



# NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

## 2014 Pre-Budget Consultation Submission to the House of Commons Standing Committee on Finance

### Executive Summary

Neurological Health Charities Canada (NHCC) is a collective of 24 organizations that represent the millions of Canadians with chronic, often progressive, neurological, disorders and injuries. NHCC’s role is to provide leadership, evaluating and advancing new opportunities for collaboration specific to advocacy, education and research projects, related to brain health.

NHCC’s vision is that the brain will soon be valued as a critical determinant of the human experience, and that matters of the brain are considered a social, health and economic priority for all levels of government. Our ultimate goal is for a Canada where individuals living with chronic brain conditions are supported to live to their full potential and to make choices within an informed and understanding society.

In 2009, the Government of Canada committed \$15 million to fund Canada’s first-ever National Population Health Study of Neurological Conditions (the Study). The Study was co-led by the Public Health Agency of Canada and NHCC and consists of 13 research projects, three national surveys, and seven microsimulation models that together will deliver an unprecedented understanding of the scope and impact of neurological conditions for individuals, families and Canadian society overall.

NHCC would like to take this opportunity to thank the Government for focusing on neurological conditions and for partnering with us on this innovative approach to the development of better knowledge about neurological conditions. NHCC is looking forward to our continued partnership in 2015 and beyond as we move to the knowledge translation and dissemination phase of the Study later this year.

NHCC can assure the Committee that the recommendations put forward in this pre-budget submission will only be strengthened when the new evidence from the Study is made available.

NHCC’s recommendations for the 2015 Budget target two of the six themes offered during this process, which are:

- Supporting families and helping vulnerable Canadians by focusing on health, education and training;
- Increasing the competitiveness of Canadian businesses through research, development, innovation and commercialization.

NHCC’s recommendations are specifically focused on building new knowledge about brain conditions in Canada; and increasing public and health care provider awareness of brain conditions.

**NHCC’s recommendations total \$65.8 million.**

NHCC’s requests of government are made in full awareness of the requests made by some of our member organizations, as well as other external partners. Listed below are some of those of which we are aware - and which NHCC supports – that we believe will have a positive impact on Canadians dealing with neurological conditions.

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### Members:

- ALS Society of Canada
- Alzheimer Society of Canada
- Alzheimer Society of Ontario
- Brain Injury Association of Canada
- Canadian Alliance of Brain Tumour Organizations
- Canadian Epilepsy Alliance
- Canadian Neurological Sciences Federation
- Centre for ADHD Awareness Canada
- Dystonia Medical Research Foundation of Canada
- The Foundation Fighting Blindness
- Headache Network Canada
- Heart and Stroke Foundation of Canada
- Huntington Society of Canada
- March of Dimes Canada
- Mood Disorders Society of Canada
- Multiple Sclerosis Society of Canada
- Muscular Dystrophy Canada
- Ontario Federation for Cerebral Palsy
- Ontario Neurotrauma Foundation
- Ontario Rett Syndrome Association
- Parkinson Society Canada
- Parkinson Societies in Ontario
- Spina Bifida & Hydrocephalus Association of Ontario
- Tourette Syndrome Foundation of Canada

## **Recommendations:**

### **Building Knowledge and Understanding of Brain Conditions in Canada**

#### **1. Addressing knowledge gaps identified in the National Population Health Study of Neurological Conditions (“the Study”).**

NHCC recommends that the Government of Canada continue to partner with NHCC to identify the most pressing research needs from the knowledge gaps presented in the Study; and undergo further development and implementation of these research needs.

Continued partnership on research studies with NHCC will ensure research in the field of neurological conditions links directly with Canadians impacted by these conditions, health and community service providers, and a broad spectrum of researchers.

Three key areas that have already been identified by NHCC members as needing immediate further investigation are: neurological conditions with an early life onset (i.e. from birth, infancy or childhood), the relationship between mental health and neurological conditions, and prevention and risk factors that are associated with the development of brain conditions.

#### **Investment**

NHCC is seeking **\$20 million over five years** to continue to partner with the Government of Canada to further investigate the knowledge gaps identified in the Study and to begin to address the immediate research needs related to brain conditions in Canada.

#### **Rationale**

The National Population Health Study of Neurological Conditions was an investment of \$15 million in partnership between the Government of Canada and NHCC. This investment has provided us with a snapshot of what neurological conditions look like in Canada and how they are experienced by Canadians. In order to get more in-depth knowledge about the specific needs and issues related to neurological conditions, more funding is required to undertake a targeted approach. The investment in new and more focused research into neurological conditions will provide a better understanding of specific needs and how to better tailor policy and programs so they are most effective for Canadians impacted by brain conditions.

#### **2. Ongoing and expanded surveillance of neurological conditions.**

NHCC recommends that the Government of Canada commit to ongoing and expanded surveillance of neurological conditions.

Surveillance provides comprehensive data collection on various conditions, which supports the planning of effective evidence-based policies and programs. This level of data collection is required for the growing numbers and impacts of neurological conditions.

#### **Investment**

NHCC asks that surveillance systems in Canada be adequately funded to include a broader focus on neurological conditions.

### 3. Enhancing the Canadian Longitudinal Study on Aging (CLSA).

NHCC recommends that the Government of Canada invest in necessary enhancements to the CLSA to improve diagnostic measures, data analysis of information on neurological conditions, and expanded research.

The CLSA will be one of the most comprehensive studies of its kind undertaken to date, not only in Canada but around the world. The CLSA is collecting information on the changing biological, medical, psychological, social, lifestyle and economic aspects of people's lives. These factors will be studied in order to understand how, individually and in combination, they have an impact in both maintaining health and in the development of disease and disability as people age.

In order to get the most comprehensive data on the growing numbers and challenges associated with neurological conditions in Canada, it will be imperative that the CLSA be improved in three key areas:

1. New diagnostic measures in the form of MRI and fMRI scans at two time points over three years on 600 CLSA participants;
2. Conduct data analysis on the neurological conditions captured in the CLSA in relation to biological, physical, psychological and social aspects of aging;
3. Conduct a multi-generational research study on a younger cohort in relation to neurological conditions.

#### Investment

NHCC is seeking **\$40.8 million over six years** for enhancements to the CLSA in the three key areas identified.

#### Rationale

1. New Diagnostic Measures:

MRI and fMRI scans at two time points over 3 years on 600 CLSA participants has been estimated by the CLSA to cost \$1.6 million.

2. Conduct Data Analysis

Analysis of data captured in the CLSA on neurological conditions in relation to biological, physical, psychological and social aspects of aging is estimated by CLSA to cost \$150,000 per year. NHCC is requesting this amount per year for six years, which totals \$900,000.

3. Conduct a Multi-generational Research Study

The following would be required for the Study: 15,000 pairs (child of the CLSA participant and grandchild of the CLSA participant) who would be followed through telephone interviews only; 10,000 pairs (child of the CLSA participant and grandchild of the CLSA participant) who would be followed through face to face interviews and collection of bio-specimen. CLSA estimates the budget for this Study to be \$38.3 million over six years.

## **Increasing awareness, understanding and competency in the diagnosis, treatment and management of neurological conditions in Canada**

### **4. Increasing awareness about neurological conditions among the public and health care providers.**

NHCC recommends that the Government of Canada partner with NHCC to develop and implement a public awareness campaign with the goal of improving Canadians understanding of neurological conditions and reducing the stigma that is experienced by individuals living with a neurological condition from the public and health care field.

Stigma, as has been identified within the mental health sphere (i.e. a priority for the Mental Health Commission of Canada), is also a major concern for individuals and families living with neurological conditions. Neurological conditions affect all aspects of a person's life, including their ability to communicate, move, and function. This impacts a person's ability to get an education, participate in the workforce, and socialize. Stigma experienced by people with neurological conditions leads to social isolation, lack of education and financial instability.

#### **Investment**

NHCC is seeking **\$5 million over two years** to develop and implement an awareness campaign in partnership with the Government of Canada to help combat the misunderstandings and stigma that surround neurological conditions, which prevent Canadians with neurological conditions from fully participating in society.

#### **Rationale**

In 2008, the Government of Canada committed to the Federal Elder Abuse Initiative (FEAI). This was a three-year, \$13 million, multi-departmental initiative. A cornerstone of the FEAI was an elder abuse awareness advertising campaign, *Elder Abuse – It's Time to Face the Reality*, which ran in 2009 and 2010 and included television, print and internet. Public opinion research demonstrated that general awareness of elder abuse in Canada increased significantly from 71% in 2009 to 91% in 2011.

A \$5 million investment, along with a partnership with NHCC, will produce a successful awareness campaign as was accomplished for elder abuse in 2009/2010. As was done through extensive stakeholder engagement during the development of the National Population Health Study of Neurological Conditions, NHCC will bring to this partnership the lived experience of people with neurological conditions, along with an extensive reach to stakeholders across Canada.

## **Support for Other Recommendations**

NHCC's member organizations work closely with other coalitions, as well as individually to advance policy and program changes to benefit people living with neurological conditions. The following are recommendations being put forward by other groups, which NHCC supports (more information on the HCCC and MS Society of Canada recommendations can be found in their submissions):

### **Health Charities Coalition of Canada (HCCC)**

HCCC recommends that the Government of Canada expand the Employment Insurance Compassionate Care Benefit to provide better income security and enable caregivers to provide vital support to Canadians who are living with disease by:

- Increasing the benefit period from 6 to 26 weeks within a 52 week period;
- Broadening eligibility criteria to allow for partial weeks over a longer period;
- Eliminating the mandatory two week waiting period to receive benefits; and
- Extending eligibility to caregivers who are providing support to those who require care due to a serious chronic or episodic medical condition.

### **MS Society of Canada**

MS Society of Canada recommends the following income security measures:

- The federal government needs to create and expand more flexible employment programming to improve job retention rates for those affected by episodic disabling diseases like MS.
- The federal government needs to improve income security programs for people affected by MS and other episodic and chronic diseases and disabilities.
- The federal government needs to initiate the development of a National Caregiver Action Plan working with provinces, territories, caregivers, employers and organizations to: reduce financial burden, improve access to resources, create flexible workplace environments, and recognize caregivers' vital roles.

### **Canadian Coalition for Genetic Fairness (CCGF)**

Genetic Fairness has been a longstanding priority for NHCC. In partnership with the CCGF, NHCC has been working to ensure that all Canadians are treated equitably regardless of their genetics. In 2013, we welcomed the government's focus on genetic fairness in the Throne Speech. We'd like to thank the government for recognizing this need and committing to eradicating genetic discrimination in Canada.

NHCC, in partnership with the CCGF, is prepared to work with the government on the introduction of measures that will prevent employers and insurance companies from discriminating against Canadians on the basis of genetic testing.

## **Conclusion**

In conclusion, NHCC would like to thank the Standing Committee on Finance for the opportunity to provide input into the Federal Budget 2015. We ask that you consider our recommendations within the context of our current and longstanding partnership with the Government of Canada, as well as our collective commitment to advancing key areas of need that will be evermore realized with the release of the Study.

Representatives from NHCC would be pleased to have an opportunity to appear before Committee members this fall to further discuss NHCC's recommendations.

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