



HOUSE OF COMMONS
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CANADA

**FOCUSSING ON THE BRAIN:
AN EXAMINATION OF
NEUROLOGICAL DISEASES IN CANADA**

**Report of the Standing Committee on
Health**

**Joy Smith, M.P.
Chair**

JUNE 2012

41st PARLIAMENT, FIRST SESSION

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has the honour to present its

TENTH REPORT

Pursuant to its mandate under Standing Order 108(2), the Committee has studied neurological diseases in Canada and has agreed to report the following:

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FOCUSSING ON THE BRAIN: AN EXAMINATION OF NEUROLOGICAL DISEASES IN CANADA

INTRODUCTION

On March 26, 2009, the House of Commons Standing Committee on Health (hereafter the Committee) passed a motion to establish a Subcommittee on Neurological Diseases (hereafter the Subcommittee) to examine neurological diseases in Canada.¹ Once established, the Subcommittee agreed that its study would focus on: fostering research on the causes, prevention, diagnosis and treatment of neurological diseases; examining ways in which to make treatment patient-driven and patient-focused; identifying achievable targets in the prevention and diagnosis of neurodegenerative diseases; easing the challenges facing caregivers and the families of those with neurological disease; and collecting and disseminating research information related to neurological diseases. It further agreed that the study would focus on five specific neurological diseases, including: Autism Spectrum Disorder (ASD), Multiple Sclerosis (MS), Amyotrophic Lateral Sclerosis (ALS), Parkinson's Disease (PD) and Alzheimer's Disease (AD). In total, the Subcommittee held eleven hearings and heard from 55 witnesses, including: researchers, neurological charities, individuals living with neurological diseases and their caregivers, and government officials. On March 26, 2011, the Subcommittee on Neurological Diseases was dissolved due to the 41st General Election in May 2011.

On December 14, 2011 and February 7, 2012, the House of Commons Standing Committee on Health agreed to update the study originally undertaken by the Subcommittee on Neurological Diseases and report on its findings. It held an additional three hearings ending in May 2012 and heard from a total of 17 witnesses.

This report summarizes testimony from hearings held by both the Committee and the Subcommittee and where possible, updates have been provided to ensure the accuracy of the report. The report also identifies areas in which the federal government could take further action to address neurological diseases in Canada. The report is structured to reflect the three broad themes that emerged throughout the course of study, including: focusing on the brain as a whole; fostering neurological research in Canada; and improving the quality of life of those with neurological diseases and their families. The first chapter presents an overview of neurological diseases in Canada and highlights the views of witnesses regarding the need for a shift in perspective from targeting individual neurological diseases separately to focussing on the common needs and challenges inherent to neurological diseases as a whole. The second chapter examines different ways in which neurological research could be promoted in Canada. Finally, chapter three highlights key factors affecting the quality of life of those suffering from neurological diseases and their families, including: income security issues; the social and economic costs of care giving; access to drugs, treatments, care, and supports; social stigma; and genetic discrimination. This chapter aims to capture the voices and stories of the patients and caregivers who presented before the Committee, as well as provide recommendations

responding to their concerns. Finally, it is important to note that the particular needs and challenges related to each of the five diseases selected for the study are highlighted within the context of these broader chapters.

CHAPTER 1: SHIFTING FOCUS TOWARDS THE BRAIN

A. Overview of Neurological Diseases in Canada

Neurological diseases refer to a broad range of disorders affecting the brain, spinal cord and nervous system. There are approximately 600 known neurological diseases.² Neurological conditions can arise from a variety of causes, including: communicable diseases; maternal causes; conditions arising from the perinatal period; nutritional deficiencies; non-communicable diseases; intentional and unintentional injuries; and genetic and environmental factors.³ The causes of neurological conditions have been difficult to define and in some cases, they may have more than one cause or contributing factor. Neurological conditions include both neurodegenerative conditions that are progressive, as well as neurodevelopmental conditions, which appear in childhood and affect cognitive and/or behavioural development during a lifetime.⁴ According to the National Institute of Neurological Disorders and Stroke, some of the major types of neurological disorders include: neurogenetic diseases (such as Huntington's disease and muscular dystrophy), developmental disorders (such as cerebral palsy), degenerative diseases of adult life (such as Parkinson's disease and Alzheimer's disease), metabolic diseases (such as Gaucher's disease), cerebrovascular diseases (such as stroke and vascular dementia), trauma (such as spinal cord and head injury), convulsive disorders (such as epilepsy), infectious diseases (such as AIDS dementia), and brain tumours.⁵

According to a 2007 report published by the World Health Organization (WHO), neurological disorders are currently estimated to affect as many as a billion people worldwide.⁶ According to witnesses appearing before the Committee, approximately one million Canadians are estimated to be affected by neurological disorders and suffer from the challenges associated with long-term disability and reduced function as a result.⁷ However, the Subcommittee and the Committee also heard from witnesses that determining the exact incidence and overall prevalence of neurological diseases in Canada is difficult due to limitations in the availability of data, the absence of a single recognized category for all brain and nervous system disorders, and the lack of a comprehensive study of neurological diseases in Canada.⁸ Witnesses further noted that these data limitations mean that it is also difficult to accurately estimate the total economic cost of neurological diseases in Canada.⁹

However, government officials appearing before the Committee in 2012 indicated that these data gaps are currently being addressed by the first ever National Population Study of Neurological Conditions announced on June 5, 2009, which was brought about by the Neurological Health Charities Canada (NHCC) and the Public Health Agency of Canada (PHAC).¹⁰ As part of this study, research teams are working across Canada to build a better understanding of the incidence and prevalence of brain conditions in Canada, their impact on individuals and families, the best health and support services needed to live well, and risk factors for their onset and progression. The Committee heard that the data from the National Population Study of Neurological Conditions would be available at the end of the study in 2013.¹¹

As mentioned above, the Committee and Subcommittee’s study focused in particular on five neurological diseases, including: Autism Spectrum Disorders (ASD), Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS), Parkinson’s Disease (PD), and Alzheimer’s Disease (AD). A brief overview of these diseases, their prevalence in Canada, and total economic consequences are outlined in the table below. The table outlines the most recent data available; unless otherwise noted, it is based upon the following report: Canadian Institute for Health Information, *The Burden of Neurological Diseases, Disorders and Injuries in Canada*, 2007.

Table 1: Overview of the Prevalence and Economic Consequences of Select Neurological Diseases in Canada

Disease	Overview	Prevalence	Economic Consequences ¹²
Autism Spectrum Disorders (ASDs) /Pervasive Development Disorders (PDDs) ¹³	ASD/PDDs represent a range of neurodevelopment disorders, which are characterized by impairments in communication and social behaviour, activities and interests. There are five PPDs, including: Childhood Disintegrative Disorder; Rett’s Disorder; Autistic Disorder; Pervasive Developmental Disorder Not Otherwise Specified; and Asperger’s Disorder. Causes of ASDs are unknown, but research currently focuses on abnormalities in brain structures, functions and chemical differences, genetic and environmental factors; immune system deficiencies; birth complications; and other medical conditions.	The onset of ADSs begins in early childhood, ranging from 6 months to 3 years. Epidemiological studies are still in the early stages in Canada and therefore accurate data on the prevalence of ASDs is not available. However, it is estimated that rates of ASDs are 6.5 per 1,000 in Canada. ¹⁴	N/A

Disease	Overview	Prevalence	Economic Consequences
Multiple Sclerosis (MS) ¹⁵	<p>MS is a disease of the central nervous system, which includes the brain and the spinal cord. The cause of the disease is unknown. It attacks the myelin which is a protective covering wrapped around the nerves of the central nervous system.¹⁶ There are many types of MS. Two main types include: relapsing-remitting (characterized by episodic relapses and remissions) and primary-progressive (characterized by a steady slow progression). Symptoms of MS include vision difficulties, muscle weakness, loss of balance and coordination, pain, extreme fatigue, bladder and bowel problems and changes in cognitive functions.</p>	<p>It is estimated to affect approximately 55,000-75,000 Canadians, one of the highest prevalence rates of MS in the world;</p> <p>Affects up to 3 times as many women as men;</p> <p>Age of onset ranges from 20 to 50 years;</p> <p>Relapsing-remitting MS occurs in approximately 85% of patients.</p>	<p>Total direct and indirect costs associated with MS in 2000-2001 were \$950.5 million, not including the direct and indirect costs incurred by informal care givers.</p>
Amyotrophic Lateral Sclerosis (ALS) ¹⁷	<p>A neurodegenerative condition that is characterized by a degeneration of a select group of nerve cells and pathways in the brain and spinal cord, which leads to progressive paralysis of the muscles. Eighty percent of those diagnosed with the disease die within two to five years of diagnosis, typically from respiratory failure.</p>	<p>Affects approximately 2,500-3,000 Canadians;</p> <p>Affects men and women between the ages of 40 and 70;</p> <p>5-10% of cases are hereditary.</p>	<p>Total direct and indirect costs of ALS in 2000-2001 were \$182.4 million, not including drug expenditure morbidity costs, or the direct and indirect costs incurred by informal care givers.¹⁸</p>

Disease	Overview	Prevalence	Economic Consequences
<p>Parkinson's Disease (PD)¹⁹</p>	<p>PD is a slowly progressing neurodegenerative disease that affects muscle movement and control, leading to severe limitations in daily activity and quality of life. PD results from the loss of nerve cells in the part of the brain called the <i>substantia nigra</i>. These nerve cells supply the neurotransmitter dopamine, which acts as a messenger between the cells of the brain that control the body's movements.</p> <p>Two recent studies have suggested that protein accumulation in the gastrointestinal tract could serve as a biomarker²⁰ of PD.²¹ This discovery could possibly enable earlier and faster diagnosis of the disease.²² This research further raises the possibility that PD could originate from toxic or infectious agents in the gastrointestinal tract.</p>	<p>Approximately 100,000 Canadians have PD;</p> <p>It affects 1% of the population over the age of 65 and 2% of those 70 and older;</p> <p>Between 15% and 20% may have their onset before the age of 65.</p>	<p>Total direct and indirect costs associated with PD in 2000-2001 were \$446.8 million, not including the direct and indirect costs incurred by informal care givers.</p>
<p>Alzheimer's Disease (AD)²³</p>	<p>AD is a progressive degenerative disease characterized by a general decline in mental abilities involving memory, language and logical thinking.</p>	<p>There are approximately 500,000 Canadians with AD and other related dementias.²⁴</p> <p>Prevalence and incidence of dementia increase with age.</p> <p>AD is the most common form of dementia in Canada (occurring in 64% of all cases).</p> <p>Women are at higher risk of developing AD, partly because they live longer than men.</p>	<p>A 2010 report produced by the Alzheimer's Society found that the total direct and indirect costs associated with AD and other related dementias amounted to \$15 billion.²⁵ It is important to note that this study included the direct and indirect costs experienced by informal care givers as well.</p>

B. The Federal Role in Addressing Neurological Diseases in Canada

As it is generally agreed that the provinces and territories are primarily responsible for the delivery of most health services under the *Constitution Act, 1867*, this study focuses on neurological diseases in Canada based upon the legislative competencies of the Parliament of Canada.

The federal government currently addresses the neurological diseases in Canada by investing in research and surveillance through the Canadian Institutes of Health Research (CIHR), the Canadian Institutes for Health Information (CIHI) and PHAC.²⁶ In addition, the federal government provides income supports to those with neurological diseases and their families, such as: the Employment Insurance (EI) Compassionate Care Benefit Program, the Caregiver Tax Credit, the Child Disability Benefit, the Medical Expense Tax Credit and the Disability Tax Credit.²⁷ Further details regarding these federal research programs and income supports are provided in subsequent chapters of this report.

Finally, the federal government also provides funding for health care services under the *Canada Health Act*, which establishes conditions and criteria that provinces and territories must adhere to in order to receive the contribution for their health care insurance plans.²⁸ Among them, health care insurance programs must be publicly administered, comprehensive, universal, portable, and accessible.²⁹ With regards to comprehensiveness, it is important to note that the *Canada Health Act* only specifies that provinces or territories must cover all insured “medically necessary” health services provided by hospitals, physicians or dentists, or other health professionals, where the law of the province or territory so permits.³⁰ However, it does not determine which specific treatments are considered medically necessary for a particular disease or condition.³¹ Rather, this is determined by provincial and/or territorial health legislation and regulations, which are developed by provincial and territorial governments in consultation with their respective professional medical associations.³² Finally, the sanction on a province or territory for a breach of any of the *Canada Health Act*'s conditions is the reduction or withholding of transfer payments by the federal government.³³

The federal government also has a role in neurological diseases, as it provides certain health care programs and benefits to groups it has specific responsibility for under section 91 of the *Constitution Act, 1867*, including: First Nations and Inuit; refugees; members of the Royal Mounted Canadian Police (RCMP); members and veterans of the Canadian Forces; and federal inmates.³⁴ It is important to note that if passed by the Parliament of Canada, Part One of the *Budget Implementation Act 2012* would amend the *Canada Health Act* so that members of the RCMP are included in the definition of “insured person,” meaning that the RCMP would then participate in the health care system of their province or territory of residence, rather than being enrolled in a unique federal health care system of their own, as they are now.

Finally, the federal government is also responsible for the regulation of drugs used in the treatment of neurological diseases under the *Food and Drugs Act*.³⁵ Specifically, the federal government is responsible for authorizing the sale of drugs in Canada, which it

bases upon a review of scientific evidence examining both their safety and efficacy.³⁶ The federal government's Special Access Program also allows practitioners to have access to drugs and medical devices that have not yet been approved for sale in Canada in special cases where conventional therapies have failed, are unavailable or are unsuitable, and the patient has a serious or life-threatening condition.³⁷ It is important to note that the provision of public drug insurance to cover the costs of pharmaceuticals is the responsibility of the provinces and territories, including decisions related to which specific drugs are covered by these public programs in different jurisdictions.³⁸

C. How to Address Neurological Diseases in Canada

The Committee and Subcommittee heard from witnesses that there was a need for an innovative approach in addressing neurological diseases in Canada.³⁹ Both the Committee and Subcommittee were told that funding and supports should be directed towards brain diseases as a whole, rather than towards specific neurological diseases, as one witness stressed:

While it is important to make distinctions between conditions for a host of reasons...it's also very important to think collectively in what is called a non-categorical way, about these conditions and what they have in common. The idea that has been argued for many years, with evidence to support it, is that these conditions have a lot in common. And the way we think about them and deal with them should recognize that reality.⁴⁰

Witnesses appearing before the Subcommittee further pointed out that supporting neurological research as a whole rather than disease-specific research was necessary because breakthroughs in treatments for one condition may arise out of discoveries in other areas of research.⁴¹ For example, the Subcommittee heard that drugs initially developed for epilepsy were now being used effectively in the treatment of Alzheimer's, while drugs originally developed for diabetes were now being tested in patients with Parkinson's.⁴²

Researchers appearing before the Subcommittee explained that this cross-fertilization in research was due to a greater understanding of the underlying commonalities between neurological diseases.⁴³ They articulated that while different neurological diseases such as ALS, AD and Huntington's Disease each involved different neurons, these different neurons followed similar degenerative pathways. Therefore, insight gained from understanding the degenerative pathways in one neurological disease could be translated into greater knowledge of another neurological disease. Furthermore, researchers pointed out that many persons with neurological diseases also experienced psychiatric conditions and that there were often underlying linkages between these different conditions. As such, the study of neurological diseases could not be separated from that of other brain diseases, such as psychiatric diseases. Consequently, witnesses argued that research is needed to move away from the traditional model of disease-specific research, towards multidisciplinary research focusing on the underlying commonalities of brain diseases. However, some witnesses did articulate that it was important at the same time to ensure that some of the less common neurological diseases, such as ALS, still receive adequate funding within the context of larger neurological research efforts.⁴⁴

In addition to commonalities in research, witnesses articulated that while persons with different neurological diseases had unique needs, they also faced common challenges related to their quality of life. In particular, both the Subcommittee and the Committee heard that persons with neurological diseases often must rely on the support of informal caregivers, who experience high social and economic costs in relation to their role, including the loss of income and burnout from care giving responsibilities. Witnesses articulated that though each caregiver copes with the unique challenges of their particular situation, all caregivers face the same economic cost, regardless of the disease.⁴⁵

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

Finally, the Subcommittee also heard that it was important to provide services and supports to people based upon their level of function rather than based upon their particular disease diagnosis for ethical reasons.⁴⁶ The Subcommittee was told that there were different ranges of disability within each neurological disease. For example, a person with Tourette's syndrome may have greater impaired functioning than a person with a mild form of autism.⁴⁷ However, prioritizing services and supports for one neurological condition over another means that persons with less common neurological diseases may not receive the same access to services and supports as those with other neurological diseases with higher profiles. Similarly, some neurological diseases, such as Parkinson's disease, affect a smaller proportion of the population; therefore the needs and challenges associated with less common neurological diseases may be overshadowed at the policy level by those conditions that are perceived as having a greater impact on society.⁴⁸ Witnesses thus emphasized that programs, services and supports should be given on the basis of functionality to promote participation in daily life, rather than based upon disease diagnosis alone.⁴⁹

For these reasons, some witnesses appearing before the Subcommittee and the Committee articulated that there is a need to have a national strategy for all neurological diseases.⁵⁰ They heard that 25 organizations representing different neurological diseases had come together to form the Neurological Health Charities of Canada (NHCC). The NHCC has developed *A Brain Strategy for Canada*, a document identifying seven areas for action in support of neurological diseases, including: research, prevention, integrated care and support, caregiver support, income security, genetic privacy and public education and awareness.⁵¹ The Subcommittee and Committee heard that the federal government could work with the provinces and territorial governments, people with neurological diseases and the organizations that represent them, in the development and implementation of this national brain strategy.⁵² The Committee also heard from other witnesses that a national strategy for neurological diseases would also have to include a public health approach that would focus on some of the upstream factors linked to the development of neurological diseases.⁵³

The Committee heard from government officials that in order to move forward in developing a policy approach to address the overall burden of neurological diseases in Canada, it was first necessary to address the significant gaps in information related to these diseases.⁵⁴ Consequently, the Committee heard that the Government of Canada had invested \$15 million over four years in a National Population Study on Neurological Conditions in 2009 that was being implemented in partnership with the NHCC.⁵⁵ The Committee heard that the overall objectives of the study include determining the actual number of Canadians that suffer from neurological conditions and the impact that these conditions have on their daily lives and those of their families, and on the broader health care system.⁵⁶

The Committee heard that the study is supporting a range of projects and surveys.⁵⁷ Eight of these projects will focus on the incidence, prevalence, and co-morbidities of 18 neurological conditions and will include an examination of specific subgroups, including First Nations, the elderly, and children. Four projects will examine risk factors in the development and progression of neurological conditions, which allow for the development of targeted interventions that will prevent and improve disabilities. Several witnesses applauded this initiative by the Government of Canada.⁵⁸ An additional four projects and a national survey will be used to examine the impact of neurological conditions on daily activities, independence, emotional states and financial situations of those affected. Six projects will measure the use of health services, including gaps in services and the identification of novel approaches to providing care for persons with neurological conditions. Finally, the National Population Study on Neurological Conditions also includes a micro-simulation model that will combine data from the projects with projections of population growth and age to predict future demands and needs in relation to neurological conditions, as well as identify the most cost-effective way to meet these needs.

The Committee heard from government officials that the results of these studies would be compiled into a comprehensive report in March 2014. The report would serve as the basis of a consensus conference that will be held with policy makers that same year to discuss its findings and examine approaches for moving forward in this area.⁵⁹ The Committee heard from witnesses who hoped that the results of the National Population Health Study would be used for the development of a national strategy for neurological diseases under the auspices of the PHAC.⁶⁰ The Committee also heard from witnesses that the federal government should not wait until 2014 to move forward in addressing the immediate needs of those with neurological diseases, in areas outlined in the NHCC's National Brain Strategy.⁶¹

D. Committee Observations and Recommendations

The Committee heard from witnesses that approximately one million Canadians are currently being affected by a neurological disease.⁶² The Committee also heard that neurodegenerative diseases are expected to affect a larger proportion of Canadians due to the overall aging of the population, as many neurodegenerative diseases have their onset ranging from age 40 onwards.⁶³

In order to address neurological diseases in Canada, the Committee heard from some witnesses that there was a need for the federal government to develop a national strategy for neurological diseases that would address the common needs and challenges associated with all neurological diseases, such as: research and surveillance, income security, caregiver supports, and education and awareness raising.⁶⁴ However, the Committee also heard from witnesses that there were significant gaps in information regarding the actual prevalence of neurological diseases in Canada, as well as the current and future socio-economic impact of these conditions.⁶⁵ The Committee heard that this information was necessary in order to develop evidence-based policies and programs that would meet the needs of Canadians with neurological diseases and their families. In order to address this data gap, the Committee heard that the PHAC had established the National Population Health Study, whose findings would be made available to policy makers from across the country in 2014, who would then determine what further steps should be taken to address neurological diseases in Canada.⁶⁶

The study will help to fill knowledge gaps and will forecast the impact of neurological diseases over the next 20 years. It will provide a clearer picture of the state of neurological diseases in Canada and give Canadians living with neurological diseases, as well as their caregivers, a chance to tell their stories. The study will aid governments and stakeholders in planning programs and providing health services for Canadians with neurological conditions. It will provide Canadians with key information to improve our knowledge about the extent of neurological disease, risk factors, use of health services, economic costs and impact of those conditions.

The Committee heard from witnesses that the federal government should establish a national strategy for neurological diseases based upon the findings of the National Population Health Study. The Committee therefore recommends that:

- 1. The Government of Canada consider using the results of the National Population Health Study on Neurological Diseases in collaboration with the provinces and territories, as the basis of a pan-Canadian strategy for neurological diseases;**
- 2. The Government of Canada continue to promote brain disease research and consider including multidisciplinary research that underlies the commonalities in brain diseases.**

CHAPTER 2: PROMOTING NEUROLOGICAL RESEARCH AND SURVEILLANCE IN CANADA

A. Overview of the Neurological Research Landscape in Canada

We have good research infrastructure all across Canada. We now have access to new technologies, new molecular tools that were not previously available. So it is the perfect time to invest in health research to continue being world leaders in health research and neurological diseases in particular, as the Canadian population is growing old, and adult onset diseases are increasing.⁶⁷

The Committee and Subcommittee heard that the federal government was investing in neurological research primarily through the Canadian Institutes of Health Research (CIHR) and the Public Health Agency of Canada (PHAC). According to witnesses, CIHR represents the major source of public funding for health research in Canada with a budget of \$980.8 million in 2010-2011.⁶⁸ The Committee heard that since its inception in 2000, CIHR had invested \$1.1 billion in neuroscience research and spends approximately \$120 million a year on neuroscience research through various programs and initiatives.⁶⁹ For example, the Subcommittee heard that Alzheimer's disease was a research priority for CIHR and therefore, it was investing more than \$30 million per year in investigator-initiated grants, salary awards, and targeted team grants in this area.⁷⁰ In addition, the Subcommittee heard that CIHR was also funding the Canadian longitudinal study on aging to provide information on why some people are able to age well, while others do not age well and develop Alzheimer's disease. Finally, the Subcommittee and the Committee heard that CIHR was investing \$25 million to develop an international collaborative research strategy for Alzheimer's disease that would focus on prevention, early diagnosis and early treatment of Alzheimer's disease.⁷¹ The Subcommittee and the Committee heard that as part of this initiative, CIHR had established partnerships with the Alzheimer Society of Canada, the Quebec Network for Research on Aging funded by the Fonds de la recherche en santé du Québec (FRSQ), and with France, the United Kingdom, Germany, Italy, Ireland, Belgium, China and the United States. The Subcommittee also heard that CIHR was investing \$45 million in MS research, as it was also considered a priority because Canada was facing one of the highest rates of MS in the world with three people in Canada being diagnosed with the disease per day.⁷²

One researcher testified before the Subcommittee that he had received a number of offers from research labs in the United States and Europe. However, thanks in part to an initiative by ALS Canada, which together with CIHR, had set up a post-doctoral bursary program called the Tim E. Noël Fellowship in ALS Research, the researcher decided to stay in Canada in order to devote his research to ALS and to the various pathophysiological mechanisms involved in this disease.⁷³

The Committee also heard that CIHR investments were leading to new treatments for Parkinson's Disease.⁷⁴ For example, the Committee heard from CIHR-funded researcher Dr. Bin Hu, who had developed an innovative tool called a "gait reminder" that uses music cues to help people with Parkinson's Disease improve their walking

movements. This new device computes leg movements and reminds individuals through musical cues to take large steps to remain stable, which in turn prevents falls and prolongs the functional mobility of individuals living with Parkinson's Disease.

In addition, the Committee heard that CIHR had supported clinical studies examining the beneficial effect of deep brain stimulation surgery for the treatment of motor features of Parkinson's Disease, including motor fluctuations and involuntary movements.⁷⁵ The Committee heard that this six-hour brain surgery was reducing the amount of medication required by Parkinson's patients that could be quite costly, ranging from \$20,000 to \$25, 000 a year.⁷⁶ Indeed, the Committee heard directly from a recipient of deep brain stimulation surgery that the surgery had greatly improved his motor function.⁷⁷ The success of his surgery led him to conclude that, "Canada is a leader in both pure research and bedside research. At the Toronto Western Hospital, where I had my surgery, there were doctors and post-docs from literally all over the world – China, South America, Asia, Europe – coming to study at that facility to see the latest in surgical intervention techniques."⁷⁸ The Committee heard that there were many patients that could benefit from this treatment, but its availability was currently limited due to its costs, as brain stimulators could cost up to \$25 000.⁷⁹ Some witnesses, therefore, noted that as this beneficial treatment became more mainstream, it would represent a significant cost to health care systems.⁸⁰

In addition to specific initiatives aimed at neurological diseases, the Committee heard that CIHR had several more general initiatives that would benefit neurological research, including its \$67.5 million investment in personalized medicine in partnership with Genome Canada, which would be matched by private and provincial partners for a total investment of \$135 million. According to CIHR officials, this initiative seeks to understand the genetic prevalence and signatures of diseases in order to offer treatments that are targeted to a person's individual genetic code.⁸¹ According to CHIR President Dr. Alain Beaudet, "this major investment will help us offer new diagnostic and therapeutic approaches for a variety of disorders, including neurodegenerative diseases (...) Personalized medicine is also very useful in the drug industry. Once randomized treatment trials are carried out, only groups of people that can respond to the treatments being tested will be targeted. The Government of Canada hopes that this will enable it to conduct randomized treatment trials on fewer patients and that it will not have to submit patients to treatments that they are unlikely to respond to. In the case of neurological diseases, it is often not a matter of specific diseases, but syndromes that, presumably, cover various genetic identities."⁸²

In addition, Dr. Alain Beaudet explained that, "to better understand the interaction between genetic and environmental factors in the development of neurological diseases, CIHR has recently launched a Canadian epigenetics, environment, and health research consortium. We hope this initiative will help us develop better prevention and treatment programs, and rapidly translate epigenetic discoveries into new diagnostic procedures."⁸³

In order to improve access to innovative treatments for different diseases and conditions, the Subcommittee also heard that CIHR had developed a strategy in 2009 for patient-oriented research, which focuses on providing funding for research that is

necessary to support the introduction of new treatments into health care systems across Canada in a manner that is both safe and cost-effective.⁸⁴ This includes funding along a continuum from initial studies examining the effectiveness of a drug or treatment in humans, to examinations of new diagnostic procedures and finally, clinical trials evaluating the effectiveness of new treatments or procedures in comparison to existing ones. This information can then be used by clinicians and policy makers to evaluate whether new treatments should be introduced into the health care system.

The Subcommittee also heard about the role of PHAC in promoting research and surveillance of neurological diseases in Canada.⁸⁵ Health surveillance is an ongoing core public health function, and it is a critical part of the work done at PHAC. Surveillance is ongoing and includes a systematic process of data collection, expert analysis and interpretation; and most importantly, communication of the resulting information for public health action. The information used may include rates of a health condition; emerging trends overtime; variations in the occurrence of a health condition according to specific populations or geography; where these populations live; information about risk; and protective factors. With surveillance information, governments, health care providers, public health practitioners, researchers and Canadians can take action to prevent disease and promote health. The responses may be in the form of policy and program development, changes in clinical or public health practices, the provision of advice and education to the public or research. There is a broad range of uses for the surveillance information provided by PHAC and the organization is very careful to collect that information to meet the needs.

The Committee heard that the federal government had established the Canadian MS Monitoring System that was currently being developed by the Canadian Institutes for Health Information (CIHI) in collaboration with the provinces and territories, the Canadian Network of MS Clinics and the MS Society of Canada.⁸⁶ The aim of the monitoring system is to collect data on MS, including monitoring the outcomes of various treatments and the quality of life of those with the disease.⁸⁷ According to Ms. Kim Elmslie, Director General, Centre for Chronic Disease Prevention and Control, Health Promotion and Chronic Disease Prevention Branch, Public Health Agency of Canada:

The new monitoring system will help make good information available on the treatment of MS for Canadians who live with this devastating disease. It will compile data from multiple independent data systems across the country. It will provide a standardized way of collecting those data, and will create a national data system on MS, its treatment, and information on the quality of life of those living with this disease. Over the longer term, this system will monitor patient outcomes and help identify the most effective therapies in the treatment of MS. The information gathered and distributed through the monitoring system will help health information gathered and distributed through the monitoring system will help health professionals identify future needs and plan resources to ensure that those diagnosed with MS have access to the care they need.⁸⁸

While witnesses recognized the importance of these new surveillance initiatives, they also felt it was necessary that the Committee recommend that neurological conditions be added to the existing Canadian Chronic Disease Surveillance System.⁸⁹

Finally, the Subcommittee also heard that PHAC was in the process of developing an autism surveillance program that may eventually be used to monitor the prevalence of other neurodevelopmental conditions.⁹⁰ The aim of this surveillance system is to address the lack of complete and reliable epidemiological data on ASDs in Canada.⁹¹ As part of the development of its surveillance system, the Subcommittee heard that PHAC was working with Queen's University to develop and test surveillance methodologies for ASD. In addition, the Subcommittee also heard that PHAC was in the process of establishing a scientific advisory committee that would be responsible for developing common definitions and indicators, as well as best practices in data collection that would serve as the basis of the autism surveillance system. The Agency expected that the work of this scientific advisory committee would begin early in the 2011-12 fiscal year. The Committee notes that the Autism Surveillance Advisory Committee has been established for a two-year period and held its first meeting in March 2012. This expert committee is made up of researchers, clinicians, surveillance experts and autism organizations.

In addition to federal research and surveillance initiatives, the Subcommittee and the Committee heard that neurological charities were playing an important role in funding and promoting neurological research in Canada. The Committee heard that neurological charities invest between \$20 million to \$25 million per year on neuroscience research.⁹² For example, the primary mandate of ALS Canada was to fund research in support of greater knowledge of the disease and its treatment.⁹³ Through its budget of \$2 million, ALS Canada funds operating grants for senior scientists, and has established clinical research fellowship programs, as well as a clinical trials network for ALS. Similarly, the Subcommittee heard that Autism Speaks Canada had contributed over \$142.5 million to global autism research initiatives through 2014, while Parkinson Society Canada was investing \$4.2 million to fund Canadian investigators in basic clinical and psychosocial research for Parkinson's Disease.⁹⁴ Finally, the Subcommittee heard that the Multiple Sclerosis Society of Canada had funded \$120 million in health research, an amount that was growing by approximately \$10 million per year.⁹⁵

The Subcommittee heard that neurological charities also play an important role in promoting innovations in neurological research. For example, Brain Canada, a national, non-profit foundation dedicated to supporting research into new diagnostics, treatments and cures for brain disorders, in partnership with CIHR, communities and voluntary health organizations, had developed a series of grants for multi-disciplinary, multi-institutional pilot studies focusing on common mechanisms of brain disorders.⁹⁶ The Subcommittee heard that this pilot program, called the Brain Repair Program, had proved to be a successful model in translating research findings into better clinical practice in relation to the diagnosis and treatment of brain disorders. Similarly, ALS Canada was able to develop a clinical trial network for ALS research that addressed the challenges associated with conducting clinical trials for diseases that affected a small proportion of the Canadian population.⁹⁷ This could serve as a model for other rare diseases. The Subcommittee also heard that neurological charities, such as ALS Canada, were able to provide grants for investigators exploring new avenues of research that may not otherwise be funded through traditional public funding agencies.

The Committee heard that the federal government was also supporting research investments made by neurological charities through the development of a public-private partnership with Brain Canada called the Canada Brain Research Fund.⁹⁸ The federal government is investing \$100 million in the Canadian Brain Research Fund, monies that would be matched by Brain Canada and its partners. The Committee heard that these funds would be invested in a three-pronged research program that would include: multi-disciplinary team grants modelled on the brain repair program; training fellowships to develop the next generation of researchers; and operational support for national technology platforms in neuroimaging, neurogenomics, neuroproteomics, and disease models.⁹⁹ The Committee heard that the aim of the Canada Brain Research Fund was to focus research investment on the brain as one complex system, rather than a collection of diseases, and promote private investment in this area.¹⁰⁰

In addition to these investments, the Committee learned that, “in 2011 in Brussels, CIHR and their European Union counterparts implemented an international initiative of over \$50 million to address traumatic brain injury. In addition to that initiative, efforts are being invested nationally to advance research in this area. As part of those efforts, the Ontario Neurotrauma Foundation and the Hotchkiss Brain Institute recently joined CIHR in order to develop a Canadian national initiative on traumatic brain injury.”¹⁰¹

B. Neurological Research in Canada

(i) Research Funding

Though many witnesses stressed the importance of CIHR’s existing research initiatives, they also articulated that more funding for neurological research was necessary. For example, the Subcommittee heard that of the total grant applications received by CIHR, between 15% and 20% were successful.¹⁰² Researchers noted that this success rate was higher than that of other jurisdictions, explaining that the success rate of grant applications at the United States’ National Institute on Aging was much lower at 4%.¹⁰³ However, researchers noted that despite this high success rate relative to other jurisdictions, other excellent research applications remained unfunded due to funding limitations within CIHR.¹⁰⁴ Dr. Rémi Quirion, Executive Director of the International Collaborative Research Strategy for Alzheimer’s Disease, Canadian Institutes for Health Research, noted that “there are maybe 10% of grants that are not funded that should be funded.”¹⁰⁵

The Subcommittee also heard that CIHR was currently investing \$179 million in operating grants for research, which includes mental health, addiction and the sensory organs, while the voluntary organizations, the ones organized under the Neurological Health Charities combined, were only able to disburse an additional \$20,000 per year.¹⁰⁶ For some witnesses, this was seen as not enough to meet the current and future costs of neurological diseases in Canada.¹⁰⁷ Furthermore, the Subcommittee heard that increased investments in neurological disease research were necessary because they could also reduce the future costs associated with these diseases. For example, Alzheimer’s prevention research could result in reducing costs of treating the disease by delaying its

onset by two years. This in turn would reduce the overall cost of treating the disease by half over the next 30 years, resulting in a savings of almost \$400 billion.¹⁰⁸

Witnesses further identified specific areas where more research funding was needed. First, the Subcommittee heard that researchers required more operating grants to offset the costs of running their labs.¹⁰⁹ Second, witnesses said there was a need for funding mechanisms that promote the multidisciplinary research necessary to address the many different facets of neurological diseases.¹¹⁰ Finally, the Committee heard from witnesses that the federal government could fund the establishment of a “Centre of Excellence for Neurological Diseases,” through its Networks of Centres of Excellence Program, that would bring together different disciplines to conduct research into specific neurological degenerative diseases such as Alzheimer’s Disease, Parkinson’s Disease, or Multiple Sclerosis.¹¹¹

(ii) Administrative Challenges of Grant Applications

The Subcommittee heard that researchers must spend a considerable amount of time completing numerous comprehensive grant applications from different research organizations in order to have their studies funded. To be able to run a lab and be internationally competitive, researchers need to secure as many as five different grants.¹¹² Witnesses articulated that CIHR could reduce the administrative burden required for their application process by reducing the page number requirement for its grant applications.¹¹³ The Subcommittee heard that the Alzheimer’s Society of Canada only requires a five-page application. In addition, witnesses articulated that CIHR could offer more multi-year grants to reduce the frequency with which researchers needed to apply for more funding, as well as provide greater stability to their research efforts.¹¹⁴ The Subcommittee heard that offering three- to five-year grants were preferable to one-year grants.¹¹⁵

(iii) Access to Clinical Trials for New Drugs and Treatments

The Subcommittee heard that people with neurological diseases in Canada had difficulty gaining timely access to new and innovative drugs and treatments for their diseases because of difficulties gaining access to clinical trials evaluating those drugs and treatments. For example, MS patients are unable to gain access to a treatment for chronic cerebrospinal venous insufficiency syndrome (CCSVI), a condition characterized by flow blockages of the internal jugular and azygous veins system which results in insufficient drainage from the brain.¹¹⁶ The Subcommittee heard from witnesses with MS that due to the progressive nature of their disease, it was of vital importance for them to gain early access to this new possibly effective treatment.¹¹⁷

The Subcommittee heard that CIHR was addressing these concerns by establishing a scientific expert working group made up of researchers, members of Canadian, U.S. and Italian MS societies, provincial and territorial representatives and experts from CIHR that would undertake a systematic review of the of the evidence regarding CCSVI and MS, including the association between venous abnormalities and MS, and the benefits and harms of endovascular treatment.¹¹⁸ The Subcommittee heard that based upon the results of this systematic review, the working group would then decide

if funding should be provided for a clinical trial that would evaluate the safety and efficacy of endovascular treatment.

In an update presented to the Committee in March 2012, CIHR officials articulated that the expert working group had decided, following the analysis of the results of seven studies, that sufficient evidence existed to support the establishment of phase one clinical trials that would examine the safety of endovascular treatment for CCSVI in persons with MS and a phase two clinical trial that would examine its efficacy.¹¹⁹ The Committee heard that an applicant for the CCSVI clinical trial had been selected on April 18, 2012 and that the trial would commence, once an ethics review had been completed by university and hospital ethics boards.¹²⁰

The Committee heard that funding for the clinical trials would be provided by CIHR and the MS Society of Canada. The Committee heard from witnesses that the Canadian MS Monitoring System would also monitor the outcomes of those Canadians who had travelled abroad to receive endovascular treatment for CCSVI.¹²¹ In addition, the Committee heard from witnesses that provincial governments were conducting studies examining the impact of the treatment of those who had received treatment abroad, while others were offering programs and supports. For example, the Government of Ontario is developing guidelines for physicians to help provide follow-up treatment for patients who had endovascular treatment abroad, while the Government of New Brunswick set up a program to assist with the costs associated with having the procedure.¹²² In addition, the Government of Saskatchewan is partnering with the Albany Medical Centre with Dr. Siskin to undertake clinical trials.

In addition to the example of treatment for CCSVI and MS, the Subcommittee heard that few clinical trials for new drugs for rarer neurological diseases, such as ALS, were being conducted in Canada.¹²³ Large pharmaceutical companies are unwilling to fund large clinical trials for diseases such as ALS because it only represents a small market for potential new drugs, while smaller biotech companies researching ALS do not have the funds to conduct large enough clinical trials. For these reasons, the ALS Society of Canada had focused on establishing and funding clinical trial networks in Canada to promote the examination of new drugs and treatments for the disease. One witness suggested that this gap could also be addressed by the Government of Canada playing an intermediary role by matching researchers making preliminary discoveries in university labs with biotech companies looking to invest, a model that has been developed in the United Kingdom.¹²⁴

The Subcommittee also heard that Alzheimer's research focusing on drugs that could prevent then onset of the disease required longer clinical trials in the range of seven to ten years.¹²⁵ Longer clinical trials are inhibited by the *Patent Act*, as the patents currently available under the Act would expire during the course of a longer clinical trial. This is a deterrent to pharmaceutical companies, who want to conduct longer clinical trials in Canada. Consequently, witnesses recommended that the Government of Canada consider amending the *Patent Act* to promote long-term clinical trials in Canada focusing on the prevention of Alzheimer's disease.

C. Committee Observations and Recommendations

The Committee heard that significant investments are being made in neurological research in Canada by the federal government in partnership with neurological charities and provincial governments.¹²⁶ The Committee also learned from government officials that surveillance data for neurological diseases would improve due to PHAC's National Population Health Study of Neurological Conditions and the ongoing development of its new autism surveillance program.¹²⁷ The Study will provide a clear picture of the state of neurological conditions in Canada, and will help governments and stakeholders plan programs and health services for Canadians living with these conditions, and identify the scope for prevention.¹²⁸ However, witnesses felt that there was still a need to add neurological conditions to the existing Canadian Chronic Disease Surveillance System. The Committee heard that research investments should focus on promoting multi-disciplinary research through the establishment of larger team grants and centres of excellence that bring different disciplines together to research and treat neurological diseases.¹²⁹ The Subcommittee heard that CIHR could cut red tape by reducing the number of pages requirements for their applications and provide longer term grants to limit the number of times researchers have to apply for funding.¹³⁰ The Committee believes that some of these research needs will now be met by the recent establishment of the \$100 million Canadian Brain Research Fund that will provide multi-disciplinary neuroscience research and training grants, as well as operational support for researchers. According to witnesses, the establishment of a new Centre of Excellence for Neurodegenerative Diseases through the federal government's Networks of Centres of Excellence Program could also support research in this area.¹³¹ This could serve to complement the existing Centre for Excellence for Neuro-developmental disorders in children, known as Neurodevnet.¹³²

With regards to access to clinical trials, the Subcommittee heard that CIHR was trying to improve access to clinical trial research in Canada through its new patient-oriented research strategy.¹³³ According to CIHR President, Dr. Alain Beaudet, "This strategy for patient-oriented research is built on the principle that there is a growing need to conduct intervention studies in order to address important clinical issues as is the case with the clinical trials on MS. These studies involve large numbers of patients who are receiving health care services in many settings across the country. The result from such trials provides the basis for clinical practices providing accurate patient diagnosis, prognosis and treatment."¹³⁴

The Committee therefore recommends that:

3. **CIHR consider developing more strategic initiatives related to neurological research;**
4. **PHAC continue to build its autism surveillance program to eventually include all neurodevelopmental diseases affecting children as it evolves;**
5. **PHAC include neurological conditions within its Canadian Chronic Disease Surveillance System;**
6. **The Government of Canada consider establishing a Centre of Excellence for Neurodegenerative conditions through its Networks of Centres of Excellence Program;**
7. **CIHR consider examining ways to streamline and reduce the administrative workload that their grant applications place on researchers;**
8. **CIHR continue to update the House of Commons Standing Committee on Health regarding the findings of its scientific expert working group regarding Multiple Sclerosis and chronic cerebrospinal venous insufficiency syndrome, including the results of future clinical trials;**
9. **CIHR update the House of Commons Standing Committee on Health as to how their patient-oriented research strategy will address access to clinical trials in Canada, as well as whether this strategy will reflect consultations regarding patient's views on research in Canada.**

CHAPTER 3: IMPROVING THE QUALITY OF LIFE OF THOSE WITH NEUROLOGICAL DISEASES AND THEIR CAREGIVERS

A. Income Security

The Committee and the Subcommittee learned about the challenges facing those with neurological diseases and their caregivers.¹³⁵ They heard that many individuals with neurological diseases and their families experience the loss of income and job insecurity resulting from their disability.¹³⁶ For example, many individuals with neurological diseases have to quit their jobs or close their businesses due to disease-related complications and others face periods where they have to take extended leaves from their jobs, only to have to fight to retain their jobs upon return. The Committee and Subcommittee also heard that many people with neurological diseases faced discrimination from their employers and lacked the energy to defend themselves and lost their jobs as a result. As a result of their inability to work, persons with neurological diseases instead had to rely on disability benefits provided through employment insurance. Many of these people focus their energies instead on volunteering and advocating on behalf of persons with their disease or condition. For persons with neurological diseases, the benefits of working extend beyond financial remuneration, allowing them to receive the physical, emotional and mental benefits of working and being involved in their communities.

B. Care Giving

Both the Committee and Subcommittee heard that those caring for persons with neurological diseases also faced significant economic and social costs. For instance, many informal caregivers of persons with neurological diseases are often forced to choose between continuing to work, or leaving the workforce to care for their loved ones. Meanwhile, the economic contribution of their unpaid informal care giving services for Alzheimer's Disease alone could be estimated at \$5 billion.¹³⁷

The Subcommittee heard that informal caregivers experience burnout from working full time, providing informal care and navigating health and social services to find appropriate treatments and supports for their loved ones. Caregivers of those with neurodegenerative conditions are tired and stressed, as they face the decline of those they love most:¹³⁸

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

The Subcommittee heard that families of children with neuro-developmental conditions, including ASDs, also faced similar economic and emotional issues.¹³⁹

Our own personal family experience is that it is an enormous stress, on not only the family but the extended family. We have watched our daughter and son-in-law fight every step of the way for their children. We have seen the schedules they keep, with the numerous appointments, therapies, etc. It never ends. They are exhausted. My daughter has had to stop work, so there is the loss of her income.

C. Education and Awareness

Some witnesses appearing before the Subcommittee also stressed the need for education and awareness of neurological diseases in Canada. The Subcommittee heard that education and awareness campaigns were necessary to address the stigma and ignorance surrounding many neurological conditions. For example, many people with Parkinson's Disease face daily humiliations as result of people's ignorance of the disease that could be addressed through greater awareness:

People don't understand it, and because they don't understanding it, they're either afraid or they're rude. I've had a lot of rude comments put to me: they think I'm an alcoholic, because I do shake, I do have problems walking, I do stagger a bit. When those comments come out, if my son's with me, I don't need to say anything, because my son will tear a strip off the person. He's very good that way (...) My biggest thought is that we need awareness. There's this thing where everybody thinks this disease is a disease of the elderly.¹⁴⁰

The Subcommittee also heard from a witness that education and awareness campaigns were also necessary to promote the early diagnosis of neurological conditions by educating the public about the early warning signs of neurological diseases, such as dementia so that they seek diagnosis and treatment sooner.¹⁴¹

D. Access to Drugs, Treatments, Care and Supports

Though witnesses appearing before the Committee recognized that the care and treatment of neurological diseases fell under provincial and territorial jurisdiction, they highlighted the unique challenges people with neurological disease face in terms of gaining access to drugs, treatments and care and supports for their respective diseases. Witnesses articulated that the federal government could play a leadership role by bringing forth these issues in the context of F/P/T health discussions.¹⁴² It is further important to note that these challenges also varied substantially between the different diseases highlighted during the course of the Committee's study.

(i) Drug Coverage

It is the provinces and territories that decide which drugs are covered in their jurisdiction according to their needs. According to witnesses, persons with neurological diseases in Canada had less access to drugs than those in other jurisdictions because provincial and territorial drug formularies reimbursed fewer available medicines in the treatment of neurological diseases. The Subcommittee heard that while the international average for public health plan reimbursement of medicines available for the treatment of neurological conditions was 88%, public drug plans in Canada only reimbursed 28% of drugs available.¹⁴³ Because of the limited number of drugs covered by public plans, Canadians with neurological diseases, such as Parkinson's and Alzheimer's disease, may

not be able to be reimbursed for the most innovative drugs available for the treatment and prevention of their diseases. Furthermore, the Subcommittee heard that Canadians with private drug insurance through their employers faced annual caps on reimbursement that sometimes meant that they had to forgo important treatments.¹⁴⁴

(ii) Diagnosis and Treatments for Autism Spectrum Disorders

Some witnesses that appeared before the Subcommittee indicated that parents of children with ASDs experienced inconsistency across the country in terms of access to both diagnosis and treatment.¹⁴⁵ The Subcommittee heard that in some cases, parents were waiting at least a year for a proper assessment and diagnosis for ASDs and then faced long wait times to gain access to intensive behavioural therapy. Provinces and territories vary in both the types and comprehensiveness of services offered to children with ASDs. Witnesses informed the Subcommittee that early intensive intervention from a multidisciplinary team was necessary for the effective treatment of children with ASDs. The Subcommittee also, heard that once children had completed two years of behavioural therapy, there were few follow-up services and supports that could help integrate them into the school system and communities throughout their lives. In order to address these challenges, the Subcommittee heard that the Government of Canada could provide leadership and promote consistency in diagnosis and treatment across the country by working with experts, stakeholders and provinces and territories to develop national standards reflecting best practices in these areas. Some witnesses disagreed with this suggestion: “The one-size-fits-all approach is not sensible and doesn’t work. What we don’t know is what works for whom...What I know works for sure is support for families, in addition to whatever interventions are being offered for children that unequivocally matters.”¹⁴⁶ Some witnesses suggested that the *Canada Health Act* could be amended to ensure that treatment for ASD be considered medically necessary, while others advocated for a national autism strategy.¹⁴⁷

(iii) Home Care Supports for ALS

The Subcommittee heard that ALS was a rapidly progressive neurological disease that results in the loss of all mobility, as well as speaking, swallowing and breathing abilities, and eventually death.¹⁴⁸ In order to address this rapid decline in mobility, persons with ALS must spend between \$60,000 and \$140,000 in out-of-pocket expenses to ensure that they have the supports necessary to remain in their homes, including electric chair lifts, full-time care and home modifications. The Subcommittee heard that these financial costs were compounded when ALS patients needed to move into facilities that can provide long-term care needs. While equipment loan programs exist in many provinces, the demand often outreaches supply.¹⁴⁹

The Subcommittee heard about veterans who develop ALS and the benefits and supports available to them.¹⁵⁰ There had been considerable progress with all current cases of ALS claims being moved along within the Veterans Affairs program. This notable progress was made possible by the Prime Minister, The Minister of Veterans Affairs, the staff of Veterans Affairs Canada, including the ombudsman, and by many members of all parties, whose compassionate recognition of the need came to the fore.¹⁵¹

(iv) Palliative Care

Although it is a matter under provincial and territorial jurisdiction, witnesses stressed the importance of providing hospice palliative care to persons with degenerative neurological diseases.¹⁵² The Subcommittee heard from witnesses with Parkinson's Disease that palliative care was for all persons with diseases that experience long-term suffering. According to witnesses appearing before the Subcommittee, palliative care, defined as care that aims to relieve suffering and improve the quality of living and dying, serves as a model for providing care to people who live with progressive life-limiting illnesses. It allows for personalized care in smaller settings that focuses on the physical, mental and spiritual dimensions of care. The Subcommittee heard that palliative care could be introduced into the treatment of neurological diseases by the inclusion of palliative care professionals into interdisciplinary teams at the clinical level.

E. Privacy of Genetic Information

Both the Subcommittee and Committee heard from witnesses that discrimination on the basis of genetics was an emerging concern for those with neurological diseases.¹⁵³ The Committee heard that current provincial and territorial laws allow insurance companies to request health information from Canadians in order to determine eligibility, set premiums and manage risks.¹⁵⁴ They therefore articulated that either legislation or a voluntary policy was urgently needed to protect the privacy of individuals' genetic information and to protect Canadians from potentially unfair treatment in the areas of employment and health insurance.¹⁵⁵

F. Committee Observations and Recommendations

The Committee heard from witnesses that people with neurological diseases and their caregivers face many challenges that affected their quality of life, including: a lack of income security; the high social and economic costs of care giving; and the stigma resulting from a lack of awareness regarding neurological diseases. The Committee further heard from some witnesses that genetic discrimination resulting from the availability of genetic testing was also an emerging concern for those with neurological diseases and posed ethical challenges for health care professionals.¹⁵⁶ In addition, each of the diseases examined by this study faced its own unique challenges. The Committee heard from patients and caregivers that many people with neurological diseases were partially paying out-of-pocket for drugs, treatments, and/or special equipment that would allow them to stay in their homes. Finally, the Subcommittee heard from some witnesses that the quality of life of those with degenerative neurological diseases could be greatly improved if palliative care practices were incorporated into their care.¹⁵⁷ The Committee notes that in Budget 2012, the federal government announced the creation of a panel on the labour market opportunities of persons with disabilities. This panel will identify private sector successes and best practices with regards to the labour market participation of persons with disabilities, and will report to the Minister of Finance and the Minister of Human Resources and Skills Development by the end of 2012.¹⁵⁸ The Committee also heard that the federal government could also establish public awareness campaigns to combat stigma. The Committee therefore recommends that:

- 10. The Government of Canada examine existing federal legislation, including the *Privacy Act* and the *Personal Information Protection and Electronic Documents Act*, to determine whether it provides sufficient protection regarding the privacy of health information, including the results of genetic testing;**
- 11. PHAC continue to explore programs to inform Canadians about neurological diseases;**
- 12. PHAC work with stakeholders, experts and provincial and territorial representatives to identify and promote best practices related to Autism Spectrum Disorders.**

CONCLUSION

In 2009, the House of Commons Standing Committee on Health first established its Subcommittee on Neurological Diseases to further study these diseases and their challenges. The Committee also recognized that innovations were occurring in the treatment of these diseases and wanted further inquiries into the latest research. The study done over two years ago highlighted the needs and challenges of five neurological diseases in particular: Autism Spectrum Disorders, Multiple Sclerosis, Amyotrophic Lateral Sclerosis, Parkinson's Disease and Alzheimer's Disease. Throughout the study, witnesses stressed the importance of focusing on common needs and challenges facing all neurological diseases. The Committee decided to pursue its study in this Parliament and thought it would be beneficial to update the progress that the federal government has made in terms of CCSVI and new investments in Brain Canada.

- 1 The exact motion establishing the Subcommittee was as follows: "That the Health Committee should strike a subcommittee or have a conference to examine the burden of neurological disease in Canada; explore the results of clinical trials and experimental technologies, which are yielding positive results here in Canada and internationally; and investigate the possibility of bringing successful therapies to Canada," the Committee, *Minutes of Proceedings*, March 26, 2009, <http://www2.parl.gc.ca/HousePublications/Publication.aspx?DocId=3781153&Language=E&Mode=1&Parl=40&Ses=2>.
- 2 Medline Plus, National Institutes of Health, "Neurological Diseases," <http://www.nlm.nih.gov/medlineplus/neurologicdiseases.html>.
- 3 World Health Organization, "Neurological Disorders: Public Health Challenges," http://www.who.int/mental_health/neurology/neurological_disorders_report_web.pdf, p.29.
- 4 National Institute of Neurological Disorders and Stroke, "Brain Basics: Know Your Brain", http://www.ninds.nih.gov/disorders/brain_basics/know_your_brain.htm#disorders.
- 5 Ibid.
- 6 World Health Organization, "Neurological Disorders: Public Health Challenges," http://www.who.int/mental_health/neurology/neurological_disorders_report_web.pdf, p.177.
- 7 Kim Elmslie, Director General, Centre for Chronic Disease Prevention and Control, Health Promotion and Chronic Disease Prevention, Public Health Agency of Canada (PHAC), *Evidence*, March 1, 2012.
- 8 Ibid.; Neuroscience Canada, "The Case for Canada's Increased Investment in Neuroscience Research," March 15, 2006, p. 2 brief submitted to the Subcommittee in November 2010.
9. Kim Elmslie, *Evidence*, March 1, 2012.
- 10 Ibid.
- 11 Ibid.
- 12 Unless otherwise noted, economic consequences include both the direct costs of diseases to the health care system and indirect costs, which include the decline in productivity of those with these diseases. Canadian Institute for Health Information, *The Burden of Neurological Diseases, Disorders and Injuries in Canada*, 2007, http://secure.cihi.ca/cihiweb/products/BND_e.pdf.
- 13 Unless otherwise noted, this information is based upon the following: Autism Society Canada, "What are Autism Spectrum Disorders?" [http://www.autismsocietycanada.ca/DocsAndMedia/ASC Internal/info ASCwhatisautisminfosheet 27 June 07 e.pdf](http://www.autismsocietycanada.ca/DocsAndMedia/ASC%20Internal/info_ASCwhatisautisminfosheet_27_June_07_e.pdf).

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- 14 Unless otherwise noted, this section is based upon the following document: Canadian Institute for Health Information, *The Burden of Neurological Diseases, Disorders and Injuries in Canada*, 2007, http://secure.cihi.ca/cihiweb/products/BND_e.pdf, p. 73.
- 15 Ibid.
- 16 The Multiple Sclerosis Society of Canada, "What is MS," http://mssociety.ca/en/information/ms_what.htm.
- 17 Unless otherwise noted, this section is drawn from a brief submitted to the Subcommittee by the Amyotrophic Lateral Sclerosis Society of Canada on October 31, 2010.
- 18 Canadian Institute for Health Information, *The Burden of Neurological Diseases, Disorders and Injuries in Canada*, 2007, http://secure.cihi.ca/cihiweb/products/BND_e.pdf, p. 28.
- 19 Ibid, p. 83.
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- 145 Kathleen A. Provost, Executive Director, Autism Society Canada, *Evidence*, December 9, 2010.
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LIST OF RECOMMENDATIONS

1. The Government of Canada consider using the results of the National Population Health Study on Neurological Diseases in collaboration with the provinces and territories, as the basis of a pan-Canadian strategy for neurological diseases.....	11
2. The Government of Canada continue to promote brain disease research and consider including multidisciplinary research that underlies the commonalities in brain diseases.	11
3. CIHR consider developing more strategic initiatives related to neurological research.....	21
4. PHAC continue to build its autism surveillance program to eventually include all neurodevelopmental diseases affecting children as it evolves.	21
5. PHAC include neurological conditions within its Canadian Chronic Disease Surveillance System.....	21
6. The Government of Canada consider establishing a Centre of Excellence for Neurodegenerative conditions through its Networks of Centres of Excellence Program.	21
7. CIHR consider examining ways to streamline and reduce the administrative workload that their grant applications place on researchers.....	21
8. CIHR continue to update the House of Commons Standing Committee on Health regarding the findings of its scientific expert working group regarding Multiple Sclerosis and chronic cerebrospinal venous insufficiency syndrome, including the results of future clinical trials.	21
9. CIHR update the House of Commons Standing Committee on Health as to how their patient-oriented research strategy will address access to clinical trials in Canada, as well as whether this strategy will reflect consultations regarding patient’s views on research in Canada.....	21
10. The Government of Canada examine existing federal legislation, including the <i>Privacy Act</i> and the <i>Personal Information Protection and Electronic Documents Act</i> , to determine whether it provides sufficient protection regarding the privacy of health information, including the results of genetic testing.....	27
11. PHAC continue to explore programs to inform Canadians about neurological diseases.....	27
12. PHAC work with stakeholders, experts and provincial and territorial representatives to identify and promote best practices related to Autism Spectrum Disorders.....	27

APPENDIX A LIST OF WITNESSES

41st Parliament – First Session		
Organizations and Individuals	Date	Meeting
<p>Brain Canada Foundation</p> <p>Inez Jabalpurwala, President and CEO</p> <p>David Kaplan, Vice-Chair, Science</p>	2012/03/01	31
<p>Canadian Institutes of Health Research</p> <p>Alain Beaudet, President</p>		
<p>Neurological Health Charities Canada</p> <p>Vanessa Foran, Director, Policy, Partnerships and Government Relations</p> <p>Celina Rayonne-Chavannes, Director, Research Initiatives</p>		
<p>Public Health Agency of Canada</p> <p>Kim Elmslie, Director General, Centre for Chronic Disease Prevention and Control, Health Promotion and Chronic Disease Prevention Branch</p>		
<p>As an individual</p> <p>Bin Hu, Professor, Department of Clinical Neurosciences, University of Calgary</p> <p>David Simmonds</p>	2012/04/26	40
<p>Parkinson Society Canada</p> <p>Edward Fon, Director, McGill Parkinson Program and National Parkinson Foundation Center of Excellence, Montreal Neurological Institute, McGill University</p> <p>Joyce Gordon, President and Chief Executive Officer</p>		
<p>University of Ottawa</p> <p>Daniel Krewski, Professor and Director, R. Samuel McLaughlin Centre for Population Health Risk Assessment, Institute of Population Health</p>		
<p>Amyotrophic Lateral Sclerosis (ALS) Society of Canada</p> <p>Derek Walton, Member of Advocacy Committee</p>	2012/05/01	41
<p>Baycrest Hospital</p> <p>Galit Kleiner-Fisman, Neurologist and Movement Disorders Specialist</p>		

Organizations and Individuals	Date	Meeting
Multiple Sclerosis Society of Canada Deanna Groetzinger, Vice-Chair, Government Relations and Policy Marie Vaillant, Vice-Chair, Ontario Division Board of Directors	2012/05/01	41
Neurological Health Charities Canada Garth M. Bray, Chair, Scientific Advisory Committee Ian McDowell, Vice-Chair, Scientific Advisory Committee		

APPENDIX B LIST OF WITNESSES

40th Parliament – Third Session		
Organizations and Individuals	Date	Meeting
<p>As an individual</p> <p>Samuel Ludwin, Professor of Pathology (Neuropathology), Queen's University</p> <p>Sandy McDonald, Medical Doctor</p> <p>T. Jock Murray, Professor Emeritus, Dalhousie University</p> <p>Janet Salloum</p>	2010/05/11	4
<p>MS Liberation</p> <p>Rebecca Cooney, Co-founder</p> <p>Multiple Sclerosis Society of Canada</p> <p>Nadine Prévost, Director, Services and Outreach, Quebec Division</p> <p>University of Calgary</p> <p>Samuel Weiss, Professor and Director, Hotchkiss Brain Institute</p>	2010/06/01	6
<p>Steven Garvie</p> <p>Sandy McDonald, Medical Doctor</p> <p>Lianne Webb</p> <p>McMaster University</p> <p>Ewart Mark Haacke, Director, MRI Institute for Biomedical Research</p>	2010/06/08	7
<p>Amyotrophic Lateral Sclerosis (ALS) Society of Canada</p> <p>Denise Figlewicz, Vice-President, Research</p> <p>Felicia Travis Valo</p> <p>Melanie York, Board Member</p> <p>Université de Montréal</p> <p>Alex Parker, Assistant Professor, Research Centre of the University of Montreal Hospital Centre (CRCHUM), Department of pathology and Cell Biology</p>	2010/06/15	8
<p>As an individual</p> <p>Robert Maggisano, Medical Doctor, Vascular Surgeon, Sunnybrook Health Sciences Centre</p>	2010/06/15	8

Organizations and Individuals	Date	Meeting
<p>As an individual Paolo Zamboni, Medical Doctor, Director, Vascular Diseases Center, University of Ferrara</p> <p>Canadian Institutes of Health Research Alain Beaudet, President</p> <p>EUROMEDIC Specialist Clinics Marian Simka, Medical Doctor, Department of Vascular and Endovascular Surgery</p> <p>Multiple Sclerosis Society of Canada Karen Lee, Assistant Vice-President, Research</p>	2010/06/15	8
<p>Amyotrophic Lateral Sclerosis Society of Canada David Cameron, President and Chief Executive Officer François Gros-Louis, Assistant Professor Sari Jormanainen Nigel Van Loan, Board Member</p>	2010/11/02	11
<p>As an individual Greg McGinnis</p> <p>Ottawa Hospital Research Institute Michael Schlossmacher, Scientist, Neuroscience</p> <p>Parkinson Society Canada Joyce Gordon, President and Chief Executive Officer</p> <p>University of British Columbia Jon A. Stoessl, Professor, Head of Neurology, Director, Pacific Parkinson's Research Centre, Canada Research Chair in Parkinson's Disease</p>	2010/11/16	12
<p>As an individual Chris Sherwood Frances Squire</p> <p>Ottawa Hospital, University of Ottawa David Grimes, Associate Professor</p> <p>Parkinson Society Canada Carmel Boosamra, Board Member Bruce Ireland, Chair, Board of Directors</p>	2010/11/23	13

Organizations and Individuals	Date	Meeting
<p>As an individual</p> <p>Serge Gauthier</p> <p>Weihong Song, Canada Research Chair in Alzheimer's Disease, Jack Brown and Family Professorship, University of British Columbia</p> <p>Brain Canada Foundation</p> <p>Inez Jabalpurwala, President and CEO</p> <p>Canada's Research-Based Pharmaceutical Companies (Rx & D)</p> <p>Mark Ferdinand, Vice-President, Policy</p> <p>Canadian Institutes of Health Research</p> <p>Rémi Quirion, Executive Director, International Collaborative Research Strategy for Alzheimer's Disease</p>	2010/11/30	14
<p>Alzheimer Society of Canada</p> <p>Debbie Benczkowski, Interim Chief Executive Officer</p> <p>Jack Diamond, Scientific Director</p> <p>Jim Mann, Member, Board of Directors</p> <p>As an individual</p> <p>Robert Lester</p> <p>Canadian Institutes of Health Research</p> <p>Alain Beaudet, President</p> <p>Neurological Health Charities Canada</p> <p>Shannon MacDonald, Director, Policy and Partnerships</p>	2010/12/07	15
<p>Autism Canada Foundation</p> <p>Laurie Mawlam, Executive Director, Leadership Committee, Canadian Autism Spectrum Disorders Alliance</p> <p>Autism Society Canada</p> <p>Kathleen A. Provost, Executive Director, Leadership Committee, Canadian Autism Spectrum Disorder Alliance</p> <p>Autism Speaks Canada</p> <p>Suzanne Lanthier, Executive Director</p> <p>Canadian Paediatric Society</p> <p>Wendy S. G. Roberts, Paediatrician</p>	2010/12/09	16

Organizations and Individuals	Date	Meeting
As an individual	2010/12/14	17
Dennis Lendrum, Coffee Chat		
CanChild Centre for Childhood Disability Research		
Peter Rosenbaum, Professor, Paediatrics and Canada Research Chair in Childhood Disability, Mentoring and Dissemination, McMaster University		
Centre d'Intervention et de Formation Socioculturel International		
Mohamed Ghoul, Intervenor, Trainer, SocioDynamic Integration Through Art Program, Pervasive Developmental Disorders, Autism Spectrum Disorders		
Warren Jason, Contributor, SocioDynamic Integration Through Art Program, Pervasive Developmental Disorders, Autism Spectrum Disorders		
Public Health Agency of Canada		
Kim Elmslie, Director General, Centre for Chronic Disease Prevention and Control, Health Promotion and Chronic Disease Prevention Branch		
Anne-Marie Ugnat, Associate Director, Health Surveillance and Epidemiology Division, Centre for Health Promotion, Health Promotion and Chronic Disease Prevention Branch		
QuickStart - Early Intervention for Autism		
Suzanne Jacobson, Founder		
Université de Montréal		
Laurent Mottron, Full professor, Department of Psychiatry, Research Chair in Cognitive Neurosciences, Centre d'excellence en troubles envahissants du développement		

APPENDIX C LIST OF BRIEFS

41st Parliament – First Session

Organizations and Individuals

Neurological Health Charities Canada

University of Ottawa

APPENDIX D LIST OF BRIEFS

40th Parliament – Third Session

Organizations and Individuals

Amyotrophic Lateral Sclerosis Society of Canada

Autism Canada Foundation

Autism Society Canada

Canadian Autism Spectrum Disorders Alliance

Cloutier, Paul

REQUEST FOR GOVERNMENT RESPONSE

Pursuant to Standing Order 109, the Committee requests that the government table a comprehensive response to this Report.

A copy of the relevant Minutes of Proceedings from the 41st Parliament, First session, ([Meetings Nos. 31, 40, 41, 47, 48, 49, 50, 51 and 52](#)) is tabled.

A copy of the relevant Minutes of Proceedings from the 40th Parliament, Third session, ([Meetings Nos. 4, 6, 7, 8, 11, 12, 13, 14, 15, 16, 17 and 19](#)) is tabled.

Respectfully submitted,

Joy Smith, M.P.

Chair

Supplementary Opinion of the New Democratic Party of Canada

Libby Davies, NDP, Vancouver East; Djaouida Sellah, NDP, Saint-Bruno - Saint Hubert; Dany Morin, NDP, Chicoutimi-Le Fjord; and Matthew Kellway, NDP, Beaches-East York.

Neurological Diseases in Canada

The New Democrat Members of the Standing Committee on Health are concerned that the final report on *Focusing on the Brain: An Examination of Neurological Diseases in Canada*, does not reflect the depth of ideas shared by witnesses who testified before the Committee—particularly testimony on the challenges of neurological diseases and suggestions for strategies to better support persons living with neurological diseases and their families. With approximately one million Canadians currently affected by neurological disease, its prevalence means these diseases pose significant social and economic costs to Canada.

We are very concerned that the Committee's report excuses the lack of federal leadership on this issue and minimizes the federal role. Witnesses identified the federal government as having an important role to play in expanding research on neurological diseases, launching education programs, providing enhanced benefit programs to persons living with neurological diseases and their caregivers, and providing funding to improve and expand treatment options. The New Democrat members of the Committee understand the importance of federal action on this issue, and put forward this report to recommend actions the federal government can take to address the impacts of neurological diseases in Canada.

Research and Education

In order to improve the surveillance of neurological diseases in Canada, witnesses made several suggestions concerning how the federal government could increase funding for research on neurological diseases and their treatments to help improve quality of life. The Committee also heard how the federal government could increase awareness and education of these diseases and their impacts on Canadians.

Witnesses described that only about 20% of grant applications to the Canadian Institutes of Health Research (CIHR) were successful because of CIHR's limited budget. This means high quality neurological research proposals cannot always be financed. Witnesses identified 3 areas where more research funding is needed. First, the Committee heard that additional grants were needed to offset the costs of running laboratories. Second, there is also a need for funding mechanisms that promote multidisciplinary research to explore the diverse factors contributing to neurological diseases. Third, CIHR could reduce the administrative burden of applications by reducing their page requirements for applications, as well as providing longer term

grants to limit the number of times researchers have to apply for funding and to provide stable funding.

Witnesses also suggested that the federal government could increase CIHR's overall budget by 1% of total health care costs, as recommended in the Senate Committee on Social Affairs, Science, and Technology's 2002 report *The Health of Canadians: the Federal Role*. In addition, witnesses suggested that through the Network of Centres of Excellence Program, the federal government could fund the establishment of a Centre of Excellence for Neurological Diseases that would coordinate multi-disciplinary research into specific neurological degenerative diseases such as Alzheimer's Disease, Parkinson's Disease, and Multiple Sclerosis. Witnesses suggested that more funding could be provided if CIHR increased the number of team grants available, which has been substantially reduced in recent years. Additional grants could also be provided for training, particularly to train younger researchers. Finally, witnesses suggested that a \$10 million per year investment over the next 5-10 years in a Centre for Neurological Diseases would also help prevent the projected increasing financial burden that is expected to be posed by degenerative neurological conditions over the next 2 decades.

The Committee heard that the federal government could establish a four-year National Population Health Study on Neurological Conditions that will look at, among other things: the incidence, prevalence, and co-morbidities of neurological conditions.

Witnesses also discussed the need for further research on the treatment of cerebrospinal venous insufficiency syndrome (CCSVI) as a treatment for Multiple Sclerosis. They noted that a lack of access to treatment of CCSVI in Canada meant that many Canadians have travelled to clinics abroad to receive the procedure. Health Canada was encouraged to conduct clinical trials as quickly as possible.

The Committee heard that witnesses encouraged the federal government to raise the profile of neurological diseases in Canada, to draw attention to their prevalence and the need for further research and treatment options. Witnesses suggested the Public Health Agency of Canada could establish a public awareness program to inform Canadians about neurological diseases. To help raise awareness about neurological diseases, the federal government could also declare 2014 'The Year of the Brain', as the Public Health Agency of Canada's National Population Health Study on Neurological Diseases is expected to be completed then.

The Social and Economic Costs of Neurological Diseases

Witnesses estimated, based on the data in Health Canada's *Economic Burden of Illness in Canada 1998* and the *Economic Burden of Mental Health Problems in Canada 2001* studies, as well as the World Health Organization's *The Global Burden of Disease 1990* study, that the economic burden of neurological and psychiatric diseases, disorders, and injuries represents 14% of the total cost of illness in Canada. This figure includes both the direct costs to the health care system as a result of these conditions, as well as indirect costs from the loss of productivity due to disability. Witnesses also suggested that the economic burden of these illnesses would increase with the age of

Canada's population, as many neurodegenerative diseases have an onset between the ages of 40-65 years.

The Committee also heard that the federal government could be doing more to support the caregivers of persons living with neurological diseases. Witnesses suggested that the federal government should create a more flexible employment insurance benefit program for persons with episodic diseases, chronic illnesses, or disabilities, so that recipients are able to retain their employment. Witnesses also recommended that existing regulations be amended so that people could work part-time while receiving partial benefits. While persons with disabilities can currently work part-time and receive employment insurance sickness benefits, they are limited to 25% of their salary or \$50 per week, which is a disincentive to gainful employment.

Witnesses also encouraged the federal government to introduce a refundable Disability Tax Credit for low-income Canadians. The Subcommittee heard that many families of persons with neurological diseases did not generate enough taxable income to benefit from the existing Disability Tax Credit. Making this credit refundable would mean that anyone with a severe and prolonged disability would be eligible to receive the benefit regardless of their level of income. Finally, the Committee heard that the federal government should streamline its application processes for the Disability Tax Credit and Canada Pension Plan Disability benefits, to make it easier for persons with physical and/or cognitive impairments to apply for them.

Witnesses also told the Committee that the federal government could do more to support informal caregivers, including allowing a more flexible Compassionate Care Benefit Program. The current program only provides six weeks of benefits in a six-month period, but witnesses encouraged that an adjusted program allow for partial weeks over a longer period of time. They also asked for amendments to the Caregiver Amount Tax Credit, which currently only applies to spouses or partners in the workforce or who pay income tax. Witnesses suggested that all spouses and partners should be able to claim this benefit. The Committee heard that to improve income security issues for both persons with neurological diseases and their caregivers, the federal government could establish an Advisory Committee on Income Reform that would explore options for income security programs for persons with disabilities and their caregivers.

Witnesses gave further suggestions to improve the quality of life for persons living with neurological diseases. Canada ranks 26th out of 29 OECD countries for public health plan reimbursement of neurological and psychiatric medications and many Canadians with neurological diseases face out-of-pocket expenses for medications for innovative treatments or once they have reached their ceiling coverage with employer insurance plans. Thus, some witnesses called for the establishment of a pan-Canadian prescription drug coverage plan. A pan-Canadian plan would provide Canadians access to drugs at a more affordable cost. However, the NDP acknowledges, as noted in the 2004 Health Accord, the jurisdiction of the Government of Québec over its healthcare system and that Québec already has its own program in place.

The Committee heard from witnesses that palliative care was not just for persons who were immediately dying, but for all persons with diseases that experience long-term suffering. They articulated that palliative care was a model of care for all people who live with progressive life-limiting illnesses. Witnesses suggested palliative care professionals could be introduced into multidisciplinary neurological disease care teams, and that greater investments be made to allow persons with neurological disease to access palliative care options rather than long-term care.

Witnesses also described concerns about discrimination when applying for various types of insurance, and that the sharing of genetic information about neurological diseases could influence their applications. Now that genetic information is available for neurological diseases, insurance companies can request information from applicants and then share it through a medical information bureau. Witnesses called on the federal government to create legislation to protect Canadians from genetic discrimination, and noted that this legislation would be necessary to ensure Canadians benefitted from CIHR's new personalized medicine initiative.

NDP Recommendations

- 1. We urge the federal government to declare 2014 as 'The Year of the Brain'.**
- 2. We urge the federal government to increase the Canadian Institutes of Health Research's budget to 1% of health costs, as recommended in the Senate Committee on Social Affairs, Science, and Technology's 2002 report *The Health of Canadians: the Federal Role*.**
- 3. We urge the Minister of Health to ask the Canadian Institutes of Health Research to examine ways to streamline and reduce the administrative workload that their grant applications place on researchers and provide multi-year grants to researchers.**
- 4. We urge the federal government to explore ways through the Minister of Finance and the Minister Human Resources and Skills Development, to reform income security programs and tax benefits for persons with disabilities and their caregivers.**
- 5. We urge the federal government to establish an Advisory Committee on Income Reform to explore options for better income security for persons with disabilities.**
- 6. We urge the federal government to make existing tax credits, such as the Disability Tax Credit, the Caregiver Tax Credit, and the Family Caregiver Tax Credit, refundable in order for them to be of greater benefit to low-income Canadians; and that the application for such benefits be streamlined and applications made more accessible for those with physical and/or cognitive disabilities.**
- 7. We urge the federal government to amend the Compassionate Care Benefit program to provide more flexibility, including: coverage of partial weeks over extended periods of time and increasing the benefit to a maximum of 52 weeks within the last year of life.**

- 8. We urge the federal government to revise the Compassionate Care Benefit eligibility criteria for persons with a terminal illness, changing the criteria from ‘significant risk of death’ to ‘significant need of caregiving because of fatal illness’.**
- 9. We urge the Minister of Health and the federal government to work with their provincial and territorial counterparts to create a universal prescription drug plan, to provide all Canadians with access to affordable medications.**
- 10. We urge the Minister of Health to direct the Canadian Institutes of Health Research and Genome Canada to work with relevant stakeholders to develop guidelines for health professionals in the use and sharing of genetic information.**
- 11. We urge the Minister of Health and federal government to play a leadership role in working with provincial and territorial partners for better access to drugs, treatments, care, and supports for neurological diseases.**

Conclusion

There is a clear federal role to improve treatments and supports for Canadians living with neurological diseases and their caregivers. Witnesses highlighted areas where the federal government could take action to improve the quality of life for those living with neurological diseases, including: research and surveillance; income security; caregiver supports; the privacy of genetic information; and awareness. This Committee’s study also revealed that greater efforts were needed to promote clinical trial research that would lead to a more timely introduction of innovative treatments and drugs for neurological diseases in the Canadian health care system.

We are concerned by the lack of coherence in the policies of the Conservative government. On one hand, the Conservatives want to control the costs of health care, but at the same time they refuse to invest now in research and prevention that would result in long term savings. We need now, more than ever, a coherent plan and action from the federal government in health care to ensure that Canadians will be healthier and can be treated effectively when necessary. The New Democratic Party, in accordance with the testimony heard from witnesses at the Standing Committee on Health, urges the federal government to take action to improve the quality of life of those suffering from neurological diseases in Canada today.

LIBERAL PARTY OF CANADA DISSENTING REPORT

Kirsty Duncan, Member of Parliament

Introduction

This dissenting report first thanks all the witnesses, many of whom were living with a neurological condition and many of whom were providing care, and for sharing often difficult information about their personal lives in order to provide a better quality of life for other Canadians. The report recognises their courage, their sense of ethics, fairness, and humanity.

Over time, brain conditions, such as amyotrophic lateral sclerosis (ALS), multiple sclerosis, Alzheimer's disease and Parkinson's disease, separate people from their work and society, as they are no longer able to leave home, and eventually from their family, as they are no longer able to communicate. Over time, they are systematically removed from everything they once knew, and they become one of the forgotten, hidden behind closed doors.

Tragically, this report falls far short of reflecting the voiceless, reflecting what was heard by the sub-committee and the committee, and whitewashes issues of tremendous importance to the 5.5 million Canadians, who live with a brain condition, and their families.

Witnesses came in good faith to testify, and expected that the report would honestly reflect their concerns, their needs, and the action and investments they needed their government to take. The report instead protects the status quo and recognizes and celebrates any action taken by the government; the report could have been so much more with real recommendations for families who are hurting, and direction that could have made Canada a leader.

It was the job of the committee's report to defend the voiceless, and to fight hard for their issues. It fails in its attempt, and therefore this dissenting report apologises to all those who took the time and effort to testify.

General

Before, identifying the serious flaws of the committee's report, it is necessary to stress that there is currently no strategy for neurological conditions--either as part of the National Mental Health Strategy or as a standalone strategy: therefore the committee's report should have been of the utmost importance.

Sadly, not all perspectives are to be found in the committee's report: for example, missing are the voices that asked for action, including a "Year of the Brain" and a "National Brain Strategy", voices that asked for investment, and voices that asked for income security. Yet the voice of the government, and all its good actions, take a disproportionate amount of space in the report.

Not all information is included, even when it is from reliable sources, such as Health Canada or the World Health Organization. In general, sections addressing caregiver supports, income security, privacy of genetic information, and research are watered down.

History is included when it is favourable to the government, and absent when it is not. While chronic cerebrospinal venous insufficiency (CCSVI) was examined by the sub-committee on neurological disease in May-June 2010, the history, such as the fact that internationally-renowned experts recommended clinical trials at that time is not included, until the government actually took action. And information is provided that does not match the actual facts--for example, "the expert working group had decided, following the analysis of the results of seven studies, sufficient evidence existed to support the establishment of phase one clinical trials". This is a ridiculous statement, as it implies the seven studies were completed by June 2011, which is patently false. The Canadian Press reported on January 27th, 2012 that, "the complete results will be available only after completion of all the studies, which will involve more than 1,300 people representing a spectrum of forms of MS, as well as individuals with other neurological diseases and healthy controls." Clearly, all the studies were not completed a half a year later in January, 2012.

Other times in the report, only one side of the issue is presented; for example, the report highlights the importance of the government's MS monitoring system, but does not acknowledge that it was to begin in July, 2012, and now September 2012, 33 months after Canadians first began travelling overseas for treatment for CCSVI.

The government does not recognise the increasing numbers of neurological conditions, the human costs of brain conditions, and their associated economic costs. It is deeply concerning that the significant economic costs to families are not sufficiently recognised in the report, and, particularly the fact that many individuals and families live in poverty as a result of the brain condition with which they must contend: hence, ALS is known as the "bankruptcy disease". In fact, the report downplays the economic challenges people face.

More disturbing still is the fact that there are no recommendations to address income security, a problem which was brought up repeatedly by those living with a brain condition, their caregivers, and non-governmental organizations.

Finally, a real concern is the use of "consider" throughout the report. Despite the committee's hearing from stakeholders across the country, including academics, caregivers, patients, practitioners, etc., the government might still choose to delay action, or choose not to take any action at all.

Recommendations

Recommendation 1: That the government declare 2014 as the "Year of the Brain" in order to: draw political attention to the human and economic costs of brain disease, now and in the future; build international collaborations in education and science to enhance brain health across the world; and leave a lasting legacy in Canada of increased awareness and better understanding of brain health and disease, and improved diagnoses and treatments.

Recommendation 2: That the government develop a pan-Canadian brain strategy, including, an education and awareness campaign, a pan-Canadian brain injury prevention strategy, an integrated treatment and support program, genetic discrimination protection, poverty protection, caregiver support, and accelerated investment in neuroscience research.

Recommendation 3: That the government develop a pan-Canadian dementia strategy to address the rising tide of dementia.

Recommendation 4: That the government recognise that: phase II and phase III clinical trials for CCSVI are already taking place; phase I trials should be reconsidered; a scientific expert working group with expertise in diagnosis and treatment of CCSVI should be established; anyone who has a conflict of interest/perceived conflict of interest should step down from any expert working group; and follow-up care should be assured to anyone who has had the treatment for CCSVI.

Recommendation 5: That the government re-build trust with those living with MS, and develop a monitoring system in which they can put their faith.

Recommendation 6: That the government recognise the economic and social costs of care giving, make existing tax credits (e.g. caregiver tax credit, disability tax credit, and the family caregiver tax credit) refundable, and explore ways to reform income security programs.

Recommendation 7: That the government should recognise that genetic discrimination is a real issue, that it should review its existing legislation to determine whether it provides sufficient protection, and if not, it should ensure protection from discrimination.

Recommendation 8: That the government establish and fund a Centre of Excellence for Neurodegenerative conditions.

Recommendation 9: That the government provide transformative multi-investigator grants to accelerate research from discovery to the development of new treatments and therapies for neurological conditions, develop a coordinated pan-Canadian program to develop technology platforms in neurogenomics, neuroimaging, neuroproteomics, and disease models; and fund a pan-Canadian training program to nurture the next generation of neuroscientists, with stable funding.

Recommendation 10: That the government should: work in collaboration with the provinces and territories and all relevant stakeholders to establish a pan-Canadian comprehensive autism spectrum disorder (ASD) strategy to enable children, adolescents, and adults with ASD to lead full and meaningful lives, and ensure the strategy is based on the best available evidence, and includes awareness and education campaigns, child, adolescent, and adult intervention and supports, innovative funding arrangements for the purpose of financing therapy, surveillance, respite care, community initiatives, and research.