

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

**By: Brain Tumour Foundation of Canada
February 1, 2024**

Brain Tumour Foundation of Canada Recommendations

- **Recommendation 1:** In partnership with the provincial and territorial governments, implement a National Pharmacare program by the end of 2024 with a national formulary that includes standard take at home cancer treatments (THCDs).
- **Recommendation 2:** Create a dedicated federal unit to monitor, detect, and address pharmaceutical drug shortages.
- **Recommendation 3:** Support the development and funding of programs and standards for housing for people with neurological conditions as a first step in the implementation of the National Neurological Strategy recommended by Neurological Health Charities Canada (NHCC).
- **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 core 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 40 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. There are more than 120 types of brain tumours, both malignant and non-malignant. Malignant tumours are the leading cause of cancer-related death in children, and the third leading cause of solid cancer deaths in young adults. Those affected by non-malignant tumours usually live with a host of chronic symptoms that can include seizures, memory loss, mobility issues, etc. Although treatment options remain limited, data has recently shown that people with brain tumours are living longer. To date, there has been no specific federal strategy to address the needs of those living with brain tumours and other neurological conditions, and significant gaps in care remain.

Recommendation 1: Implement National Universal Pharmacare and a basic national formulary that includes standard cancer treatments taken at home.

Canada is the only developed nation outside of the U.S. that does not provide seamless, universal access to the drug treatments for brain tumours that are taken outside of hospitals. This includes the standard treatment for the most common and deadly type of brain tumour, glioblastoma multiforme (GBM). The current patchwork system of provincial, territorial, and federal public drug programs leaves many patients on their own to secure coverage of a critical, time sensitive treatment. Inevitably, this poses a risk to delays in treatment. Brain Tumour Foundation of Canada has created a 'temozolomide map' to show how treatment access varies across the country.¹

It is critical that the federal government implement a National Pharmacare program this year, and that a national formulary include standard ("1st line") cancer treatment drugs that taken at home. The Brain Tumour Foundation of Canada stands with the Cancertainty² coalition and many other patient organizations in stating that it is time for cancer treatment to be consistently available across Canada. Brain tumour treatment cannot wait.

Recommendation 2: 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. This includes the recently announced discontinuation of lomustine, which is used to treat brain cancers

¹ Regional Variations in How Temozolomide is Accessed in Canada Map, <https://www.braintumour.ca/advocating-for-equal-access-to-care/>

² <https://www.cancertaintyforall.ca/>

after initial options fail. It was clear when this discontinuation was announced that Canada lacks a framework for accountability in the management of shortages and discontinuations.

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. There are so few drug treatment options for brain tumours, and a sudden disruption in supply puts many people at significant risk.

Brain Tumour Foundation of Canada supports the steps taken by the federal government to create a mandatory reporting system for anticipated shortages and appoint a drug shortages committee to review specific shortage concerns. We urge the government to take a step further and fund a permanent Drug Supply Unit within the Canada Drug Agency with a clear mandate, responsibilities, and powers to address drug shortages and discontinuations.

Recommendation 3: Support the development of standards and funding for housing for those living with neurological conditions, as a first step in the implementation of a National Neurological Strategy.

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 Canada³ to address the patchwork approach to neurological health that has a profoundly negative impact on the quality of life of millions living with neurological conditions.

The Brain Tumour Foundation of Canada supports the recommendation of the NHCC to focus on standards for housing as a necessary and logical first step in the adoption of a National Neurological Strategy⁴. Those living with brain tumours need better access to housing options that provide a basic level of safety, and to levels of supportive housing that address their progressing neurological symptoms. No one living with a brain tumour should have to live in a tent or a shelter or decide between living in an unsafe home or moving to a nursing facility. Brain tumours have no cure, and those with a brain tumour are living longer. A strategy is urgently needed to ensure that the safety and quality of life of those living with brain tumours can be maintained throughout their life span.

Recommendation 4: Increase federal funding for brain tumour research.

As part of a National Neurological Strategy, Brain Tumour Foundation of Canada calls upon the federal government to implement dedicated funding into brain tumour

³ National Neurological Strategy for Canada. <https://mybrainmatters.ca/wp-content/uploads/FrameworkNeuroStratFinal-2022-EN.pdf>

⁴ <https://mybrainmatters.ca/wp-content/uploads/NHCC-PrebudgetBrief2024-Final.pdf>

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 Canada was launched with the goal of collecting data on every diagnosed malignant and non-malignant brain tumour in the country. The first surveillance report was issued in 2022, providing data on the incidence and prevalence of brain tumours in Canada⁵. Brain Tumour Foundation of Canada is pleased to have been a driving force behind the creation of the 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: Provide sustained core funding for charities and non-profit organizations, including health charities serving Canadians affected by brain tumours.

Brain Tumour Foundation of Canada fully supports Imagine Canada's priority for stable core funding for the non-profit and charitable sector⁶. Many nonprofits are reliant on project-based funding and donations 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.

This instability was evident during the COVID-19 pandemic. The challenges faced by brain tumour patients were exacerbated by cancelled surgeries, isolation, home care inconsistencies, and treatment delays. They needed our support more than ever and our enquiries increased. Although our staff showed tremendous resilience and worked hard to transform support programs to a virtual environment, the experience demonstrated our fragility and the need for stable core funding to ensure critical support programs can continue in times of national crisis.

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 funding, improving project-based funding as recommended in the 2019 Catalyst for Change Senate Report⁷, and prioritizing an equity-based approach to the provision of core funding to address historical inequalities.

⁵ <https://braintumourregistry.ca/2022-survival-and-prevalence-report/>

⁶ <https://www.imaginecanada.ca/en/policy-priority/core-funding>

⁷ https://sencanada.ca/content/sen/committee/421/CSSB/Reports/CSSB_Report_Final_e.pdf

In Conclusion

Each day, 27 Canadians hear the words, “You have a brain tumour”. 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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