



**NHCC**

NEUROLOGICAL HEALTH CHARITIES CANADA

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# **Submission for the Standing Committee on Science and Research for its Study of International Moonshot Programs**

## **The Case for a Canadian Brain Research Moonshot**

Neurological Health Charities Canada

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## **The Case for a Canadian Brain Research Moonshot**

As Canada emerges from the COVID-19 pandemic, Neurological Health Charities Canada (NHCC) believes it is time to tackle one of the most challenging but ultimately solvable health issues of the twenty-first century: the prevention, treatment, and cure of neurological conditions. It is time for unprecedented collaboration, resolve, and funding through a Canadian Brain Research Moonshot.

### **The Impact of Neurological Conditions**

Neurological conditions — neurological illnesses, disorders, and injuries — are one of the leading causes of disability in Canada and worldwide. The range of neurological conditions is astounding with more than 400 neurological disorders. These include cerebrovascular diseases, neurodegenerative diseases, neurodevelopmental disorders, and rare diseases. They can occur at any stage of life, from birth to older adults (see Appendix One for examples of how neurological conditions occur across the life course).

NHCC estimates one in three Canadians (more than 10 million) will have a neurological condition in their lifetime. Neurological conditions lead to personal suffering and tragedies, but also impact society as a whole.

- Neurological and mental health disorders cost the Canadian economy \$61 billion annually<sup>i</sup> – more than cancer and cardiovascular disease combined;
- Working-age Canadians with neurological conditions are five times more likely to be permanently unemployed than Canadians without those conditions<sup>ii</sup>;
- Between now and 2031, indirect costs due to working-age premature death and disability will increase<sup>iii</sup> and total health care costs for Parkinson’s disease and dementia will double<sup>iv</sup>.

NHCC urges this committee to examine how an unprecedented focus on brain research through a Moonshot-type approach could lead to the breakthroughs that are needed to make significant impact on neurological conditions and mental health disorders across Canada.

## **NHCC Partnering with the Canadian Brain Research Strategy**

NHCC recognizes that collaboration in neurological and mental health research is key to making progress on preventing, treating, and ultimately curing neurological conditions. NHCC has been actively involved for several years as a partner organization in the development of the Canadian Brain Research Strategy<sup>v</sup> (CBRS), bringing the voices of people with lived experience to this unique approach to brain research. As a coalition of neurological charities, NHCC recognizes the value of working together to solve problems. We agree with the vision of CBRS that a coordinated pan-Canadian research effort will yield knowledge and innovations that will ultimately benefit individuals living with neurological conditions.

By tackling brain conditions together, there is a better chance of understanding all and helping all. For example, many neurological diseases have related underlying causes; sharing new knowledge about one condition in a coordinated, systematic way could benefit other conditions in preventative measures and the development of new treatment approaches.

NHCC wholeheartedly supports the many existing individual organization and institution brain funding research programs. A number of our member organizations fund important research in their respective focus areas. These research programs are important in driving knowledge forward and would be increasingly impactful if they had more opportunities to partner with and learn from a well-funded, collaborative research approach.

The Canadian brain research community is well recognized as being strongly interconnected despite its small size relative to other countries. We suggest it is time to build on this strength. NHCC believes that the over-arching strategy of CBRS, including principles of collaborative, trans-disciplinary, open, and ethical research will make a profound difference in how Canadian brain research is carried out and will accelerate the acquisition of scientific knowledge leading to better treatments for Canadians living with neurological conditions.

## **Neurological Health Charities Canada**

Neurological Health Charities Canada is a coalition of organizations that represent millions of Canadians living with neurological diseases, disorders, and injuries. In addition to supporting research, NHCC proposes the development of a National Neurological Strategy for Canada to address the patchwork approach to neurological health that has a profoundly negative impact on quality of life for the millions of Canadians living with neurological conditions. This holistic



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approach recognizes the importance of research, health policies, and health care delivery within an overall ethical framework. NHCC is ready to help lead this unprecedented collaborative approach which would drive knowledge to action and result in the best quality of life for Canadians affected by neurological conditions.

### **NHCC Member Organizations**

[Brain Injury Canada](#)

[Brain Tumour Foundation of Canada](#)

[Canadian Epilepsy Alliance](#)

[Canadian Neurological Sciences Federation](#)

[Dystonia Medical Research Foundation Canada](#)

[GBS/CIDP Foundation of Canada](#)

[Huntington Society Canada](#)

[Hydrocephalus Canada](#)

[March of Dimes](#)

[National ME/FM Action Network](#)

[Ontario Federation for Cerebral Palsy](#)

[Ontario Rett Syndrome Association](#)

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## Appendix One

### Neurological Conditions Occur Across the Life Course

There are hundreds of neurological conditions, some that affect hundreds of thousands of individuals in Canada, and some that affect just a few. All can be devastating to individuals' quality of life and their families and caregivers. Many share similar risk factors and outcomes.

- **At birth** – Cerebral palsy, characterized by the loss or impairment of motor function, results from brain damage caused by injury or abnormal development while a child's brain is still developing - before birth, during birth or immediately after birth. Cerebral palsy is the most common childhood disability<sup>vi</sup>;
- **Childhood** – Rett syndrome is a neurodevelopmental condition. It has a devastating impact: loss of spoken language, gross motor and fine motor skills and many other medical complications. There is currently no cure<sup>vii</sup>. While brain tumours can occur at any age, in children they are a leading cause of death<sup>viii</sup>;
- **Adulthood** – Conditions such as Huntington disease and multiple sclerosis (MS) occur most frequently in midlife (from 30 to 55). In addition, dystonia, MS and other conditions such as depression and other mental illnesses are often episodic in nature, resulting in periods of disability that can vary in severity and duration, and persist for the rest of the lifespan<sup>ix</sup>;
- **Older adults** – Neurodegenerative conditions like Parkinson's disease and various types of dementia most typically occur in adults over 60, with the incidence rising with increasing age<sup>x</sup>. While stroke can happen at any time, it occurs more frequently in those over 65<sup>xi</sup>. Stroke is the tenth leading cause of disability in Canada<sup>xii</sup>.
- **Entire lifespan** – Epilepsy and traumatic brain injury (TBI) can occur across the entire lifespan from young children to older adults, all genders and all ethnicities. Epilepsy is the most common, chronic brain disease with seizures being an important symptom. It can be a consequence of other brain conditions. Traumatic brain injury ranges from concussion to severe impairment. TBI occurs frequently in males between 15 and 25 years of age, often as the result of bicycle, motorcycle or motor vehicle collisions or sports-related injuries, and in older adults because of falls<sup>xiii</sup>.

## References

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<sup>i</sup> 2016 Report of INMHA Evaluation Panel from the CIHR Institute of Neurosciences, Mental Health and Addiction

<sup>ii</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, p. 24.

<sup>iii</sup> Mapping Connections, p. 30.

<sup>iv</sup> Mapping Connections, p. 46.

<sup>v</sup> The Canadian Brain Research Strategy is a pan-Canadian grassroots endeavour of research leaders which aims to link brain research initiatives and projects, public and private funders, and patient organizations in a uniquely collaborative effort that will push the frontiers of brain science. It coordinates Canada's participation in the International Brain Initiative. Accessed at [www.canadianbrain.ca](http://www.canadianbrain.ca)

<sup>vi</sup> Accessed at <https://www.ofcp.ca/about-cerebral-palsy>

<sup>vii</sup> Accessed at <https://www.rett.ca/rett-syndromertt/what-is-rett-syndrome/>

<sup>viii</sup> Accessed at <https://www.braintumour.ca/2494/brain-tumour-facts>

<sup>ix</sup> Accessed at <http://episodicdisabilities.ca/home.php>

<sup>x</sup> Licher S, Darweesh SKL, Wolters FJ, et al Lifetime risk of common neurological diseases in the elderly population *J Neurol Neurosurg Psychiatry* Published Online First: 02 October 2018. doi: 10.1136/jnnp-2018-318650: <https://jnnp.bmj.com/content/early/2018/08/26/jnnp-2018-318650>

<sup>xi</sup> Kelley-Hayes M, Influence of Age and Health Behaviors on Stroke Risk: Lessons from Longitudinal Studies. *J Am Geriatr Soc.* 2010 Oct; 58(Suppl 2): S325–S328. Accessed at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3006180/>

<sup>xii</sup> Lang JJ et al. Global Burden of Disease Study trends for Canada from 1990 to 2016. *CMAJ* November 05, 2018 190 (44) E1296-E1304, Accessed at <http://www.cmaj.ca/content/190/44/E1296>

<sup>xiii</sup> Chan V, Zagorski B, Parsons D and Colantonio A. Older adults with acquired brain injury: a population-based study. *BMC Geriatr.* 2013; 13: 97. Published online 2013 Sep 23. doi: 10.1186/1471-2318-13-97.