Welcome
NHCC Fall Members’ Meeting

December 12, 2019
Thank you, Joyce. We wouldn’t be here without you!
In the beginning...

- Joyce brought brain health charities together to influence government & make life better for people affected by brain conditions
  - **January 2008** – charities gathered to share what they knew and, importantly, what they didn’t know about their respective conditions
  - **June 2008** – lobby day in Ottawa to push for research into neurological conditions
  - **October 2008** – promise in Conservative platform for a national study of neurological conditions
  - **2009** – Study is launched with NHCC co-managing it with Public Health Agency of Canada, Health Canada and CIHR
  - **2014** – Mapping Connections released – report of most comprehensive study ever in Canada of brain conditions
Study launch 2009
Mapping Connections launch 2014
Providing leadership - always
Spreading the message
“As a founding member I have been privileged to work with Joyce over the years. Joyce’s steadfast leadership and engagement with not only ourselves but all the members of NHCC stands as a testament to her collaborative sprit and commitment to the vision of NHCC. A lot of the success of NHCC can be attributed to Joyce. On behalf of ONF and all the members, Thank You..”

Kent Bassett-Spiers, Chief Executive Officer Ontario Neurotrauma Foundation.
“I first met Joyce close to 10 years ago and from that first meeting considered her a friend, advisor and confident. Joyce has had an incredible sustainable impact on our sector, on so many levels. Individuals dealing with many neurological conditions will benefit for years to come, because of Joyce’s strategic vision and commitment to making life better for all Canadians. Thank you, Joyce for your support. I look forward to our continued friendship.”

Bev Heim-Myers, Chief Executive Officer - Interim Huntington Society of Canada
“Dear Joyce, You are an exceptional and gifted lady who inspires others with warmth and kindness. I respect you so much for your energy and commitments to others, especially to those who have a disability. Joyce, it was a privilege and honour to work with you on NHCC goals and objectives from almost day one. May you have the best and most fulfilling retirement. Enjoy!”

Gordana Skrba, Executive Director - Interim Ontario Federation for Cerebral Palsy
For all of this and more, thank you, Joyce!
2020 Planning: Determining our direction

NHCC Members’ Meeting
December 12, 2019
Key accomplishments 2019

• Developed succinct input to party platforms & met with all platform teams prior to campaign start
• Two PHAC-NHCC roundtables – second roundtable focussed on Indigenous brain health
• Increased collaboration re neuro-ethics research (2 academic papers)
• For first time Change-Maker award presented to three recipients
Survey results – question 1

• Which of the following NHCC focus areas are policy priorities for your organization in 2020?
  ▫ Advocating to federal government for overall Canadian Action Plan for Brain Health
  ▫ Advocating to federal government for increased funding for brain health research as identified in Mapping Connections study
  ▫ Advocating to federal government for improved financial security for Canadians affected by brain conditions through better support programs and policies
Brain Action Plan advocacy #1 choice

- Brain Action Plan advocacy (4)
- Mapping Connections findings advocacy (3)
- Financial security advocacy (3)
Mapping connections advocacy #2

 Ranked #2

- Brain Action Plan advocacy (5)
- Mapping Connections findings advocacy (4)
- Financial security advocacy (1)
Financial security advocacy #3

Ranked #3

- Brain Action Plan advocacy (1)
- Mapping Connections findings advocacy (3)
- Financial security (6)
Gaps identified in Mapping Connections

- Gaps in the knowledge of the impacts of neurological conditions on affected individuals, their families, caregivers, and communities:
  - Impact of neurological conditions on Canadians living in varying social and economic situations;
  - The impact of neurological conditions on First Nations, Inuit and Metis individuals;
  - The impact of neurological conditions on children affected by a neurological condition, and those living with an affected parent or sibling;
  - Impact on formal caregivers for individuals with severe, debilitating neurological conditions;
  - Canadians who were excluded from surveys such as CCHA ad SLNCC;
  - Canadians with less prevalent conditions (ie: ALS, Huntington’s disease).
Gaps in knowledge of health services use, availability of services

- Inconsistent availability of multidisciplinary care;
- How application of eligibility criteria affect access to services for individuals with a neurological condition;
- Data on health services for Canadians living with a neurological condition were lacking or deficient in:
  - Distribution and quality of health services across various regions and jurisdictions;
  - Costs of providing care for individuals with a neurological condition in continuing care and acute care;
  - Personal cost of medications for individuals with each neurological condition;
  - Perceptions of health care providers on the accessibility, timeliness and quality of health services for individuals with a neurological condition;
  - Provision of health care for First Nations, Inuit and Metis populations, for vulnerable populations, and for children with a neurological condition.
Gaps in knowledge of the scope of neurological conditions - prevalence, incidence, comorbidities -1

- Lack of epidemiologic and administrative data on:
  - Certain neurological conditions in the early stages (e.g., multiple sclerosis and Parkinson’s disease);
  - Less prevalent conditions, (e.g., ALS, dystonia and Huntington’s disease);
  - Neurological conditions typically excluded from participation in national population surveys;
  - Extent of neurological conditions among children (cerebral palsy, epilepsy, multiple sclerosis, brain injury and stroke), and the persistence of these conditions into adulthood.
Gaps in knowledge of the scope of neurological conditions - prevalence, incidence, comorbidities - 2

- Infrastructure gaps included the need for:
  - Standardization of diagnostic codes used in physician billing claims and hospital data in all provinces/territories;
  - Standardization of case definitions and algorithms as well as their periodic review;
  - Ongoing consideration and incorporation of newly available data, e.g., pharmaceutical or costing data;
  - Data capture and reporting of benign brain tumours in existing provincial/territorial cancer registries.
Gaps in knowledge re risk factors for development & progression of neurological conditions

- Clinical or public health relevance of statistically validated risk factors;
- Risk factors for the progression of neurological conditions, with respect to the potential improvement or deterioration of the condition;
- Relative and population-attributable risk of modifiable risk factors for the onset of neurological conditions, (assessment of the potential effectiveness of prevention measures at the individual and population levels).
Additional suggestions from survey

- An issue for persons with epilepsy is living in poverty.
- I suggest exploring policy changes that we would like to see that all NHCC members feel would value their respective communities.
- Pharmacare Program and the funding of drugs specifically related to our disease groups. This rates #1 for our community.
- Investigate how to become affiliated with Kids Brain Health Network, Brain Canada.
Reaction?

Additional thoughts?
Survey results – question 2

• Internally, where should NHCC focus its work?
  ▫ Growing **NHCC membership** to increase influence & reach within government, research & brain health charity communities
  ▫ Being a **leader in advocacy work** for neurological based charitable organizations & for individuals impacted by brain disorders and conditions (as per items listed above)
  ▫ Positioning NHCC as the organization that will **work with government to bridge the gap** for individuals impacted by brain conditions
  ▫ **Being an information hub** for NHCC member organizations & others in the brain health community
Work with government to bridge gaps
#1 choice

Ranked #1

- Bridge gaps (4)  
- Advocacy leader (3)  
- Information hub (2)  
- Grow membership (1)
Leader in advocacy #2

Ranked #2

- Advocacy leader (5)
- Bridge gaps (2)
- Information hub (2)
- Grow membership (1)
Growing membership #3

- Grow membership (5)
- Advocacy leader (2)
- Bridge gaps (2)
- Information hub (1)
Being information hub #4

Ranked #4

- Information hub (5)
- Grow membership (3)
- Bridge gaps (2)
Reaction?

Additional thoughts?
Working group selections

- Working group to assist in developing the NHCC 2020 work plan **(4 volunteers)**
- Working group to assist in membership growth and maintenance **(2 volunteers)**
- Working group to assist with advocacy priorities in 2020 including potential Hill Day **(2 volunteers)**
- Working group to assist with communication across numerous platforms (Facebook, Twitter, Instagram, etc.) **(2 volunteers)**
Next steps
• Visit www.mybrainmatters.ca
  • Register to receive regular updates

• ‘Like’ us on Facebook:
  www.facebook.com/MyBrainMatters

• Follow us on Twitter: @MyBrainMatters