



# HELP MAKE CANADA'S FIRST BRAIN TUMOUR REGISTRY A REALITY



*DATA IS A KEY ELEMENT OF SUCCESSFUL RESEARCH.*

*DATA IS NEEDED TO FIND THE CAUSE OF AND CURE FOR BRAIN TUMOURS.*

Right now in Canada, there are no accurate statistics on how many people are actually diagnosed with a brain tumour. Data currently used only reflects certain tumour types or is taken from US statistics and applied to the Canadian population.

Without an exact count of how many Canadians have a brain tumour, and what types make up the tumours diagnosed, researchers are at a disadvantage to see patterns or changes within patient groups.



**braintumour**  
foundation  
OF CANADA



Brandon and his beloved dog

Brandon and his mom, Jennifer, have worked tirelessly to establish Canada's first brain tumour registry. In fact, even while Brandon was on his own brain tumour journey, he and Jennifer helped develop a Private Members Bill that called for the creation of a national registry to capture data on **all** brain tumours, both malignant and non-malignant. **TODAY, WE NEED YOUR HELP TO MAKE THIS REGISTRY A REALITY.**



Brandon and Prime Minister Harper

“ We think there are twice as many non-malignant brain tumours as cancerous cases and know that only 33% of non-malignant diagnoses are tracked through a Canadian registry – one meant primarily for malignant tumours. Due to their location, we know **all** brain tumours pose significant harm and by capturing non-malignant cases within the registry, we can better support the improvement of treatment and care for the full spectrum of brain tumours in Canada. ”

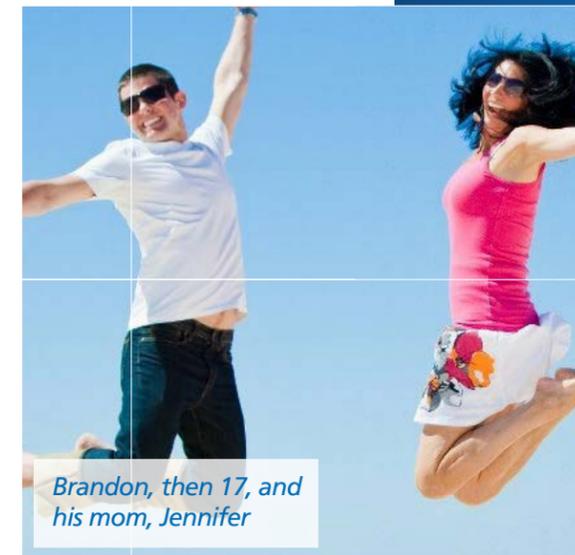
Dr. Faith Davis, Research Lead, Canadian Brain Tumour Registry



## THE SOLUTION: CANADA'S BRAIN TUMOUR REGISTRY

As part of a special collaboration with Brain Canada, donations directed to the registry project will be **matched dollar-for-dollar**.

- PHASE I**  Supplement registry activities to obtain data on non-malignant brain tumours.
- PHASE II** Create the Canadian brain tumour surveillance report similar to that published by CBTRUS in the US.
- PHASE III** Develop approaches to support collaborative research.
- PHASE IV** Develop recommendations for collection of relevant molecular data and tumour classification critical for monitoring treatment decisions and patient outcomes.
- PHASE V COMPLETED BY 2019** Fund a collaborative project that explores clinical case identification and coding for patients on Avastin to provide insight on the efficacy of this drug treatment for a larger brain tumour population.



Brandon, then 17, and his mom, Jennifer

## THE IMPACT: BETTER RESEARCH, BETTER OUTCOMES

The more known about brain tumours, the more patients will benefit from research into a cure and better treatment options.

- A registry integrating Canadian brain tumour demographics will assist researchers to identify trends, changes and patterns in diagnosed cases and survivability statistics.
- Data from the Canadian Brain Tumour Registry will accelerate studies due to readily available patient information and potential clinical trial candidates already pre-screened and identified.
- Treatment options will be enhanced or expanded with new data collected on experimental drug therapies within specific patient groups.
- With accurate and credible data to support findings, Canadian researchers are empowered to participate in research opportunities on an international scale, advancing the global work to find a cure for brain tumours.



**HELP RAISE \$230,000 BY 2019 TO MAKE THE REGISTRY A REALITY.**

# BRANDON'S JOURNEY

Brandon was just 4 years old when his family learned he had a non-malignant mass on his brain. That's when his mom Jennifer quickly found out about the inconsistent tracking of brain tumours in Canada. At that time, in 1998, some provinces and territories didn't collect any data on brain tumour types.

Sadly, Brandon passed away in October 2012 at 18 years of age. After more than a decade of near-perfect health, a scan that fall showed a new inoperable tumour in his brain and this time it was cancer. Despite being terminally ill, Brandon asked his mom to continue the fight for better brain tumour data and a national registry to track the disease.



*Hope carried Brandon throughout his life but also gave him a sense of peace in the face of death. Now we have hope that someday we'll have a better understanding of the cause of brain tumours and, most importantly, we hope there will be a national registry to ensure each and every brain tumour gets counted in Canada.*



*Jennifer, Brandon's mom*

MAKE THE BRAIN TUMOUR REGISTRY A REALITY.

**DONATE NOW:**

**BrainTumour.ca/Registry**

## ABOUT BRAIN TUMOUR FOUNDATION OF CANADA

We believe in the importance of funding ground-breaking research to improve the quality of life for every Canadian diagnosed with a brain tumour, while exploring the incredible possibilities for a cure.

Since the charity's founding in 1982, more than \$4 million has been directed to brain tumour studies at centres of research excellence across Canada and North America.



Brandon's daily mantra



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