

Improving Quality of Life for Canadians living with a Brain Condition

August 2011



NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

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Brains Matter

[Français](#)

Working together to improve the lives of people living with chronic neurological diseases, disorders & injuries in Canada

Brain News

Research News

Public Policy News

Events

Traumatic brain injury increases risk of Parkinson's disease, UCLA researchers say

Some worry girls' concussions are being ignored
Much of the concern about young athletes and concussions centres around the obvious heavy-hitters: football,

Neuroanatomy—A Primer

Neural Network Mimics Schizophrenia-like Dopamine Release in the Brain

UPCOMING EVENTS

[The 8th Annual Brain Injury Association of Canada Conference](#)

Brain Injury Association of Canada
University of Prince Edward Island
Charlottetown, Prince Edward Island

[Canada's national conference on acquired brain injury...](#)

[Read More >](#)

[18th Annual Conference of the](#)

MEMBER ORGANIZATIONS

CABTO  ACOTC


Spirit, Breakthrough & Hope
Societe Brulure et Hydrocephalus
Association of Ontario

JOIN NOW!

Join the Canadian Brain Community
Register Today to Stay Connected

Are you a:

- Person Living with a Neurological Condition
- Caregiver or Family Member
- Researcher
- Healthcare Professional
- Service Provider / Allied Health Professional
- NGO Staff or Volunteer

Name:

Email:

Postal Code:

Province:

Country:

* denotes a required field.

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Summaries

NPHSNC Presentat...

Project Summaries ...

Project 13 Summar...

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Study Matrix (Rea...

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What is the NHCC?

- Coalition of neurological charities (research & service organizations) working together to improve the lives of people living with brain conditions.
- Established 2008
- 26 member organizations
- Driving policy change at all levels of government



Growing Membership

ALS Society of Canada
ALS Society of Ontario
Alzheimer Society Canada
Alzheimer Society of Ontario
Brain Injury Association of Canada
Canadian Alliance of Brain Tumor
Organizations
Canadian Epilepsy Alliance
Canadian Neurological Sciences Federation
Canadian Stroke Network
Centre for ADD Awareness Canada
Dystonia Medical Research Foundation Canada
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
NeuroScience Canada
Ontario Federation for Cerebral Palsy
Ontario Neurotrauma Foundation
Ontario Rett Syndrome Association
Parkinson Society Canada
Parkinson Societies of Ontario
Spina Bifida & Hydrocephalus Association
of Ontario
Tourette Syndrome Foundation of Canada



NHCC 2020 Vision

1. National Brain Strategy supported by findings of a national population-based study
2. Increased research dollars for brain & related disorders
3. Investments to enhance education & awareness
4. Integrated strategies to help people live well
5. Better quality of life for people living with brain conditions – including universal access to more appropriate care and supports



NHCC Objectives

1. Build community
2. Position brain conditions as priority health, social & economic issues for all levels of government
3. Focus on commonalities
4. Generate better data to inform better policy



How did we get started?

- 2008 - coalition of neurological charities came together to improve the lives of people living with brain conditions.
- Began with 9 members, grown to 26 today
- June 2008 - Approached Government of Canada to address the paucity of data about neurological conditions in Canada
- October 2008 – platform commitment for \$15M to fund Canada's first-ever NPHSNC





National Population Health Study of Neurological Conditions (NPHSNC)

NPHSNC

- 4-year study co-led by NHCC & the Public Health Agency of Canada
- Research teams across Canada building a better understanding of neurological conditions in Canada:
 - Incidence, prevalence and co-morbidities
 - Impact on individuals & families
 - Risk factors for onset & prognostic factors
 - Best practice health & support services



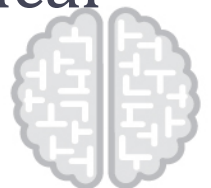
NPHSNC Early Groundwork

- June 2008: members of NHCC met with representatives of the Government of Canada to discuss the lack of information about neurological conditions in Canada.
- October 2008: Conservative Party made campaign commitment of \$15M to fund a 4-year study
- NHCC began working with the Public Health Agency of Canada, the Canadian Institutes of Health Research (CIHR) and Health Canada to plan the study



NPHSNC Early Groundwork

- Jan - March 2009: on-line stakeholder consultation (over 3,000 responses) and a 2-day technical workshop involving approximately 40 researchers from across Canada
- June 5, 2009: The Honourable Leona Aglukkaq, Minister of Health, formally announced the government's commitment to the 4-year \$15M National Population Health Study on Neurological Conditions (NPHSNC)



“This study will arm us with the knowledge we need to help alleviate some of the burden associated with these conditions (for individuals, families and society overall). It will allow both government and health charities to better develop and plan programs and health services.”

*Leonna Aglukkaq
Minister of Health
June 5, 2009*



NHCC's Role in the Study

- Co-Lead with Public Health Agency of Canada
- Support Scientific Advisory Committee
- Build a 'Canadian Brain Community'
- Share information about the study via:
 - NHCC website
 - e-newsletters to update community
 - media relations
 - annual progress meetings
 - presentations at meetings & conferences
 - dissemination of findings to stakeholders

Community Engagement

- Study rooted in the communities of people living with neurological conditions and neuroscience researchers
- 2009: began by seeking input about priority areas of study from NHCC stakeholders
 - More than 3,000 completed questionnaires
- 2014: will conclude by seeking input from stakeholders about the findings, conclusions and next steps



Governance

- The Honourable Leona Aglukkaq, Minister of Health
- Director General, Chronic Disease, PHAC
- Implementation Committee
 - Co-Chairs, PHAC & NHCC
 - Representation from CIHR, PHAC, HC & NHCC
- Scientific Advisory Committee
- Principle Investigators & Project Managers



Fields of Research

- Incidence, prevalence, co-morbidities of neurological conditions
- Risk factors for the development and for the progression of neurological conditions
- Use of health services, gaps in services, and recommended improvements
- Impact of neurological conditions now and projected over the next 20 years including economic cost



Conditions to be Studied

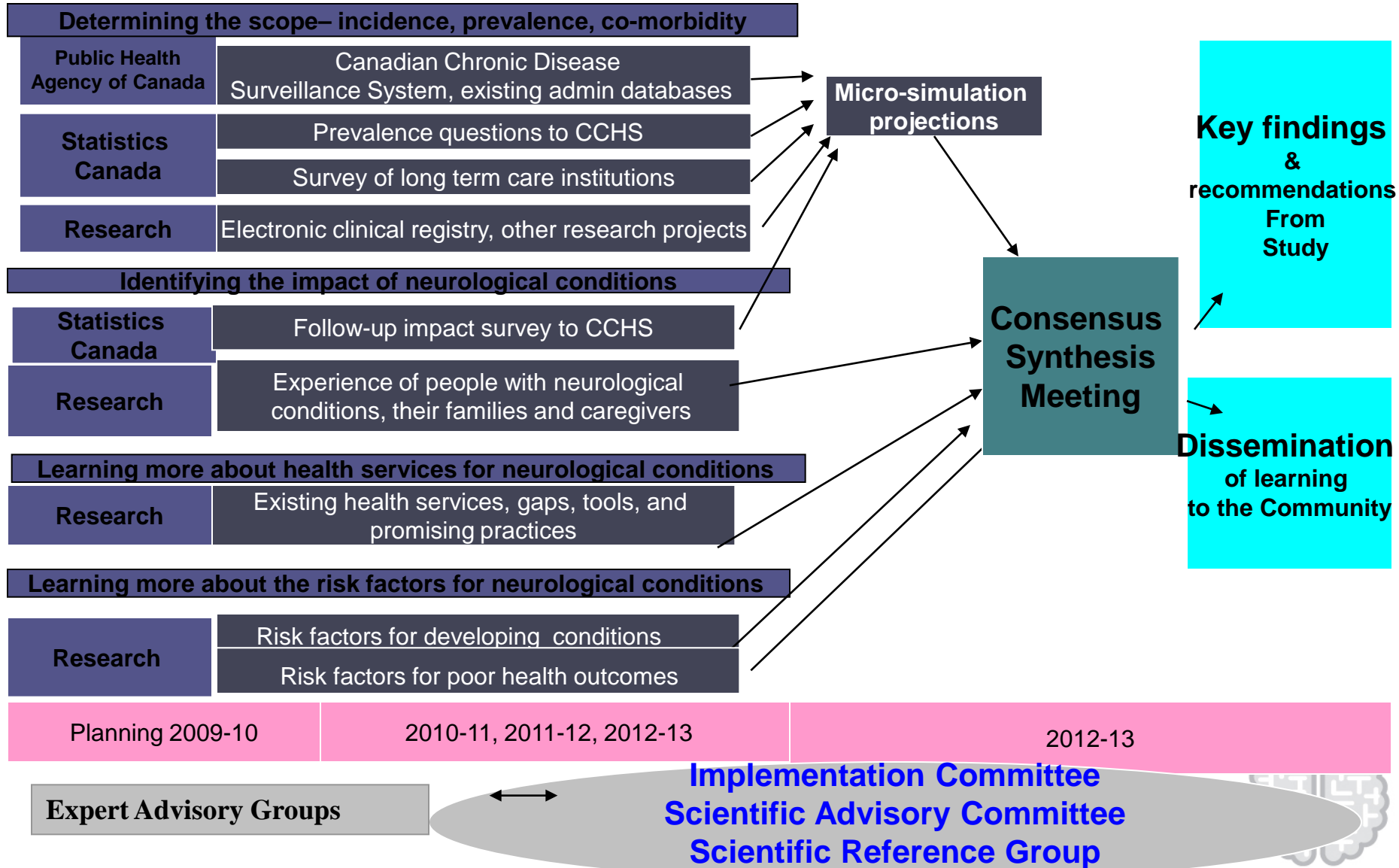
- ALS
- Alzheimer's disease & other dementia
- Brain Injury
- Brain Tumour
- Cerebral palsy
- Dystonia
- Epilepsy
- Huntington's disease
- Hydrocephalus
- Migraine
- Multiple sclerosis
- Muscular dystrophy
- Parkinson's disease
- Spina bifida
- Spinal cord injury
- Spinal cord tumour
- Stroke
- Tourette's syndrome

Components

- 3 National Surveys
- 13 Pan Canadian Research Projects
 - 10 Pan-Canadian research projects underway
 - 3 projects awaiting approval
- Micro-Simulation project
- Consensus Development & knowledge Synthesis



National Population Health Study on Neurological Conditions



National Surveys

- **Canadian Community Health Survey (CCHS) 2010-2011**
 - In field – April – December 2011
 - Preliminary findings Sept 2012
- **Survey on Living with Neurological Conditions in Canada (SLNCC)**
 - In field – Oct 2011 – March 2012
 - Preliminary findings Dec 2012
- **Survey of Neurological Conditions in Institutions in Canada**
 - In field – October 2011 – Feb 2012
 - Preliminary findings TBD
- **Final Reports: 2013**



Pan-Canadian Projects



The Everyday Experience of Living With and Managing a Neurological Condition

-The LINC Study –

Dr. Tanya Packer, Dalhousie University

Dr. Joan Versnel, Dalhousie University

“Although each neurological disorder has its own aetiology, they share symptoms which can impact on participation in everyday activities and the health and well-being of individuals and family members”



LINC Study Summary

- The impact of a neurological condition on the everyday life experiences of Canadians, including parents of children with neurological conditions;
- The complex inter-dependence between children and adults with a neurological condition and their families; and
- The ability of health, social and community services and agencies to support individuals and families to self-manage life with a neurological condition.



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

- **John P. Hirdes, Ph.D. (PI)**

- **Ontario Home Care Research and Knowledge Exchange Chair**
- **University of Waterloo & Homewood Research Institute**

“Any effort to understand populations affected by neurological conditions must take a cross-sectional approach to examining health service utilization, and it must also consider formal and informal sources of support.”



interRAI



ideas PNC

- The ideas PNC project will use clinical and administrative health care data from eight Canadian provinces and territories to explore the prevalence of neurological conditions across the continuum of care.





Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement



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

Christina Wolfson, PhD

McGill University
and
Research Institute –McGill University Health Centre

CLSA

- Location: National data collection + in-depth data collection in Qc (2 sites); NFLD (1 site); NS (1 site); Ont (2 sites), Man (1 site); AB (1 site); BC (3 sites)
- To develop a research program embedded within an ongoing national study of aging to:
 - a. Facilitate the estimation of the prevalence and incidence of the selected neurological conditions;
 - b. Examine putative risk factors for selected conditions using both cross sectional (at baseline) and prospective approaches;
 - c. Assess the impact of the selected conditions on the individual, the family, caregivers and the healthcare system using a combination of direct individual data collection and linkage with administrative databases.



Neurological Conditions in British Columbia:

Phase 1: Feasibility of Identifying and Defining Conditions using ICD Codes

Bob Fisk, Director, Population Health Surveillance and Epidemiology, BC Ministry of Health Services

Kim Reimer, Project Coordinator, Population Health Surveillance and Epidemiology, BC Ministry of Health Services

“Prior to developing policies and targeting programs of care, jurisdictions must have an accurate understanding of the number of people impacted by neurological conditions”

Neurological Conditions in BC

- ***The expected result of the project is:***
 - Accurate estimates of the number of people in BC with selected chronic neurological conditions, the comorbidities they experience, and their health care utilization and cost, as well as projections of future prevalence
 - A body of work that contributes to the ongoing development and refinement of methodologies employing administrative datasets for chronic disease surveillance
 - Enhanced collaboration between clinicians and the BC Ministry in its data steward role
 - New techniques and strategies that can be shared with other jurisdictions



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

Daniel Krewski, PhD MHA

Professor and Director

McLaughlin Centre for Population
Health Risk Assessment



uOttawa

L'Université canadienne
Canada's university



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

- Objectives:
 - to systematically assess and synthesize the world literature on risk factors for the onset and progression of priority neurological conditions, including biological, lifestyle, socioeconomic, environmental, and psychosocial factors, as well as co-morbid conditions and mechanisms of action.



Validation of administrative data algorithms to determine population prevalence and incidence of Alzheimer's disease, dementia, MS, epilepsy and Parkinson's disease

Karen Tu (PI)
Nathalie Jette
Paul O'Connor
Rob Lam

Liisa Jaakimainen (coPI)
Mark Guttman
Noah Ivers

Debra Butt (coPI)
Nathan Herrmann
Mary Tierney

March 1-2 2011- Toronto

Electronic Medical Record Administrative data Linked Database (EMRALD)

Validation of Administrative Data Algorithms to determine population prevalence



- Administrative data holdings for the province of Ontario
- Validate administrative data algorithms for the most common priority neurologic conditions using primary care physician EMR records as a reference standard
- This will then facilitate the assessment of population prevalence of these conditions

The Canadian Primary Care Sentinel Surveillance Network (CPCSSN): neurological conditions project

**Neil Drummond¹
Richard Birtwhistle²
Anita Lambert Lanning³
Inese Grava Gubins³**

**on behalf of the
Canadian Primary Care Sentinel Surveillance Network**

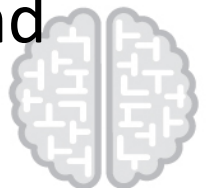
**1 Depts of Family Medicine and Community Health Sciences,
University of Calgary**

2 Dept of Family Medicine, Queen's University

3 College of Family Physicians of Canada

CPCSSN: Neurological Conditions Project

- The Canadian Primary Care Sentinel Surveillance Network (CPCSSN) derives de-identified clinical data from the electronic medical records of participating sentinel family physicians across Canada in order to study the epidemiology of chronic disease, (including prevalence, incidence, health care utilization, and determinants of outcomes) and to report findings in a timely and accessible manner.
- CPCSSN has added dementia, Parkinson's disease and epilepsy to its suite of diseases of interest.



Principal Investigators:

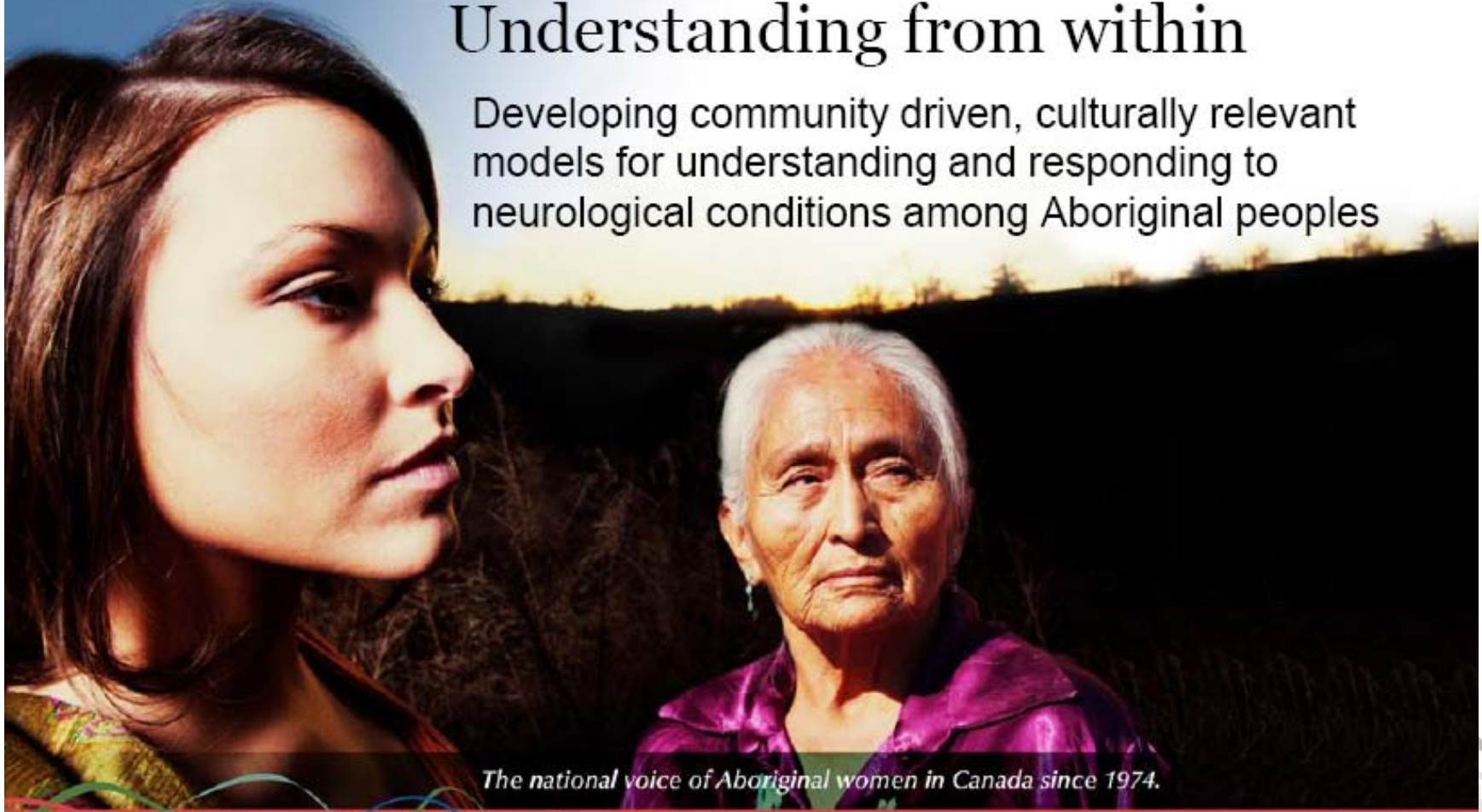
Billie Allan, NWAC (Ontario)

Dr. Carrie Bourassa, FNUC, IPHRC (Saskatchewan)



Understanding from within

Developing community driven, culturally relevant models for understanding and responding to neurological conditions among Aboriginal peoples



The national voice of Aboriginal women in Canada since 1974.



Understanding from Within

- Mixed methods study to improve:
 - Understanding of how Aboriginal peoples conceptualize neurological conditions
 - The impact on their families and communities
 - The needed resources and supports to provide culturally safe and appropriate care.



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

NOMINATED PI: DR NATHALIE JETTÉ

CO-PI: DR TAMARA PRINGSHEIM

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

- While neurological conditions are known to account for a significant proportion of the global burden of disease, estimates of the incidence and prevalence of many of these conditions is unknown.
- National surveillance of neurological conditions aside from stroke is currently lacking in Canada.
- In order to ensure adequate health services are in place for those with neurological conditions, it is critical to have an understanding of:
 - The epidemiology of each condition (Who? Where?)
 - To identify the best ways to carry out surveillance for each condition.



Additional Projects

- **Use and Gaps in Health and Community-Based Services for Neurological Populations: A Systems Analysis**
 - **Principal Investigator**- Susan Jagal, University of Toronto
- **Neurological Registry Best Practice Guidelines and Implementation Toolkit**
 - **Principal Investigator** – Lawrence Korngut, University of Calgary
- **Expansion of a Canadian Multi-Regional Population-Based Cerebral Palsy Registry**
 - **Principal Investigator** – Michael Shevell, NeuroDevNet



Micro-Simulation Project

- Project burden of key neurological conditions over the next 5, 10, 15 and 20 years.
 - incidence
 - prevalence
 - life expectancy
 - health-adjusted life years
 - direct health care costs
 - indirect health care costs



The NPHSNC will deliver more data about neurological conditions in Canada than we've ever had...what will we do with it?



National Brain Strategy

- Submitted framework to Government in January 2010
- Strategic framework for priority-setting & decision-making:
 - Research
 - Prevention
 - Integrated systems of care & support
 - Caregiver Support
 - Income Security
 - Genetic Discrimination
 - Public Awareness & Education



Developing Provincial Working Groups

- Ontario
 - Worked with government to develop a provincial strategy
 - Advocating for implementation of the strategy
- BC
 - Health Charities coming together as a working group – led by MS, Alzheimer's and Parkinson's organizations
- Nova Scotia
 - Just beginning to come together – led by Epilepsy organization



Recent progress: Good News!

- Federal Election, April 2011:
 - Issues related to living with a brain condition included on every national party platform (first time ever)
- Federal Budget, June 2011:
 - \$100M for brain research over 10 years
 - \$2K annual caregiver tax credit introduced



Realizing the NHCC Vision

- ✓ National Population Health Study of Neurological Conditions
- ✓ Increased research dollars for brain & related disorders
- ❑ Investments to enhance education & awareness
- ❑ Integrated strategies to help people live well
- ❑ Better quality of life for people living with brain conditions – including universal access to more appropriate care and supports



Getting Involved

- Visit www.mybrainmatters.ca
 - Register to receive regular updates
- ‘Like’ us on Facebook:
www.facebook.com/MyBrainMatters
- Follow us on Twitter:
[@MyBrainMatters](https://twitter.com/MyBrainMatters)





NHCC

NEUROLOGICAL HEALTH
CHARITIES CANADA

Celina Rayonne Chavannes, MBA
Director, Research Initiative, NHCC

Project Manager, NPHSNC
celina@mybrainmatters.ca

(416) 305-8380

www.mybrainmatters.ca