

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

**By: Brain Tumour Foundation of Canada
August 7, 2020**

Brain Tumour Foundation of Canada Recommendations

- **Recommendation 1:** 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 filling gaps in health care services to individuals, their families, and caregivers.
- **Recommendation 2:** That the federal government continue to work with the provincial and territorial governments to make home care and palliative care more available across the country.
- **Recommendation 3:** That the federal government continue to implement national universal Pharmacare that includes a national formulary and a rare disease drug strategy to help Canadian families afford high-cost drugs.

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. Established more than 38 years ago, 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 affected by this devastating disease. Our mission is to provide support through: information gathering and sharing; education; and funding of brain tumour research.

Brain tumours are relentlessly unbiased affecting, men and women, the young and the elderly, and individuals of all cultures and walks of life.

- Brain tumours are the leading cause of cancer-related death in children under the age of 20, and the third leading cause of solid cancer death in young adults age 20-30.
- The most common type of primary malignant brain tumour is glioblastoma multiforme (GBM) with an average survival rate, (with aggressive treatment) of approximately one year.
- There are more than 120 different types of brain tumours, thereby making effective treatment very complex.

Complicating matters further, individuals with brain tumours of all types have experienced many negative impacts because of the COVID-19 pandemic affecting both their survival and quality of life. They have experienced cancelled or postponed physician and hospital appointments, delays in treatments including surgery, chemotherapy and radiation, and the shutdown of access to rehabilitation and other support services which impact their physical and mental quality of life.

In addition, individuals with brain tumours, their families, and caregivers, have found that programs and services offered by Brain Tumour Foundation of Canada and other non-profit and charitable organizations supporting their community, have changed, or been cancelled altogether. This has created a sense of urgency for our organization to make the following recommendations of measures the federal government could take to restart the Canadian economy, as it recovers from the COVID-19 pandemic, and to ensure that brain tumour patients, their families and those who care for them, have the support they need now and in the future.

Recommendation 1: 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 filling gaps in health care services to individuals, their families, and caregivers.

Brain Tumour Foundation of Canada fully supports Imagine Canada's call for a **Sector Resilience Grant Program**¹ that would provide grants to cover core operating costs to allow organizations, like ours, to respond to our community needs and costs. This support is needed quickly to offset the collapse of revenue sources such as donations and

¹ Imagine Canada, Sector Resilience Grant Program, <https://www.imaginecanada.ca/en/covid19-advocacy>

earned income that are used to support operations outside of wages that are not addressed by the wage subsidy. We believe this support would strengthen the sector, including our organization, for the longer term and improve resiliency in the face of COVID-19. This sector-wide request is for an additional \$7.2 Billion to establish a Stabilization Fund aimed at ensuring that non-profit and charitable organizations can continue to provide services during the Covid-19 crisis, where feasible, and are in a position to serve and help rebuild communities as the nation emerges from the crisis.²

Specifically, as a member of the non-profit sector and a registered charity, Brain Tumour Foundation of Canada is calling on the federal government for immediate grant funding support in the amount of **\$1 Million** to replace our organization's current and projected lost revenues for 2020.

While Brain Tumour Foundation of Canada quickly and largely successfully transitioned to delivering online programs and services, it is impossible to replace in-person support upon which the community relies. Our organization has had to do this in the face of declining fundraising revenues of more than 80 percent in April of this year, and 30 percent in both May and June. As we look ahead, we are being challenged to sustain our services without further cancelations or reductions in programs, decreased brain tumour research funding, and layoffs of dedicated and experienced staff. While government subsidies have helped, we have found the federal government's emergency relief programs difficult to access. Receiving this requested immediate grant funding support would ensure that Brain Tumour Foundation of Canada continues its critical mission to provide support, information, education and hope through research for individuals affected by brain tumours in Canada.

Recommendation #2: That the federal government continue to work with the provincial and territorial governments to make home care and palliative care more available across the country.

In May 2019, the Brain Tumour Registry of Canada³ 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.

The Brain Tumour Registry of Canada is now positioned to help inform health care planning for our brain tumour community. In May of 2019, Dr. Faith Davis (a brain tumour epidemiologist at the University of Alberta) and her team released the initial Canadian incidence report based upon four provinces, BC, Alberta, Manitoba, and Ontario. More recently the first survival report was released based upon the same four provinces. In

² Imagine Canada Partners in Well-being Report, https://drive.google.com/file/d/1dv0_NN843Up_PNPFeg0Fo7Cbus2QUppV/view

³ Brain Tumour Registry of Canada website, www.braintumourregistry.ca

2020, we look forward to the release of a Pan-Canadian Incidence and Survival report through collaboration with the Public Health Agency of Canada. This data will greatly enhance decision-making on new drug submissions, provincial programs, and federal health strategies.

Brain Tumour Foundation of Canada is pleased to have been a driving force behind the creation of this invaluable resource, with support from the Honourable Bill Casey, former MP and Chair, Standing Committee on Health.

The latest data from the Brain Tumour Registry of Canada shows individuals with brain tumours are surviving longer: 64% of patients with a primary brain tumour survive 5 or more years, while 25% of those with a malignant primary brain tumour (cancer) survive 5 or more years.⁴ Yet most provinces do not have the necessary services to support those with brain tumours in their community – e.g. rehabilitation services, vocational services, recreation therapy, etc.

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.

The COVID-19 pandemic has further negatively impacted access to these life changing services for brain tumour patients. These services have been postponed or cancelled during the pandemic and made in-home care more challenging. It is crucial that in the COVID-19 pandemic recovery plan that the federal government continue to make home care and palliative care a priority and work with the provincial and territorial governments to improve access for all patients, including those affected by brain tumours, across the country.

Recommendation #3: That the federal government continue to implement national universal Pharmacare that includes a national formulary and a rare disease drug strategy to help Canadian families afford high-cost drugs.

The most common type of primary malignant brain tumour is glioblastoma multiforme or GBM. Survival, even with treatment is about a year. This tumour cut short the lives of iconic Canadians Gord Downie, Neil Peart, Gerry Pencer, Tom Cheek, and respected physician Dr. Don Low. Brain tumours also touch the lives of many other Canadians. Stories of courage and grace can be viewed at www.braintumour.ca/stories

The most effective treatment for GBM includes the use of temozolomide, an oral chemotherapy medicine. This treatment has been available in Canada for many years and is now produced in generic form. It is considered standard 1st line care for GBM around the world. Research has proven that patients who receive this treatment regimen have a 1 in 4 chance of surviving two years, when compared to the previous standard of care, which gave patients a 1 in 10 chance of surviving two years.

⁴ Brain Tumour Registry of Canada Survival Report, www.braintumourregistry.ca

In Canada, access to this chemotherapy treatment is highly variable across the country. This is because it comes in pill form and is a chemotherapy drug that is taken at home. In several provinces, patients are asked to use their insurance to purchase it, with the province offering subsidy if insurance is not available (i.e. provincial Pharmacare). In other provinces, it is funded as a universal benefit at 100%. This variability means some patients in Canada face delays in accessing the drug, while others do not. Brain Tumour Foundation of Canada recently created the temozolomide “road map” to show how access timelines vary across the country because of this inconsistent approach.⁵

In creating a national formulary, it is imperative that temozolomide be considered an essential medicine and included in the national formulary. Access also needs to be seamless to reduce the risk of treatment delay.

Key to the success of the program is to help Canadian families afford high-cost drugs. The impact of the COVID-19 pandemic on the loss of jobs and reduced financial security for families heightens the critical need for this program to be implemented and made affordable for all Canadians. As we recover from the pandemic, it is critical that the federal government continue to move forward with a national universal Pharmacare program and implement a national formulary which includes an essential medicine like temozolomide for brain tumour patients.

In Conclusion

Each day 27 Canadians hear the words “You have a brain tumour”.⁶ The COVID-19 pandemic has not changed that statistic. What the pandemic has changed and created is an uncertain future for brain tumour patients and their families. The pandemic has had negative impacts on immediate health care services whether in-hospital, in-home or in the community, as well as patient survival and quality of life. As an essential service for the brain tumour community, Brain Tumour Foundation of Canada is committed to bringing hope through information, support, education, and research. As we recover from this pandemic it is critical that the federal government recognize the contribution that non-profit and charitable organizations like ours make to the health care of Canadians while continuing to move forward with the mandate of the Federal Minister of Health to strengthen public health care for the long term and build resiliency in the face of COVID-19.

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⁵ Regional Variations in How Temozolomide is Accessed in Canada Map, <https://www.braintumour.ca/get-involved/advocacy/>

⁶ Brain Tumour Registry of Canada Fact Sheet, www.braintumourregistry.ca