

**Written Submission for the Pre-Budget
Consultations in Advance of the Upcoming
Federal Budget**

**By: Brain Tumour Foundation of Canada
February 10, 2023**

Brain Tumour Foundation of Canada Recommendations

- **Recommendation 1:** As part of the federal government's discussions with provincial and territorial governments on increased federal funding for healthcare, implement the National Neurological Strategy for Canada.
- **Recommendation 2:** Implement National Universal Pharmacare and a basic National Formulary that includes essential Take Home Cancer Drugs.
- **Recommendation 3:** Create a dedicated, federal unit to monitor, detect, and address pharmaceutical drug shortages.
- **Recommendation 4:** Increase federal funding for brain tumour research, building on the findings of the Brain Tumour Registry and recent advances in clinical research.
- **Recommendation 5:** Provide sustained funding for charities and non-profit organizations, including health charities serving Canadians affected by brain tumours, recognizing their vital role in providing crucial programs and supports that fill gaps in health care services for brain tumour patients and their families.

As Canada's only national brain tumour organization, Brain Tumour Foundation of Canada is well positioned to speak on behalf of Canadians affected by brain tumours from coast to coast to coast. For more than 41 years, we have been a cornerstone of support for patients and families across the country who have been affected by a brain tumour diagnosis. Our vision is to find the cause of and a cure for brain tumours while improving the quality of life for the estimated 55,000 Canadians currently affected by this devastating disease. Our mission is to provide support through information gathering and sharing, education, and funding brain tumour research.

Brain tumours affect Canadians of all genders, ages, and walks of life. They are the leading cause of cancer-related death in children, and the third leading cause of solid cancer deaths in young adults. The survival rate for the most common type of brain tumour, glioblastoma multiforme (GBM) is less than one year. With over 120 different types of brain tumours, treatment can be extremely complex, and many patients and families require a range of medical and psychological supports.

The impact of a brain tumour diagnosis is devastating and extensive. Access to primary treatments remains inequitable across Canada and requires urgent attention to improve the standard of care and health outcomes for the brain tumour community.

Recommendation 1: As part of the federal government's discussions with provincial and territorial governments on increased federal funding for healthcare, implement the National Neurological Strategy for Canada.

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represents millions of Canadians living with neurological diseases, disorders, and injuries. Brain Tumour Foundation of Canada fully supports NHCC's proposed development of a National Neurological Strategy for Canada¹ to address the patchwork approach to neurological health that has a profoundly negative impact on quality of life for the millions of Canadians living with neurological conditions. This holistic approach recognizes the importance of research, sound health policies, and effective health care delivery within an overall ethical framework. Brain Tumour Foundation of Canada looks to NHCC as a leader of this unprecedented collaborative approach that would drive knowledge to action and result in improved quality of life for Canadians affected by neurological conditions.

The Government of Canada has recognized that strategies are important to managing and treating a variety of neurological health conditions, including the National Mental Health Strategy (launched 2012), the National Dementia Strategy (launched 2019), and the National Autism Strategy (launched 2020). In addition, the Canadian Brain Research Strategy received funding in 2020 for development work. Building on this important work and the findings in the seminal report Mapping Connections: An

¹ National Neurological Strategy for Canada, [FrameworkNeuroStratFinal-2022-EN.pdf](#) (mybrainmatters.ca)

understanding of neurological conditions in Canada², NHCC proposes the creation of a National Neurological Strategy for Canada to allow all Canadians to maximize brain health while ensuring adequate care for those affected by neurological conditions, including brain tumours.

The COVID-19 pandemic vividly exposed shortcomings in the health care system, especially regarding access to home care and palliative care. The brain tumour community experienced many adverse impacts as a result, including cancelled or postponed appointments, delays in time-sensitive and critical treatments, and the shutdown of access to rehabilitation and other support services that are critical for survival and quality of life. Many of these shortcomings and delays remain an issue for Canada's health care system and for the brain tumour community.

The latest data from the Brain Tumour Registry of Canada shows individuals with brain tumours are surviving longer³, yet most provinces and territories do not have the necessary services to support those with brain tumours in their respective communities, including rehabilitation services, vocational services, recreation therapy, etc. This data from the registry provides long-awaited insight into brain tumours, and would help inform decision-making on new drug submissions, provincial programs, and federal health strategies.

For a disease where there is no cure, ensuring good quality of life and preserving dignity at the end of life are of paramount importance. It is crucial that the federal government continue to work with the provincial and territorial governments to make home care and palliative care a priority and improve access for brain tumour patients across the country.

Recommendation 2: Implement National Universal Pharmacare and a basic national formulary that includes essential Take Home Cancer Drugs.

Brain Tumour Foundation of Canada welcomed the announcement of funding for a Canadian Drug Agency and the formation of a national formulary and subsequent Pharmacare program.

Canada is the only developed nation outside of the U.S. that does not provide seamless, universal access to treatment for the most common and deadly type of brain tumour, GBM. The current patchwork system of provincial, territorial, and federal programs means some patients must arrange for funding on their own, leading to critical delays in treatment.

The most effective treatment for GBM includes the use of temozolomide, an oral

² Mapping Connections: An understanding of neurological illnesses in Canada, <https://www.canada.ca/en/public-health/services/reports-publications/mapping-connections-understanding-neurological-conditions.html>

³ Brain Tumour Registry of Canada Survival Report, www.braintumourregistry.ca

chemotherapy medicine, which is considered standard first-line care for GBM around the world. In Canada, access to temozolomide is highly variable across the country. Some patients face delays in accessing the drug while others do not. This variability has caused roadblocks and undue hardship for Canadians accessing this crucial treatment. Brain Tumour Foundation of Canada has created a ‘temozolomide map’ to show how access timelines vary across the country because of this inconsistent approach.⁴

It is critical that the federal government continue to move forward with a National Universal Pharmacare program and implement a National Formulary that includes and enhances the delivery of essential Take Home Cancer Drugs⁵ (THCDs) like temozolomide to reduce the risk of treatment delay brain tumour patients.

Recommendation 3: Create a dedicated, federal unit to monitor, detect, and address pharmaceutical drug shortages.

Brain Tumour Foundation of Canada is aware of and concerned about the increasing frequency of pharmaceutical drug supply shortages across Canada. Many common generic medicines are used for the treatment of brain tumours, and to manage and prevent debilitating symptoms. A reliable supply of these drug products is critical to the safety and well-being of those living with brain tumours in Canada. A disruption in supply, without warning, can place many people living with brain tumours at significant risk. Of particular concern was the anticipated shortage of dexamethasone, a common steroid, during the COVID-19 pandemic.

Studies have shown that medication shortages overall have significant clinical, economic, and humanistic impacts on patients⁶, including increased mortality rates, adverse drug reactions, drug administration errors, hospitalizations, drug-resistant mutations, seizure frequency, and medication rationing.

Brain Tumour Foundation of Canada supports the steps being taken by the federal government to require manufacturers to report anticipated or actual drug shortages, and the ongoing work with stakeholders to improve supply chain management. Moving forward, Brain Tumour Foundation of Canada urges the federal government to incorporate an “essential medicines list” into drug shortage reporting systems and expand the scope of Health Canada to measure and project priority drug shortages.

Recommendation 4: Increase federal funding for brain tumour research.

Federal funding for research is the foundation for all progress against life altering diseases like brain tumours. Research also fuels an academic culture that attracts and retains the best and brightest healthcare professionals, which elevates the care of

⁴ Regional Variations in How Temozolomide is Accessed in Canada Map, <https://www.braintumour.ca/advocating-for-equal-access-to-care/>

⁵ 2023 Ontario Budget Submission: Equal Access to Take Home Cancer Drugs, [CanCertainty Coalition Ontario Budget Proposal 2023 \(FULL\).pdf \(nationbuilder.com\)](#)

⁶ The impact of medication shortages on patient outcomes: A scoping review. PLoS One. 2019; 14(5): e0215837

Canadians. Research provides a rich training ground for the next generation of scientists and healthcare professionals, fostering interest and knowledge in dedicated areas that will continue to support evolution of our toughest problems.

As part of a National Neurological Strategy, Brain Tumour Foundation of Canada calls upon the federal government to implement dedicated funding into brain tumour research. We request that this funding be additional to the currently overextended Canadian Institute of Health Research budget and be earmarked for peer review and distribution by organizations dedicated to supporting brain tumour research.

In May 2019, the Brain Tumour Registry of Canada⁷ was launched with the goal of collecting data on every diagnosed malignant and non-malignant brain tumour in the country. Previously, we struggled to understand the true numbers of those affected by brain tumours in Canada and how to plan for their care needs. We relied on data from U.S. databases to inform policy and research. Brain Tumour Foundation of Canada is pleased to have been a driving force behind the creation of the Brain Tumour Registry, with support from the Honourable Bill Casey, former MP and Chair, Standing Committee on Health. As a result of this effort, we now have a significantly better understanding of the magnitude and complexity of issues that affect brain tumour patients and survivors, but there is so much more to be done. With the support of the federal government, this current data can lay a foundation for future brain tumour research in Canada.

Recommendation 5: That the federal government provide sustained funding for charities and non-profit organizations, including health charities serving Canadians affected by brain tumours, recognizing their vital role in providing crucial programs and supports that fill gaps in health care services.

Since March 2020, programs and services offered by Brain Tumour Foundation of Canada and other nonprofit and charitable organizations supporting the community have been significantly reduced or cancelled altogether. The COVID-19 pandemic further exacerbated challenging situations faced by the brain tumour community. This has created a sense of urgency for our organization to make the following recommendations to ensure that brain tumour patients, their families, and those who care for them have the support they need now and in the future.

Brain Tumour Foundation of Canada fully supports Imagine Canada's request for stable core funding for the non-profit and charitable sector. Many nonprofits are reliant on project-based funding to cover essential operating costs, which negatively impacts the quality of services they can offer their community, the employment conditions of nonprofit workers, and the long-term sustainability of their organizations.

Brain Tumour Foundation of Canada calls on the federal government to recognize the vital role that charities and nonprofit organizations have in our health care system by reclassifying all project-based funding for charities and nonprofits to be eligible as core

⁷ Brain Tumour Registry of Canada website, www.braintumourregistry.ca

funding, improving project-based funding as recommended in the 2019 Catalyst for Change Senate Report⁸, and prioritizing an equity-based approach to the provision of core funding to address historical inequalities⁹.

In Conclusion

Each day, 27 Canadians hear the words, “You have a brain tumour”.¹⁰ Brain Tumour Foundation of Canada is committed to bringing hope to the brain tumour community through information, support, education, and research. Although we have made significant impacts, a broader, strategic federal initiative is needed more than ever to improve the health outcomes and survival of brain tumour patients and thousands of other Canadians living with a neurological disease.

We welcome the opportunity to have our recommendations considered as we continue to work towards a hopeful future for brain tumour patients and families.

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⁸ Catalyst for Change: A Roadmap to a Stronger Charitable Sector, [CSSB Report Final e.pdf \(sencanada.ca\)](#)

⁹ Imagine Canada’s Written Submission for the Pre-Budget Consultations in Advance of Federal Budget 2023, [Final Imagine Canada Pre-budget Brief - Budget 2023 \(September 2022\)](#)

¹⁰ Brain Tumour Registry of Canada Fact Sheet, www.braintumourregistry.ca