Thank You Researchers!

The projects of the National Population Health Study of Neurological Conditions are coming to an end. Later this month, we will have a wealth of new and exciting information regarding neurological conditions in Canada. We are now looking forward to taking the information from these studies, synthesizing them into a cohesive report and using all findings improve the quality life for individuals suffering from neurological conditions, their families and caregivers.

This is what some of our researchers had to say about their projects:

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

“We have found that our unique ability to combine primary care electronic medical records and administrative data together provides the most comprehensive picture of the prevalence of common chronic neurological conditions in Canada.”

From left to right: Myra Wang, Debra Butt, William Oud, Karen Tu (PI) and Jacqueline Young

Brain Matters contact:
Stacey Thompson
(416) 227-9700 ext 3476
From left to right: Tarik Bereket, Susan Jaglal (PI) and Mae Kwan

“Our study provided an important platform for numerous service providers to voice their passion and commitment to improve the lives of people living with neurological conditions. We now have an evidence base that pinpoints the various service needs and gaps and recommendations for optimizing services, across the country.”

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

Tanya Packer and Joan Versnel (Co-PIs)

“At the end of the day, what’s coming back and what do patients know? People are trying to make healthy choices for themselves. So when your research is finished, I certainly will read it.”

– Study Participant

Understanding from Within: Developing Community-Driven and Culturally Relevant Models for Understanding and Responding to Neurological Conditions among Aboriginal Peoples

“Chee si weechi tisi ying Chee kin-now-mow ind kin no weeya. This means: "to help ourselves we must teach everybody."”

Carrie Bourassa (PI)

Expansion of a Canadian Multi-Regional Population – Based Cerebral Palsy Registry

Michael Shevell (PI)

Using sophisticated methods of systematic review, our research team was able to digest an enormous volume of scientific literature on what is known about the development of 14 major neurological disorders, such as Alzheimer’s disease and multiple sclerosis, that are of major public health importance in Canada. The knowledge gained through this exhaustive scientific effort will be of great value in planning population health strategies to deal with such conditions in the future.

"Our project allowed us to examine the incidence and prevalence of neurological disorders through a systematic review of literature published worldwide. We found a great deal of variation in how researchers study incidence and prevalence. Neurological disorder prevalence depends on many factors, including the population age, gender, ethnicity, and access to health care. Canadian estimates of incidence and prevalence are available for some but not all of the priority neurological conditions for this project."
Innovations in Data, Evidence and Applications for Persons with Neurological Conditions (ideas PNC)

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

Neurological Registry Best Practice Guidelines and Implementation Toolkit

Left to right: Nathalie Jetté, Lawrence Korn gut (PI) and Tamara Pringsheim.

“This project has been a tremendous opportunity for neurological patient registries across Canada to work together in identifying common themes, obstacles and opportunities. The resulting best practice guidelines and implementation toolkit are a direct result of the Canadian registry building experience and should serve as a useful and practical guide and tool for current and future registries in Canada.”

Thank you to all of our researchers across Canada. Great Job!
Millions of Canadians are living with a brain condition today!

We need to learn more about this experience to better serve individuals and families. That's why the NHCC is collaborating with the Public Health Agency of Canada to lead Canada's first-ever National Population Study of Neurological Conditions.

Research teams across Canada are working to build a better understanding of:

- the incidence & prevalence of brain conditions in Canada
- their impact on individuals & families
- risk factors for onset & progression
- co-existing conditions
- best practice health & support services

Register to receive information and regular updates about the national study at www.mybrainmatters.ca or call the NHCC at (416) 227-9700 x3476.

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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 of 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 Societies in Ontario • Spina Bifida & Hydrocephalus Association of Ontario • Tourette Syndrome Foundation of Canada

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