transmitter but also the combination of the two classes of drugs, as

we have for diabetes and hypertension and most diseases, has an additive benefit to patients.

So we're at a standstill, because the CDR, the central review process, which currently excludes Quebec, seems to have a tendency to refuse all novel compounds. For the specific needs of Alzheimer's patients, there is one compound that has been used in Europe for over 20 years, available in Canada for four years, but reimbursed only in one province.

**Ms. Kirsty Duncan:** Thank you.

I have the privilege of serving the veterans community in Canada. I'm really concerned about PTSD and its possible links with dementia, and mild or more severe traumatic brain injury and its links with dementia, particularly because about one in five may develop PTSD.

I'm wondering if you can talk to those two issues, please.

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

Dr. Song.

**Dr. Weihong Song:** I can talk a little bit about the basic research side of that link.

Just as my colleague mentioned, in my lab we have had repetitive mild head injuries in the animal model, and it has definitely showed that there is a link between mild head injury and memory deficit, which means dementia.

That actually is a major research field, funded particularly in the States. We cannot access that from the department, but it is budgeted for there. In Canada, Alzheimer's, as a whole, is underfunded, and obviously this is the aspect of the research initiative that needs to be supported and funded.

**Ms. Kirsty Duncan:** Is there anyone else?

**Dr. Serge Gauthier:** I can add something on the clinical side, if I may.

There's been some pioneering work done by one of our McGill psychiatrists showing that some beta blockers, used at strategic times after PTSD is manifested, will suppress some of the long-lasting effects. So there is a start to pharmacological manipulation using old drugs to perhaps modify the longer-term impact. That would be under an operating grant in the single-applicant category of funding. But it could also be, perhaps for the veterans, a targeted program for the prevention of cognitive decline in Canadians who served overseas and have PTSD.

**Dr. Rémi Quirion:** Maybe just to add a little bit, this group at McGill, in partnership with a group at Harvard, has a large grant from the U.S. army to try to test this drug, this beta blocker, in the treatment of PTSD. Hopefully we'll have a response on a fairly large cohort of subjects very soon. That's coming.

In terms of head injuries, there's basic research and clinical research that has demonstrated strongly the link between head injuries and the incidence of Alzheimer's disease.

**Ms. Kirsty Duncan:** Thank you.

Worldwide there is concern regarding the human and economic costs of Alzheimer's disease. Many countries have a targeted Alzheimer's strategy. I'm wondering if we need a pan-Canadian dementia strategy. If so, should this be integrated into a larger pan-Canadian neurological strategy?

**Ms. Inez Jabalpurwala:** My perspective, and again, this is based on 10 years of really talking to everybody involved from the patient side and the research funding side and the side involving the VHOs, has been that we do need to start thinking about a national strategy that has to do with the whole brain, because of the commonalities. Some of the questions that have been raised have been linking concussion or brain trauma to Alzheimer's. And there are other types of diseases. One of our science leaders is involved in cancer research at SickKids in neuroscience. His lab is now doing Alzheimer's research, because they're discovering that certain cells and how they age is linked to eventually what happens with Alzheimer's cells.

There's so much crosscutting that I think we'll lose a lot of the potential we have in this field if we don't start to bring all these pieces together and understand how all of them fit together in an overall strategy. This does not take away from the fact that patient experiences for these various conditions may be different. That's why I think that the work the voluntary organizations are doing is really important.

But we've all come together on the basis of the science case, because we've all understood as voluntary organizations that there is a common thread that links us together. Maybe if we start working together and consolidating our efforts we can do even more in this field. Rémi mentioned CIHR; they've certainly been a leader in stimulating this type of mindset of collaboration and bringing community together.

• (1005)

**The Chair:** Thank you, Ms. Jabalpurwala. That's the key, isn't it: collaboration.

We'll now go to Mr. Brown.

**Mr. Patrick Brown:** Thank you, Madam Chair.

One question I asked the previous panels I'll ask again today. When we look at the research funding, one thing we've heard again and again is that an incredible amount of time is spent filling out applications. We've heard some people say that as much as 70% to 80% of the time is spent simply preparing applications for research grants. We've also heard that many very good projects get left off the table.

I'd be curious to hear your perspective on how much time, when it comes to studying Alzheimer's, you believe is put into the actual application process. And what type of research is being left off the table that might be very valuable in Canada?

**Dr. Weihong Song:** For me, as a Chinese Canadian, English is obviously not my native language. I spend probably two or three times more than my colleagues do writing applications. It takes a lot of time. If I want to write a single \$120,000-per-year grant, it takes me probably at least three weeks to prepare the whole grant application, which is really a lot of time.

Grants are so important to my lab, particularly the operating grants. The reason is that they allow us to hire graduate students,

post-doctoral students, which has a major impact on training the future generation of scientists. It takes lots of time to do it.

**Mr. Patrick Brown:** But three weeks for a one-year grant is a lot less time than what we've heard before.

**Dr. Weihong Song:** One grant is not enough, actually. We have to apply for multiple grants from different agencies. It takes a lot of time to write them and prepare them. Actually, you need a lot of the preliminary data, and we spend a lot of time preparing it.

**Dr. Rémi Quirion:** Most scientists who will be successful, people we have referred to here, will have at least three to four grants from CIHR, and then grants from the Alzheimer's Society of Canada. Often they will have some grants from the United States. To be able to properly run a lab in Canada, to be internationally competitive, you need maybe five of these grants, and all will have deadlines that are different during the year. So you spend a lot of time writing grant applications.

The success rate at CIHR at the moment in grant competitions is between 15% and 20%. Every time you submit, there is a likelihood that you will not get the grant, and the likelihood is much greater. That's challenging, and the success rate has been going down a bit over the years.

In the United States, it's even worse. There it's only 4% at the National Institute on Aging. A lot of scientists are spending a lot of time on that, so we need to change—

• (1010)

**Mr. Patrick Brown:** I have one quick question on that before—

**The Chair:** I think Ms. Jabalpurwala wants to answer.

**Mr. Patrick Brown:** I have one quick question for Rémi before we get to that.

So \$30 million is what CIHR funded last year. Are you saying that there were about \$150 million in applications?

**Dr. Rémi Quirion:** Yes, in the field of Alzheimer's disease, there will be five times as much as that left on the table. What's left on the table, and we should probably say that this is in the excellent category, because below that we don't want to necessarily fund, there are certainly some excellent grants that just miss the cutoff and are not funded. These guys have to try again six months later.

**Mr. Patrick Brown:** Would you put the majority of the \$150 million in applications in the excellent category?

**Dr. Rémi Quirion:** No. The excellent category I would say would be about 25%. There are maybe 10% of grants that are not funded that should be funded.

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

Go ahead, Inez, please.

**Ms. Inez Jabalpurwala:** That was actually our experience, as well, in doing the brain repair program and the large team grants.

There's another aspect to what Dr. Quirion has said, and that is that in addition to trying to cobble together a bunch of grants for one researcher, if they want to collaborate with other teams, those teams have to find the grants they need, because there are no natural grants that enable them to work together. Suddenly we have this complexity. Teams are each individual, and everyone within that lab is applying for multiple grants and is hoping that a team they want to work with is able to equally get funding so that they can finally bring their work together.

It's an enormous amount of time, because it takes a while for any kind of team to form and work together in a meaningful way and not just virtually. I think providing larger grants for at least three years, if not five years, and cutting down the process of having to apply every year for small amounts will make a dramatic difference. We saw the results, and we are a very small organization with limited funds. Our grants were \$1.5 million for three years, and we were able to do five. But we saw dramatic results.

I think this is well supported by both the science and the science community.

**The Chair:** You still have more time.

**Mr. Patrick Brown:** Thank you.

I understand that in the summer, or last year, there was an agreement signed between Canada and France and the U.K. about sharing research in the Alzheimer's field. What do you know about that, and how is that helpful to our efforts?

**Dr. Rémi Quirion:** Five teams have been funded in the context of the partnership between Quebec, Canada, and France. Some are working on the role of prions, a protein, in diseases of the brain. It's based in Vancouver, with some people in Quebec and some people in France. Then there are other animal models.

That's quite useful, because again, there's a bit of sharing of approaches and technology. And these grants are fairly large. They are bigger. They are in the \$2 million category.

With Germany and the United Kingdom, the process is just under way. Now we are trying to establish the priority—which subfield of Alzheimer's disease we should fund—in partnership. It will again be in support of a joint platform.

Serge was talking about brain imaging as a potential marker. Well, if you take your image in London, England, and you take your image in Montreal, how do you compare? It's easy to take the image. The issue is analyzing it with different machines. Basically, standardizing all these methodologies in terms of diagnosis and in terms of biomarkers is very important. That's why international partnerships are so important.

The next one developing is with China and with the States.

**The Chair:** Thank you, Dr. Quirion.

I understand that you're finished with your questioning, Monsieur Malo. Thank you.

Now we'll go to Dr. Duncan.

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

Dr. Gauthier, last time you provided a very clear example of how treatment with medicine varies across the country. I wonder if you can provide an example in terms of how care occurs. Are there different guidelines? How does care vary across the country? Do we need national guidelines? Is there somewhere it's being done extraordinarily well, and the model can be replicated?

**Dr. Serge Gauthier:** The good news is that in Canada, close to 20 years ago, we started to work together—GPs, specialists of different types, and the Alzheimer Society of Canada, representing patients and caregivers—on one set of guidelines. And we've updated those guidelines periodically. So that's national.

As far as the basic diagnostic approach and the care goes, we have harmonization across the country. There may be variations in access to specific technologies, such as CT scans and PET scans. That is a local issue, perhaps, rather than a national guidelines issue.

The surprising inequality has been access to available drugs. And it cannot be just a question of money, because they're not expensive, considering the cost of the disease. So there is something here that we don't understand about the CDR approach, which is negative. It's like going to court. You have to prove that you're a good person. There is something wrong with the current design that you may have to look at in a broader way.

My suggestion to you, at the national level, is that maybe the approach to take would be the approach of having a patients charter. There may be something like that already in existence that we can beef up. If not, maybe we should think about it.

• (1015)

**The Chair:** You can have one more question.

**Ms. Kirsty Duncan:** We talked about needing a national brain strategy. I wonder if we need a national dementia strategy.

**Dr. Serge Gauthier:** I really hope you'll stay away from the D word—

**Ms. Kirsty Duncan:** It is Alzheimer's, yes.

**Dr. Serge Gauthier:** —because Alzheimer's disease is a spectrum, from mild forgetfulness to more than that but not dementia yet. It's Alzheimer's disease.

My argument for broadening it to the brain at large is that the pathology of Alzheimer's is actually a combination of things. There is some Parkinson's in there, and Lewy body, and some small stroke components, and amyloid and other changes in the brain cells. So it's actually a complex disease with bits of different pathologies.

Some patients will have a Parkinson-like course. Others will have a more traditional dementia, a typical Alzheimer's course. And others will fall early and have incontinence because of the stroke component.

That's why there is also a pragmatic, pathological reality check. Alzheimer's is a complex of different causes, and the brain approach will pay off better in the long run than just a disease-specific approach.

I never thought I would say that, but it's true.

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

Do you have a question? Okay, go ahead.

**Mr. Wayne Marston:** How much time do I have?

**The Chair:** Five minutes.

**Mr. Wayne Marston:** Thank you very much, Madam Chair.

I'm going to take this to a personal level for a second. In 1974 I was a signal maintainer for the railway, and I had four people killed on one crossing over 11 months. Over a period of years I had mental strain as a result of that; PTSD, I guess, is the word for it.

Then in the 1980s I was involved in a car accident. I pulled a guy out of a burning truck. When I first went to the side of that vehicle, I looked in. Your mind will try to protect you: oh, no, he's already dead, don't worry. I paused for maybe 20 seconds. I had nightmares for five years after that because I even considered leaving him, when in fact we got him out.

Using a lay term, I'd call the result of all that "mental anguish". When you take that kind of thinking and you apply it to our veterans who are coming back from Afghanistan—I understand there are about 3,000 young men and women coming back from there with various injuries—what's the correlation between the mental anguish potentially causing it or a combination of physical and mental anguish leading to this kind of outcome? Is there evidence that this could be happening? And is there evidence that just the mental side alone might lead to something like this as opposed to physical head trauma?

**Dr. Serge Gauthier:** Maybe I can try to answer that with what's already known.

There were studies done about personality disorders and stress exposure in life as a factor leading to or increasing the risk of Alzheimer's disease. There's no convincing data to that effect. Perhaps it's fair to say that if you are predisposed to a disease because of your genetic makeup, you will have the symptoms at an earlier stage if you had head injuries, if you were drinking alcohol too much, if you had hypothyroidism.

So there may be accelerating factors to a disease that you will get someday. That's as far as I think we can go with the evidence.

**Mr. Wayne Marston:** So in fact we're saying these things are possible causes, but it's more genetic and it's more likely to be genetically caused.

I want to go to the discussion around a pan-Canadian strategy. I guess—and I am guessing—that you would say that because the federal government is responsible for the Canada Health Act, it

might logically fall to the federal government, even though most of the health care is provided or administered by provinces. Some form of leadership from the federal level would be very important on this.

I like it when I see all the heads starting to nod. That doesn't happen in my life that often.

The strategy you talk about sounds like it's well under way. I think you referred a moment ago to how things have been happening for 20 years on the medical side.

This is the loaded question: how do you correlate that against what's been happening on the governmental side?

• (1020)

**Dr. Serge Gauthier:** It's a bit of mystery why there's so much discrepancy in drug approval processes among the different provinces. There was hope that the central review would be a positive thing to speed things up, but actually it turned out to be the opposite.

There will also be an ethical dimension to the whole process of diagnosing Alzheimer's before dementia. What do you tell people when they're 50? Do you tell them they have Alzheimer's, that although they don't have symptoms yet, we can see it on their scan or their lumbar puncture? Do we tell them they have mild symptoms of Alzheimer's and they'll have dementia in five years?

There's perhaps an ethical dimension and a resource-use aspect. You will be using more technology, more scans, more lumbar punctures, more specialized units. There may be a social debate that would be at the national level on the ethics of earlier diagnosis if there's no effective prevention. That's one aspect of the answer.

As far as harmonizing diagnoses and management is concerned, we will continue to do that, but this is not driven by governments. This is driven by the base, which is nice. It's doctors and lay public societies, and that will continue.

**Ms. Inez Jabalpurwala:** Madam Chair, if I may, only relatively recently have we actually understood the burden of disease for the brain. I remember even 10 years ago, when I first started talking about the idea of creating an entity around the brain, people said, this is impossible. We're diseases, or we're injuries, or we're mental illness. And now this is something that is fundamentally accepted.

With cancer, the Canadian Cancer Society was founded in the early 1900s. With the brain, it's been a long way before we've been able to reach this point. So I think we've done very well considering that the science is still quite young. I think the fact that we've done so much in 15 to 20 years really is an indication, and as Dr. Quirion has mentioned with the technologies that are developing around the world and with the way science has moved, we can do a dramatic amount in the next 20 years.

This is a really great time, I think, to be in this field.

**Mr. Wayne Marston:** The reservations that I hear are around money.

**Dr. Rémi Quirion:** Yes, certainly money is an issue, but it's the role of the federal government to support research. There it's not a matter of an issue with a government of a province. There, to have a national strategy in terms of the research component, in addition to guidelines, certainly it's the place of the federal government.

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

I want to thank the panel today for some very insightful information and for your documents that you have given to us. This committee has worked very hard on the neurological disorders issues, and we've had many presentations before us, because I think it's very timely that we do this. Thank you so much for coming today.

Committee, I wanted to let you know that Dr. Beaudet from CIHR is available to appear on MS on December 7. Remember, he was originally going to come on December 14, but now it's December 7 from 8 a.m. to 8:45 a.m. He isn't able to come on the 14th, so we asked if he could come on December 7.

Is that okay with you?

**Mr. Patrick Brown:** Let's take what we can.

**The Chair:** Take what we can? All right.

We will adjourn. Thank you so much.

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