

**Members:**

***2017 Pre-Budget Submission Prepared for  
The Standing Committee on Finance***

August 5, 2016

**Helping Canada Prosper: Canadian Action Plan for Brain Health**

**Executive Summary**

Collectively, diseases, disorders and injuries of the brain are the major health challenge of the 21st century. Today, four million Canadians live with a brain condition resulting in “symptoms and functional deficits that are often chronic in nature and can have profound impacts on the life and well-being of individuals, their families, caregivers and communities.”<sup>i</sup> While awareness is increasing about some conditions, a 2014 study of brain conditions in Canada concluded that “an improved appreciation of the overall scope of neurological conditions in Canada is necessary to better meet the needs”<sup>ii</sup> of the millions affected.

For Canada, the productivity and prosperity impact is significant as brain conditions, for which there are limited treatments and no cures, impact Canadians at every age and stage of life. Focus and leadership from the Government of Canada is needed to bring policy action and targeted research investment that will improve the quality of life for so many Canadians whose issues have gone largely unnoticed to date.

**NHCC recommends the Government of Canada immediately commit to developing a Canadian Action Plan for Brain Health with the primary aim of improving the life experience, productivity and prosperity of the four million Canadians living with brain conditions and their families.**

The **Canadian Action Plan for Brain Health** would come to life as a collaboration between the Government of Canada and a newly established Canadian Brain Council to bring stakeholders together, strengthen ties across disciplines and perspectives, accelerate knowledge translation to help spread innovation and best practices, build consensus around priorities, evaluate progress and inform next steps.

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

## Who we are

Neurological Health Charities Canada (NHCC) is the voice of Canadians living with brain conditions through a coalition of more than 20 organizations that represent people with diseases, disorders and injuries of the brain, spinal cord and peripheral nervous system.<sup>iii</sup>

NHCC partnered with the Government of Canada between 2009 and 2014 to study brain health in the National Population Health Study of Neurological Conditions (the Study). In collaboration with the Canadian brain community, this work represents the most comprehensive epidemiological study of brain conditions ever conducted in this country. The Study report, *Mapping Connections: An understanding of neurological conditions in Canada*, was released in September 2014.<sup>iv</sup>

## The need

Collectively, diseases, disorders and injuries of the brain are the major health challenge of the 21st century. They can create a life-long burden of care, impacting the individual, their families and communities.

Brain conditions can begin at birth, strike young adults just as they are beginning careers and starting families or hit those who are looking forward to their retirement years. For all, their life course and that of their families will be inalterably changed because of curtailed educational opportunities, lost jobs and increasing disability and financial insecurity.

Here are just some of the impacts as found by the Study:

- Canadians living with brain conditions use more health care services than those without a neurological condition or even those with other chronic conditions;<sup>v</sup>
- Half of all recipients of home care or in long-term care facilities have a brain condition;<sup>vi</sup>
- Adults with a brain condition experienced depression twice as often as people without the condition;<sup>vii</sup>
- Unemployment among Canadians living with brain conditions is 12 times higher than the general population;<sup>viii</sup>
- Forty percent of children with brain conditions have limited educational opportunities.<sup>ix</sup>

The burden of brain conditions will only increase unless we take action now. The Study found by 2031, Canada will see a significant increase in the number of people diagnosed with all neurological conditions, but particularly, Alzheimer's disease and other dementias, Parkinson's disease and traumatic brain injury.<sup>x</sup>

This all means steadily increasing costs -- costs for the individuals with a brain condition and their families and costs for Canada as a whole. By 2031, depending on the condition, total direct health-care costs will be up to \$13.3 billion greater than health-care costs of Canadians without these specific conditions.<sup>xi</sup>

## **The need for immediate action**

The findings of the Study were clear about the numerous policy, program and funding gaps that still exist.

As noted in *Mapping Connections*: "While generating new information related to the focus areas of this Study, gaps were also identified. Generally, data on certain specific populations, such as First Nations, Inuit, and Métis communities, children, Canadians typically excluded from national surveys, or those with less prevalent neurological conditions, remain scarce. Data are still lacking or deficient regarding the distribution, quality, and costs of health services for Canadians living with a neurological condition specific to the various regions and jurisdictions of Canada."<sup>xii</sup>

W. Galen Weston, chair and president of The W. Garfield Weston Foundation, also addressed gaps recently stating: "Canada has a world-class neuroscience research community actively engaged in addressing these [neurodegenerative] diseases, but funding is significantly lower than for many other diseases, and there is a critical gap in the middle of the process."<sup>xiii</sup>

It is time for Canada to step up now to make a difference in the lives of children, young people, parents and grandparents -- everyone who has a brain condition or is caring for that person.

## **NHCC recommendation**

**To meet these challenges, NHCC recommends the Government of Canada immediately commit to developing a Canadian Action Plan for Brain Health with the primary aim of improving the life experience, productivity and prosperity of the four million Canadians living with brain conditions and their families.**

As the first step, the NHCC urges the Government to establish a Canadian Brain Council to partner with the Government and to lead unprecedented collaboration among Canadians with brain conditions, caregivers, brain health charities, health-care professionals, neuroscience and epidemiological researchers, the federal health portfolio and representatives of provincial governments. Together, these primary stakeholders will identify, align and develop robust strategies to advance priority health, economic and social imperatives to be addressed in the Action Plan, beginning with a dementia strategy in 2017.

We suggest the Canadian Brain Council convene Brain Summits to bring stakeholders together, strengthen ties across disciplines and perspectives, accelerate knowledge translation, spread effective care and policy innovation, build consensus around priorities, evaluate progress and inform next steps.

We suggest the first Brain Summit should take place in 2017 to:

- Establish the detailed work of a dementia strategy for Canada – recognizing dementias associated with a range of neurodegenerative diseases including but not limited to Alzheimer’s disease, Huntington’s disease, motor neuron disease, multiple sclerosis, Parkinson’s disease and vascular disease;
- Prioritize recommendations for data collection funding and epidemiological and risk factor research investments informed by the findings in *Mapping Connections*;
- Prioritize recommendations for increased annual funding levels for investigator-driven basic brain health research through CIHR. NHCC suggests the minimum level begin at \$150 million in 2017, as urged by the Canadian Association for Neuroscience in its 2016 budget request.<sup>xiv</sup>

**NHCC is ready to be a catalyst, convener and collaborator to assist the Government of Canada in developing a Canadian Action Plan for Brain Health.**

NHCC has a proven track record of bringing the right stakeholders together to deliver results. As co-manager of the National Population Health Study of Neurological Conditions, we worked with three federal government agencies and departments and more than 130 researchers and engaged approximately 177,000 Canadians with brain conditions and their caregivers in the Study. Through our member organizations, we have a direct connection to the millions of Canadians living with brain conditions, their families and caregivers.

NHCC believes there is a crucial need to establish a Canadian Brain Council to begin work immediately on a Canadian Action Plan for Brain Health. Many of the elements needed for an effective Canadian Brain Council are already in place including the Government of Canada health portfolio, NHCC and its sister coalitions and the Canadian Association for Neuroscience. NHCC believes it is vital that the development of a Canadian Action Plan for Brain Health use the principles of collective impact, which have been proven to be so effective in making collaboration work across many partners to achieve significant and lasting change.<sup>xv</sup>

We believe this collaborative and coordinated approach will generate innovative, cross-cutting solutions to improve quality of life for people affected by brain conditions, reduce duplication in research, spread effective care and policy innovation, and contribute to future sustainability of our health and social support systems.

### **Cost of recommendation**

For planning purposes, NHCC has estimated core costs of a Canadian Action Plan for Brain Health over three years from April 2017 to March 2020 by areas of expenditure:

#### **1. Canadian Brain Council and Brain Summits**

The Canadian Brain Council, once established, would develop the Canadian Action Plan for Brain Health, including in year one, developing a national dementia strategy. The Council would also convene a Brain Summit in 2017 and a second Summit in late 2019 or early 2020 to obtain input from the widest range of stakeholders possible.

- **Estimated cost: \$3.5 million over three years.**

#### **2. Epidemiological research and data collection**

The Canadian Brain Council would review the findings about research gaps and data needs from *Mapping Connections* and other sources and recommend, if the evidence supports, expanded data collection, the feasibility of creating a new pan-Canadian data collection survey for brain conditions, and funding needs for targeted research on risk factors for brain conditions. Expenditures would likely occur in years two and three.

- **Estimated cost: \$22 million over three years.**

#### **3. Investigator-driven basic brain research through CIHR**

Far too little is known about the causes, prevention and treatment of most brain conditions. Thanks to research, innovative therapies are available for some brain conditions. Unfortunately, many others remain untreatable. Canada needs to invest more in basic brain research. NHCC believes this is best done by increased annual funding to investigator-driven basic brain research through CIHR at a rate of \$150 million per year.

- **Estimated cost: \$450 million over three years.**
- **Total estimated cost: \$475.5 million over three years**

## **Alignment with Mental Health Strategy and Dementia Strategy**

NHCC applauds the work underway on the development of both mental health and dementia strategies. We see a Canadian Action Plan for Brain Health inclusive, collaborative and complimentary to this work for the benefit of all. The goal of better quality of life for all people affected by brain conditions will be reached faster through ongoing and active cooperation.

We also support budget requests by a number of our member organizations, relating to genetic fairness, expansion of Caregiver Compassionate Leave Benefits and greater flexibility in Employment Insurance sickness benefits as all will contribute to improved quality of life for those we serve.

## **In Conclusion**

NHCC thanks the Standing Committee on Finance for the opportunity to provide input into Budget 2017. We ask that you consider our recommendations within the context of our longstanding partnership with the Government of Canada, as well as our collective commitment to address critical areas of need for Canadians living with brain conditions, their families and caregivers.

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- <sup>i</sup> Public Health Agency of Canada. *Mapping Connections: An understanding of neurological conditions in Canada*. Ottawa (ON): Public Health Agency of Canada; 2014. 98 p. Report No.: ISBN 978-1-100-24442-6, Report of the National Population Health Study of Neurological Conditions, conducted in partnership with Neurological Health Charities Canada, p. 1.
- <sup>ii</sup> *Mapping Connections*, p. 76.
- <sup>iii</sup> Neurological Health Charities Canada (NHCC) is a coalition of 20 organizations that serves as the voice of Canadians living with brain conditions. NHCC came together as a coalition in 2008 to represent Canadians with diseases, disorders and injuries of the brain, spinal cord and peripheral nervous system.
- <sup>iv</sup> *Mapping Connections: An understanding of neurological conditions in Canada*. Ottawa (ON): Public Health Agency of Canada; 2014. 98 p. Report No.: ISBN 978-1-100-24442-6, Report of the National Population Health Study of Neurological Conditions, conducted in partnership with Neurological Health Charities Canada, p. 1.
- <sup>v</sup> *Mapping Connections*; p. 36.
- <sup>vi</sup> *Mapping Connections*; p. 57.
- <sup>vii</sup> *Mapping Connections*; p. 18,
- <sup>viii</sup> *Mapping Connections*; p. 24.
- <sup>ix</sup> *Mapping Connection*; p. 26.
- <sup>x</sup> *Mapping Connections*; p. 6.
- <sup>xi</sup> *Mapping Connections*; p. 46.
- <sup>xii</sup> *Mapping Connections*; p. 6.
- <sup>xiii</sup> Weston, W. Galen (2016, July 13). It's time for Canada to lead on brain research. Retrieved from <http://www.theglobeandmail.com/opinion/its-time-for-canada-to-lead-on-brain-research/article30902352/>
- <sup>xiv</sup> Canadian Association for Neuroscience. (2016, January 21). Recommendations to the pre-budget consultations. Retrieved from <http://can-acn.org/documents/2016/CAN-Pre-budget20160121.pdf>
- <sup>xv</sup> Kania, John and Kramer, Mark. (2011, Winter). Collective Impact. Stanford Social Innovation Review. Retrieved from [http://ssir.org/articles/entry/collective\\_impact](http://ssir.org/articles/entry/collective_impact)