



Brain Matters



Inaugural Progress Meeting – National Population Health Study of Neurological Conditions



Front: Dr. Tanya Packer (Dalhousie University), Dr. Kerstin Roger (Dalhousie University), Dr. Neil Drummond (University of Calgary), Anita Lambert-Lanning (College of Family Physicians of Canada).

Back: Pat McCrea (Blue Thorn Research & Analysis Group), Dr. Joan Versnel (Dalhousie University), Dr. Richard Birtwhistle (Queen's University), Kim Reimer (BC Ministry of Healthy Living).

On March 1-2, 2011 the inaugural progress meeting of the National Population Health Study of Neurological Conditions (NPHSNC) was held in Toronto, Ontario, Canada. With over 140 researchers, stakeholders, government officials, and NHCC members present, participants received a detailed introduction to the work currently underway across Canada.

The NPHSNC is a suite of 18 projects investigating the incidence and prevalence, impact, risk and health service utilization of 15 identified neurological conditions. Together, the components of the Study will result in a clear understanding of the neurological landscape in Canada.

The Study is divided into four sections – 1) National Surveys; 2) Pan Canadian Research Projects; 3) Economic Costing & Micro-simulation; and 4) Synthesis.

Continued on next page

Members:

- ALS Society of Canada
- ALS Society of Ontario
- 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
- Canadian Stroke Network
- Centre for ADHD Awareness Canada
- Dystonia Medical Research Foundation of Canada
- Heart and Stroke Foundation of Canada
- Headache Network Canada
- Huntington Society of Canada
- March of Dimes Canada
- Mood Disorders Society of Canada
- Multiple Sclerosis Society of Canada
- Muscular Dystrophy Canada
- NeuroScience 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

Contact Us

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NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

1. National Surveys:

The three surveys being implemented as part of the Study are:

- The addition of a neurological module to the Canadian Community Health Survey (CCHS) 2010-2011
- The Survey on Living with Neurological Conditions in Canada (SLNCC)
- The Survey of Neurological Conditions in Institutions in Canada

2. Pan Canadian Research Projects:

Collectively, the following projects will enhance our knowledge in the four fields of study – impact, risk factors, health services, and incidence/prevalence. Project titles and principal investigators are:

The Everyday Experience of Living with and Managing a Neurological Condition (The LINC Study)

- *Principal Investigators:* **Dr. Tanya Packer**, Dalhousie University, and **Dr. Joan Versnel**, Dalhousie University

Innovations in Data, Evidence and Applications for Persons with Neurological Conditions (ideas PNC)

- *Principal Investigators:* **Dr. John P. Hirdes**, University of Waterloo and Homewood Research Institute; **Dr. Nathalie Jetté**, University of Calgary; and **Dr. Colleen J. Maxwell**, University of Calgary

Canadian Longitudinal Study of Aging: Neurological Conditions Initiative (CLSA-NCI)

- *Principal Investigators:* **Dr. Christina Wolfson**, McGill University; **Dr. Parminder Raina**, McMaster University; and **Dr. Ron Postuma**, McGill University

Neurological Conditions in British Columbia

- *Principal Investigators:* **Kim Reimer**, Population Health Surveillance and Epidemiology, Population and Public Health, B.C. Ministry of Health; and **Dr. Robert Fisk**, Population Health Surveillance and Epidemiology, Population and Public Health, B.C. Ministry of Health

Systematic Review of Factors Influencing the Onset and Progression of Neurological Conditions

- *Principal Investigators:* **Dr. Daniel Krewski**, University of Ottawa; **Dr. Caroline Barakat-Haddad**, University of Toronto Scarborough; **Dr. Tamara Pringsheim**, University of Calgary; **Dr. Helen Tremlett**, University of British Columbia; **Dr. Don MacDonald**, Newfoundland and Labrador Centre for Health Information

Validation of Administrative Data Algorithms to Determine Population Prevalence and Incidence of Alzheimer's Disease, Dementia, Multiple Sclerosis, Epilepsy, and Parkinson's Disease

- *Principal Investigators:* **Dr. Karen Tu**, ICES/University of Toronto; **Dr. Liisa Jaakkimainen**, ICES/University of Toronto; and **Dr. Debra Butt**, ICES/University of Toronto

Canadian Primary Care Sentinel Surveillance Network: CPCSSN Neurodegenerative Conditions

- *Principal Investigators:* **Dr. Richard Birtwhistle**, Queen's University; **Dr. Neil Drummond**, University of Calgary; **Ms. Anita Lambert Lanning**, CPCSSN Manager; and **Ms. Inese Grava Gubins**, CFPC Director of Research

Understanding from Within: Developing community-driven and culturally relevant models for understanding and responses to dementia among Aboriginal peoples

- *Principal Investigators:* **Ms. Billie Allan**, Native Women's Association of Canada; and **Dr. Carrie Bourassa**, First Nations University

Understanding the Epidemiology of Neurological Conditions and Building the Methodological Foundation for Surveillance

- *Principal Investigators:* **Dr. Nathalie Jetté**, University of Calgary; and **Dr. Tamara Pringsheim**, University of Calgary

3. Economic Costing & Micro-simulation

The development of a micro-simulation model will be utilized to determine the present day burden of neurological conditions in Canada, and to project costs and impact over the next 5, 10, 15 and 20 years. This element of the Study will be undertaken utilizing the Statistics Canada Population Health Model (POHEM).

4. Synthesis

The Implementation Committee has initiated the development of a synthesis conference to take place in 2013. This event will ensure that the findings of the Study are presented in a manner that is meaningful to all Canadians.

For additional information about the NPHSNC and all of its components, visit www.mybrainmatters.ca/en/projects

Canada's Brain Community comes together to launch First-Ever National Brain Awareness Month

The launch of Canada's first-ever **Brain Awareness Month** was a meeting of the minds as 300 members of the Canadian brain community came together for BrainWave 2011 in Toronto on March 1st.

This dinner and awards banquet was hosted by the NHCC and brought together people with brain conditions, caregivers, researchers, clinicians, health charities and policy makers from across Canada to shine the spotlight on issues facing 11 million Canadians living with brain conditions.

"Our goal is to create a platform for dialogue about brain health, and the issues facing so many Canadians and their families."

"We hope individuals and organizations across Canada will leverage National Brain Awareness Month to increase public awareness and education, and to generate important discussions."

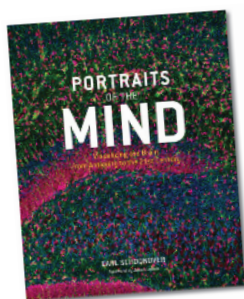
– Joyce Gordon, CEO of Parkinson Society Canada and Chair of the NHCC coalition.



Front: Michelle McLean (Mental Health Commission of Canada), Phil Upshall (Mental Health Commission of Canada), Louise Bradley (Mental Health Commission of Canada), Deanna Groetzinger (MS Society of Canada).

Back: Bill Flannagan (Statistics Canada), Bev Heim-Myers (Huntington Society of Canada), Christina Vardanis (The Globe and Mail), Guy Nicholson (The Globe and Mail).

Canadian comedian Rick Green emceed the evening and introduced keynote speakers including The Honourable Deb Matthews, Ontario Minister of Health and Long-Term Care, and Carl Schoonover, author of the book, *Portraits of the Mind: Visualizing the Brain from Antiquity to the 21st Century*.



The NHCC also presented its inaugural *Change-Maker Awards* to Baycrest, Holland Bloorview Kids Rehabilitation Hospital, and The Globe and Mail for demonstrating outstanding leadership in inclusion, innovation and integration for the benefit of Canadians living with brain conditions.

To view the photo gallery, visit www.brainmatters.ca/en/brainwave-2011



Front: Janie Toth (PrioNet Canada), Neil Cashman (PrioNet Canada), Helen Tremblett (University of British Columbia) and Caroline Barakat-Haddad (University of Toronto Scarborough).

Back: Daniel Bedard (University of Ottawa), Michael Shapiro (PrioNet Canada), Daniel Krewski (University of Ottawa, PrioNet Canada), and Paul Gomez (University of Ottawa).

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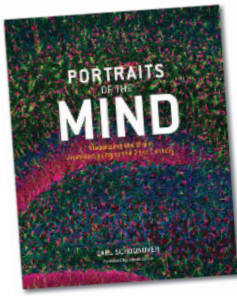
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