

Joyce Gordon, Chair, Neurological Health Charities Canada

June 5, 2009

Response to Ministerial Announcement of \$15 million to fund 4-year national population-based study of neurological conditions in Canada.

Thank you Patrick, and thank you Minister Aglukkaq. It is my honour to speak on behalf of Neurological Health Charities Canada and the millions of Canadians living with neurological conditions and their caregivers.

This is a historic day for our community. The Government of Canada, through Prime Minister Harper and Minister Aglukkaq, has demonstrated meaningful leadership in making neurological conditions a priority health, social and economic issue in Canada.

The NHCC is pleased to have brought this issue to the government's attention, and we applaud the commitment of \$15 million as a critical step in tackling an incredibly serious crisis facing individuals, families, and our society overall.

To give you a sense of the big picture, we estimate that well over 3 million Canadians are living with a neurological condition today. When we consider caregivers, the number doubles to at least 6 million. That's at least 20% of the Canadian population living with a life-altering, and sometimes life-threatening, condition like Alzheimer's, ALS, MS, Tourettes, Parkinson's, Epilepsy and dementia, to name a few.

Experts predict that within the next 20 years, neurological conditions will become the leading cause of death and disability in Canada. Something must be done and Minister, your announcement comes not a day too soon. This research will help us understand the true state and impact of neurological conditions across Canada. For the first time, governments will have the information to make the most appropriate policy and program investments for people with neurological conditions.

I'd like to take a few moments to recognize key contributions that have brought us here today. In 2004, NeuroScience Canada published a document entitled *The Case for Canada's Increased Investment in Neuroscience Research*. This document, and series of roundtable consultations, paved the way for the formation of the NHCC and for the case we presented to government last spring. NeuroScience Canada has been a leader in our field and they have been instrumental in our shared progress. Thank you.

The NHCC envisions a society where individuals living with neurological conditions are supported to live to their full potential, and make choices within an informed and tolerant society. In particular, the NHCC members rallied around the need for information about the extent and impact of brain and nervous system conditions in Canada. As our work got underway 18 months ago, a small leadership team emerged to drive this project. Scott Dudgeon (Alzheimer Society of Canada), Deanna Groetzing (MS Society of Canada), Bobbi Greenberg (ALS Society of Canada), Inez Jabalpurwala (NeuroScience Canada) and Parkinson Society Canada jumped in and have devoted countless hours. There is still much work ahead but today presents a wonderful opportunity to celebrate their commitment. Thank you.

To Patrick Brown who has championed the cause of neurological conditions, as Member of Parliament for Barrie and as a member of the Standing Committee on Health. Your personal and professional passion are evident. We have welcomed your advice and benefited from your support, and we look forward continued collaboration for the benefit of Canadians with neurological conditions and their families and caregivers.

To our partners in the federal health agencies, including the Public Health Agency, Health Canada and the Canadian Institutes of Health Research, we are grateful for the spirit of collaboration that you have brought to this work. We have forged a very productive working relationship and we are grateful for your support and your commitment to this work.

Specifically, I'd like to recognize the leadership of Kim Elmslie, Director General for the Centre for Chronic Disease Prevention and Control, along with Paula Stewart, Barbara Beckett and Anna Romano.

I'd also like to recognize the full membership of the NHCC, whose shared vision to 'put the brain on the map' and willingness to roll up their sleeves has changed how policy makers consider issues related to neurological conditions.

It will take a moment but I'd like to mention each organization - we'll save our applause for the end:

ALS Society of Canada
Alzheimer Society of Canada
Canadian Alliance of Brain Tumor Organizations
Canadian Neurological Sciences Federation
Dystonia Medical Research Foundation of Canada
Epilepsy Ontario
Huntington Society of Canada
March of Dimes Canada
Multiple Sclerosis Society of Canada
Muscular Dystrophy Canada
NeuroScience Canada
Ontario Federation for Cerebral Palsy
Ontario Neurotrauma Foundation
Parkinson Society Canada
Spina Bifida & Hydrocephalus Association
and, Tourette Syndrome Foundation of Canada.

Most importantly, I'd like to recognize everyone here today who has a neurological condition, or is a caregiver. Your road is not easy and you inspire us every day! Whether facing life with a brain or spinal cord injury, a genetic disorder like muscular dystrophy or spina bifida, or a progressive condition like Huntington's or Dystonia, the optimism and spirit you demonstrate are lessons to us all. Your perspective and your insight guide us. We know that you expect the best from us and we take that responsibility to heart.

We expect great things from this partnership between the NHCC and the Government of Canada. We share a responsibility to reduce the impact of neurological conditions on individuals, families, workplace productivity and the Canadian economy. Our stakeholders have demonstrated a willingness to be actively involved in this work and I expect that they will seize every opportunity to continue to be heard for the benefit of all Canadians living with neurological conditions.

Thank you again to the Government of Canada, to Minister Aglukkaq, and to Patrick Brown. The NHCC looks forward to working with you and maintaining an integral role in shaping and driving this much-needed research.

Thank you.