



IMPACT REPORT 2025 - 2026

Data Gaps in Health Decision-Making
→
Our Advocacy Focus:
Federal Renewal of the National Population-level Neurological Health Survey

A COLLECTIVE VOICE FOR NEUROLOGICAL HEALTH IN CANADA

Neurological and neuromuscular conditions affect millions of Canadians, often with complex, lifelong impacts on health, independence, employment, and quality of life. While each condition presents differently, the challenges are shared: gaps in care, limited awareness, fragmented data, and the need for more investment.

Neurological Health Charities Canada (NHCC) brings organizations together to address these challenges collectively. By aligning voices across conditions, NHCC strengthens advocacy, supports evidence-informed decision-making, and helps ensure that neurological health remains a national priority.



Different Types of Neurological Conditions



Canadians Diagnosed with a Brain Condition



Growth in Healthcare Costs by 2031



The Shaw Festival-hosted Defy Dementia™ (developed by Baycrest and the Centre for Aging + Brain Health Innovation (CABHI)) event in 2025. Photo: Will Innes

Nearly 1 million Canadians could be living with dementia by 2030, and it is projected to cost over \$110 billion annually by 2050

“As a pan-Canadian catalyst for aging and brain health innovation, the Centre for Aging + Brain Health Innovation (CABHI, powered by Baycrest) partners with NHCC to advance brain health solutions, strengthen research capacity, and support advocacy and education - improving the lives of Canadians affected by neurological conditions.” - CABHI



“From our first meeting, we felt welcomed and immediately began learning from others. Every meeting helps us track down resources to help with projects Dravet Canada is working on.” -
Dravet Canada

Reflecting on our 2025 Progress, Building Momentum for the Future

- Over 100,000 people reached across all members’ social media accounts.
- 190 unique political candidates across Canada reached through personalized letters.
- 7 government relations (GR) meetings with 8 federal departments/agencies/institutions.
- 13 internal meetings to advance our strategic priority.
- 6 member engagement & networking opportunities.
- 4 member education & speakers series:
 - MAID session with *Dying with Dignity Canada*
 - Patient registries with *Clinical Trials Ontario*
 - Risk management with *Management Advisory Services*
 - Session on accreditation with *Imagine Canada*

For many organizations, particularly those representing rare or lesser-known conditions, national advocacy is difficult to sustain alone. NHCC provides the scale, coordination, and shared expertise needed to move issues forward.



Laura Dickson, NHCC’s Director of Operations and Strategic Affairs at the #1 Voice Summit

SANTIS Proudly Canadian

Advocating for Brain Health During The Federal Election: Neurological Health Charities Canada

Strategic advocacy work toward a National Health Survey with Santis Health (a professional government relations firm)



NHCC participated in the Brain Economy Summit (Calgary), held prior to the 2025 G7 in Kananaskis

Collaboration Turns Shared Priorities into Action



NHCC advocacy efforts in 2008 led to the Government of Canada investing \$15 million in a series of snapshot studies on neurological health, resulting in the ground-breaking **Mapping Connections** report in 2014.

PARTNERSHIPS IN ACTION

NHCC connects organizations to empower collaboration leading to tangible outcomes in research, advocacy, and community support.

- Huntington Society of Canada and DMRF Canada launched a joint movement disorder clinical fellowship (2026)
- Hydrocephalus Canada and DMRF Canada collaborated on community programs from webinars to fundraiser walks.
- March of Dimes Canada and Brain Injury Canada partnered on accessibility initiatives.



989,000+ people living in Canada are living with the effects of stroke

“Our collective impact is far greater than what any one organization could achieve on its own.”
— **March of Dimes Canada**

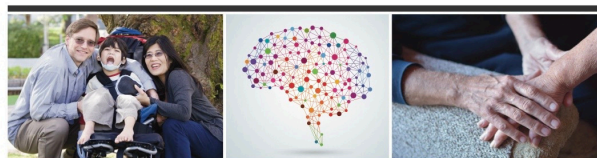


DMRF Canada & Hydrocephalus Canada at their Joint Walk in Toronto

“As small organizations, we don’t have the capacity to lead national advocacy alone. NHCC gives us the platform and partnerships to make our voice heard.” — **Dystonia Medical Research Foundation (DMRF) Canada and Hydrocephalus Canada**

MAPPING CONNECTIONS

AN UNDERSTANDING OF NEUROLOGICAL CONDITIONS IN CANADA



PROTECTING CANADIANS FROM ILLNESS



1 in 7,000 Canadians have Huntington disease (HD), and each child born to a parent with HD has a **50/50** chance of inheriting the disease

“HSC values its membership in NHCC. Through shared advocacy, research, and knowledge exchange, these partnerships strengthen support and care for Canadians — because we are stronger together.”
- **Huntington Society of Canada (HSC)**

Dystonia affects an estimated 50,000 Canadians, with nearly half experiencing moderate to severe disability despite treatment

Approx. 1 out of 1,000 babies in Canada develops hydrocephalus each year

Strengthening the National Conversation on Neurological Health



NHCC's strong relationship with the brain research community advances data, aligns advocacy, and ensures all neurological conditions are represented in national discussions.



"It's amazing to be part of a coalition that wants ALL members to be successful for the good of their communities."
 - GBS/CIDP Foundation of Canada



400,000 Canadians live with epilepsy
 (approximately 1 in 100 people)

"Through NHCC, we're part of a collective voice ensuring Canadians affected by neurological conditions are better prioritized. We've seen this work through the Canadian Epilepsy Alliance's 26-member coalition."
 - Epilepsy Alliance

BEING PART OF A STRONGER COLLECTIVE VOICE

Every member helps shape the future of neurological care, research, and advocacy in Canada.

For more information, see **Membership Criteria** at www.mybrainmatters.ca
 For information on how to become a member, contact: info@mybrainmatters.ca

NHCC Member Organizations

