# **Mapping Connections**

An understanding of neurological conditions in Canada









The National Population Health Study of Neurological Conditions





Public Health Agency of Canada Agence de la santé publique du Canada

# Leading the way in neurological research

The National Population Health Study of Neurological Conditions was jointly undertaken by Neurological Health Charities Canada and the Public Health Agency of Canada from 2009-2013 to address the lack of information about neurological conditions in Canada and to understand the impact neurological conditions have on affected individuals, their families and the health care system.

### How are neurological conditions impacting Canadians?

- Living with a neurological condition can seriously compromise an individual's
  quality of life and that of their family, due to negative impacts on mental and
  general health, work status, and financial security.
- Neurological conditions can result in significant out-of-pocket health care expenses, limitations on regular activities, and feelings of stigmatization.
- The risk of developing some of the most common neurological conditions increases with age. The number of people facing these challenges is predicted to rise as Canada's population ages and grows.







# Research that keeps the brain top of mind

The study has improved the Canadian understanding of the:

- impact of neurological conditions on affected individuals, their families, caregivers and communities, including economic impacts and quality of life now and over the next 20 years;
- risk factors related to the development of neurological conditions;
- health services needs for both those affected and their caregivers; and
- scope of neurological conditions in terms of the incidence (the number of new cases in a given time period) and prevalence (the number of individuals in the population with a neurological condition).

# What have we accomplished?

13 pan-Canadian research projects completed by over 130 researchers

3 national surveys

7 microsimulation models projecting the impacts of neurological conditions over the next 5, 10 and 20 years

Expansion of the Canadian Chronic Disease Surveillance System to include some neurological conditions **Synthesis Process:** 

A team of Canadian experts brought key information from the various products together into 1 report

Stakeholder Consultations:
Individuals across the
country reviewed the report
and added their experiences
related to neurological conditions
to the evidence

Final Report

# What is happening?

Dissemination to relevant stakeholders, including Canadians living with or affected by a neurological condition

Fact sheets for health care professionals

Ongoing research and surveillance

Toolkits and guidelines for the creation of disease registries



# A comprehensive and collaborative approach

- The study successfully engaged people with neurological conditions, caregivers, health charities, public policy leaders and over 130 academic and clinical investigators in Canada's first-ever population health study of neurological conditions, marking an unprecedented level of collaboration across fields, professions, jurisdictions, conditions, and interests, and generating a new level of understanding of the scope and impacts of neurological conditions on individuals, families and society overall.
- Neurological conditions have been estimated to affect 3.6 million Canadians living in the community and 170,000 Canadians living in long-term care facilities. Although there are varying effects both within and across conditions, individuals living with neurological conditions share many of the same functional impacts and needs.
- People living with a neurological condition use more health care services than those living with other chronic conditions, resulting in greater costs for individuals and the broader system. Therefore, understanding the issues at a population level can help many Canadians, regardless of condition.



# The National Population Health Study of Neurological Conditions Implementation Committee

#### Celina Rayonne Chavannes

Director, Research Initiatives, NHCC Co-Chair, Implementation Committee

#### Sulan Dai

Senior Epidemiologist
Public Health Agency of Canada

#### Frances Gardiner

Program Officer Public Health Agency of Canada

#### **Nathalie Gendron**

Assistant Director Institute of Neurosciences Mental Health and Addiction CIHR

### Joyce Gordon

President and CEO Parkinson Society Canada Chair, NHCC

## Deanna Groetzinger

Former Vice-President
Government Relations and Policy
MS Society of Canada

## Deanna Huggett

Senior Policy Analyst Health Canada

#### Susan Latter

Stakeholder Representative NPHSNC

#### Suzanne Nurse

Volunteer Canadian Epilepsy Alliance

## Jay Onysko

Manager, Public Health Agency of Canada Co-Chair, Implementation Committee

#### Nalini Sen

Director, Research Program Alzheimer Society of Canada

### **David Taylor**

Director of Research ALS Canada

## Stacey Thompson

Secretariat, NHCC



4211 Yonge Street, Suite 316 Toronto, ON M2P 2A9 www.MyBrainMatters.ca

# What you can do:

Join us in our mission to improve the quality of life for people living with neurological conditions, their caregivers and families.

Visit www.MyBrainMatters.ca to learn more.

### Join our Community!



Like My Brain Matters on Facebook



Follow us on Twitter @MyBrainMatters

NHCC Member Organizations: 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 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 Society of Ontario • Spina Bifida & Hydrocephalus Association of Ontario • Tourette Syndrome Foundation of Canada