



First Brain Tumour Registry for Canada Captures Real-World Patient Evidence

Brain Tumour Community Comes Together to Advance Nationwide Optimized Care Because Every Brain Tumour Matters

- In 2021 it is estimated that there will be 27 new primary brain tumours diagnosed every day in Canada.¹
- Meningioma is the most common primary brain tumour in females, while glioblastoma is the most common primary tumour in males.²

TORONTO, ON. May 14, 2019 – Brain Tumour Foundation of Canada is proud to launch the first-ever **Brain Tumour Registry of Canada (BTRC)** – a surveillance research collaborative. Working as a nationwide, multi-centre initiative, the BTRC will become a cornerstone to optimizing clinical outcomes using evidence-based decision making for the treatment and care of brain tumour patients across Canada.

“Our hope is, that by counting every brain tumour in Canada, we will get one step closer to finding the cause of all brain tumours and hopefully preventing them from occurring,” said Dr. Faith Davis, Professor at the University of Alberta, School of Public Health. “We hope to improve the availability of accurate, complete, and analyzed data of malignant and non-malignant brain tumours in the Canadian population.”

Brain Tumour Foundation of Canada identified the gap in available information on Canadian brain tumour patients and prioritized the development of a pan-Canadian surveillance report. A collaboration to explore the feasibility of this goal was developed between Brain Tumour Foundation of Canada and Dr. Faith Davis at the University of Alberta in 2012. The award of a Brain Canada grant in 2015 provided additional support to create this data collaboration.

The registry was conceived by a committee chaired by Dr. Joseph Megyesi then Chairman of the Board of Directors at Brain Tumour Foundation of Canada.³ Advocacy efforts led by Jennifer Gouchie-Terris - whose son Brandon was diagnosed with a brain tumour - focused on obtaining complete data to create evidence to support brain tumour policy and research which resulted in the passing of a Canadian House of Commons Bill M235 in February 2007.⁴ The Bill called for national guidelines for the surveillance of all malignant and benign (non-malignant) brain tumours, but funds were not aligned to accomplish this task. The Public Health Agency of Canada (PHAC) subsequently explored the gap in the collection and reporting of non-malignant brain tumour data and identified barriers to data collection within the provincial and territorial cancer registries. At the time, only three of thirteen regional registries formally collected information on non-malignant brain and CNS tumours.⁵

¹ www.braintumourregistry.ca

² www.braintumourregistry.ca

³ <http://blog.braintumour.ca/2019/04/the-brain-tumour-registry-of-canada-the-motivation-and-history-behind-counting-every-patient-with-a-brain-tumour-in-canada/>

⁴ <http://www.ourcommons.ca/DocumentViewer/en/39-1/house/sitting-103/order-notice/page-6>

⁵ Davis F, Nagamuthu C, Ross J, Megyesi J. Current Status of Brain Tumor Surveillance in Canada and Why it Matters. *J. Regist Manag.* 2015;42(4):139–45

The goal of the BTRC is to provide comprehensive data on the incidence, prevalence, and survival rates for all primary brain tumours (malignant and non-malignant) periodically by important patient characteristics (location, histology, sex, age, and region) to better understand the patterns of occurrence and survival. These patterns will stimulate hypothesis about causes, treatment, and improved outcomes in the neuro-oncology research community and will support clinical and policy guideline formation.

Today, the first incidence report from four provinces -that captures 70% of the Canadian population - will be launched at www.BrainTumourRegistry.ca. A further survival report will be released later this year and in 2020 a comprehensive national report will include the entire Canadian population, including incidence, survival and prevalence data.

“The Brain Tumour Registry of Canada is a source of hope for both myself and my son, Brandon, since he was diagnosed with a brain tumour in 1998 at the age of four. Brandon lost his battle in 2012, but it was hope that carried him throughout his lengthy illness and gave him a sense of peace in the face of death,” said Jennifer Gouchie-Terris. “For us, the creation of a national Registry was the epitome of hope by ensuring that every brain tumour matters in Canada and providing us with a better understanding of the causes of the disease.”

About Brain Tumour Registry of Canada (BTRC)

The Brain Tumour Registry of Canada ([BTRC](http://www.BrainTumourRegistry.ca)) has been established in 2019 to ensure that every brain tumour in Canada is counted. Until recently, Canada has relied on data from a number of American and Canadian data resources to guide Canadian research, raise awareness, secure government funding and provide support programs – data that is incomplete and not a true reflection of Canada’s brain tumour community. For more information, please visit: www.BrainTumourRegistry.ca.

About Brain Tumour Foundation of Canada:

Brain Tumour Foundation of Canada is the only national charity offering information and support to patients affected by any kind of brain tumour – be it cancerous, non-malignant or metastases. The organization funds ground-breaking research across North America and, since 1982, has dedicated over \$7.2 million to finding a cure and improving treatment for brain tumour survivors. Brain Tumour Foundation of Canada is funded solely through generous contributions from individuals, corporations, organizations, employee groups and special events. Learn more at Brain Tumour Foundation of Canada’s website: www.BrainTumour.ca.

For more information, confirm your attendance and or request an interview, please contact:

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