

Contents

2019-2021 Strategic Direction	1
Brain Tumour Walk	2 - 3
Hats for Hope	4
Community Creativity	5
Your Hope in Action 2018	6 - 7
Research Update	8 - 9
Brain Tumour Registry of Canada	10
Youth Education Awards	11
Volunteering	11
Looking Ahead	12 - back cover
Brain Tumour Webinar Series	
Brain Tumour Research Symposium	
Montreal Brain Tumour National Conference	
Celebration Dinner	
Caregiver Resource	

Brain Tumour Survivor
London Brain Tumour Walk

Message from the CEO

You inspire us. Through your stories, your fundraising, and the ways you raise awareness, you empower us to support everyone affected by a brain tumour in Canada, to fund innovative research, and to provide programs which fill gaps for our community.

In this edition of *Hope in Action*, you can read about some of the more creative ways that you have fundraised, the teams who come together and those who have found love through the Brain Tumour Walk program, plus the ways that we are investing the money that you have worked so hard to raise.

We are now entering a new strategic plan period. We worked with people like you across Canada, we listened, and formulated this new plan. We are looking forward to working with you to help patients and survivors live longer, better, and with hope.

Thank you for your trust and thank you for putting hope into action.



With heartfelt appreciation,

Susan Marshall
Chief Executive Officer
Brain Tumour Foundation of Canada

2019-2021 Strategic Direction

Looking to the future, the Board of Directors of Brain Tumour Foundation of Canada led the organization through a comprehensive Strategic Planning process in 2018 which engaged many stakeholders from across Canada. These included patients and families,

researchers, clinicians, allied healthcare professionals, volunteers, donors, and staff. The resulting plan for 2019 to 2021 continues to focus us on our vision and mission while building upon the growth achieved to date.

Helping Patients and Survivors Live Longer, Better, and With Hope

1 Advocate for Fairness

1. Assess and seek to remove barriers to care
2. Engage governments in providing an equitable, effective and accessible system of care

2 Expand Funding for Research

1. Support increased funding for research in basic science, treatment and quality of life
2. Grow the Brain Tumour Registry of Canada and leverage its findings

3 Increase Awareness and Education

1. Strengthen the delivery of information to our community
2. Improve awareness nationwide of the signs and symptoms of brain tumours
3. Raise awareness of the effects, incidence and prevalence of brain tumours

4 Build Our Community

1. Invest in people and tools that will allow us to achieve our goals
2. Regularly and consistently evaluate and improve our culture and engagement
3. Track our efforts for growth and success

2018 / 2019 Board of Directors



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(Aurora, ON)



Phyllis Retty
Vice-Chair
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James Scongack
Director
(Port Elgin, ON)



Robin Urquart
Director
(Halifax, NS)

Thank you for **Walking**

YOU put hope into action by ensuring no one affected by a brain tumour walks alone.

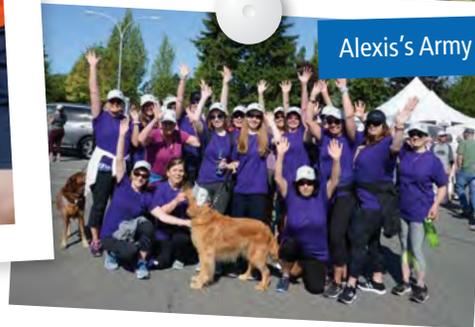


This year, the London Brain Tumour Walk event was started by Abel and Erin, two brain tumour survivors who were brought together through their same diagnosis. The couple met in a Facebook support group for brain tumour survivors and it was their matching central neurocytoma diagnosis that helped them connect. After chatting online for several years, Abel made the decision to move from California to be near his now wife and even timed his visits to line up with the local Brain Tumour Walk. Today, the couple live in London and continue to participate in the annual Walk event, saying it is a chance to not only raise important funds to find better treatments and a cure for the disease, but to also shine a light on the people affected by a brain tumour diagnosis.

Farand's - "For the Fight" (Edmonton)



Alexis's Army (Victoria)



Team Scatter Brains (Vancouver)



Windsor Cheer



Kitchener-Waterloo Walk



The coordinators were out assigning volunteers to line the route for the Toronto Brain Tumour Walk, when two volunteers stepped forward to ask if they could be assigned to marshall the next corner together. They are now dating and had met when they were volunteering for us in 2018. We are thrilled that they were able to find love at our event!

Volunteer
Bénévole

Text to Donor:
Donnez par texto:

In 2018 we were proud to present the Cup of Hope to the team who had raised the most funds during the Brain Tumour Walk program. Stephanie, team captain of Team Stephanie was presented with the award, accompanied by her twin boys, in October 2019, having raised more than \$31,000 of which \$28,000+ was raised by Stephanie herself! Thank you to everyone on Team Stephanie, and the entire Brain Tumour Walk program, for putting hope into action! Stay tuned for the 2019 Cup of Hope announcement!



Team Stephanie (Toronto)

The Defenders (Whitehorse)



Nathan's DIPG Warriors (Winnipeg)



Team Harry (Brampton)



Team Hayden (Hamilton)



This year, we witnessed the first ever marriage proposal at the Yellowknife Brain Tumour Walk event! Congratulations to the happy couple!

Thank you for Hats for HOPE

Thank you for putting on hats to raise awareness of brain tumours during International Brain Tumour Awareness Week and on the first ever Brain Cancer Awareness Day in Canada.

Throughout the week of October 24, 2018, you were a part of a flurry of activity with the hashtag #HatsForHope.

More than **450** people took part, resulting in **188,000** impressions on social media. Even singers, Olympians, and TV personalities joined in, sharing a selfie with a toque on, sharing their connection to the cause, and raising awareness of this devastating condition.



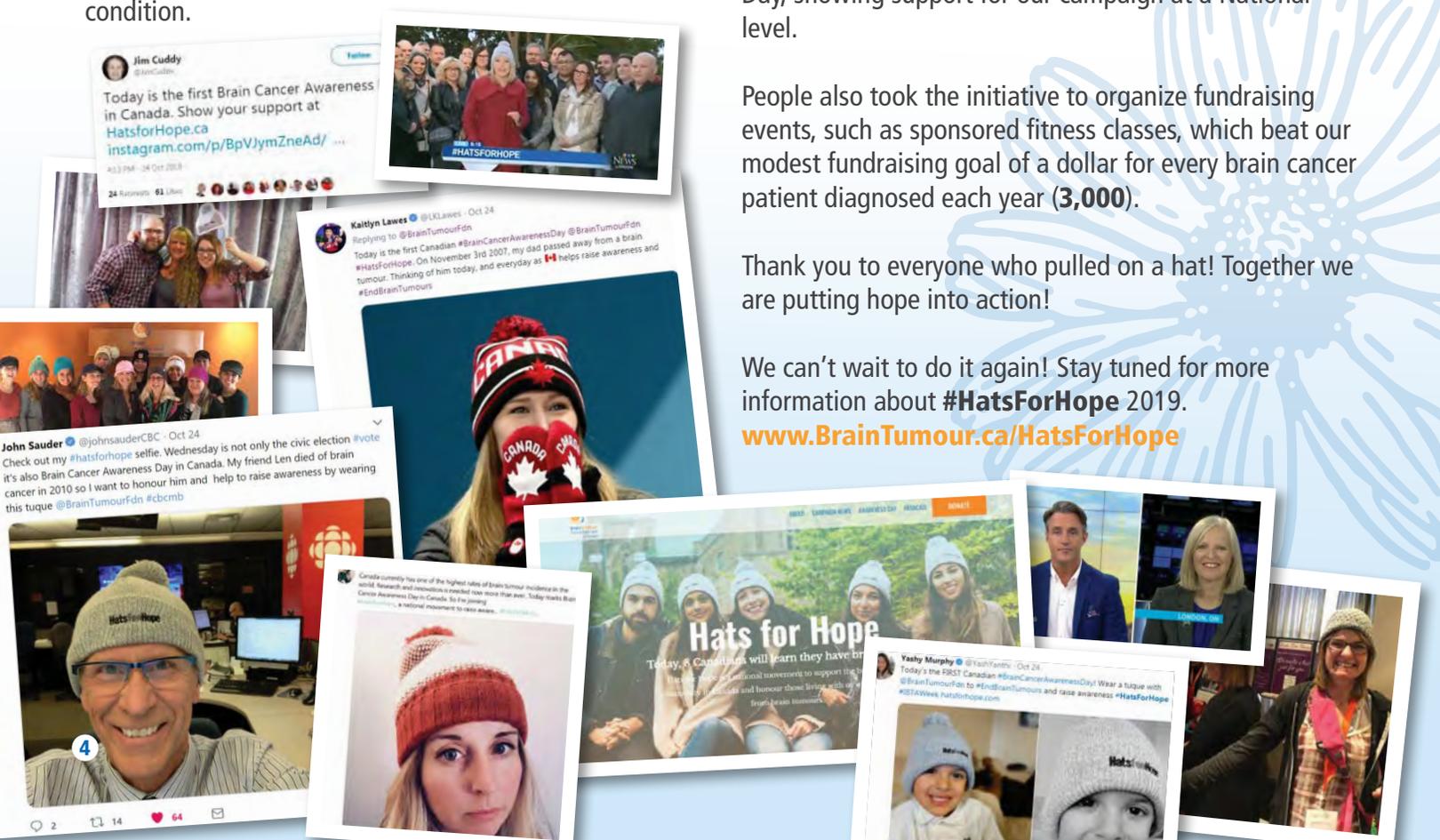
Our local MP, Kate Young, rose in the House of Commons to declare October 24, 2018 as Brain Cancer Awareness Day, showing support for our campaign at a National level.

People also took the initiative to organize fundraising events, such as sponsored fitness classes, which beat our modest fundraising goal of a dollar for every brain cancer patient diagnosed each year (**3,000**).

Thank you to everyone who pulled on a hat! Together we are putting hope into action!

We can't wait to do it again! Stay tuned for more information about #HatsForHope 2019.

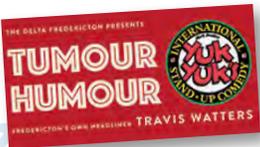
www.BrainTumour.ca/HatsForHope



Thank you
 for all the creative ways
 you support us

You
 ate pickles

You laughed



You quilted

You escaped



You kissed
 a cow

You played



You were 'Hip'

You became
 a superhero



You got temporary tattoos

Bruce Power is teaming up with Brain Tumour Foundation of Canada to boost awareness and develop innovative technologies such as making use of Cobalt-60 from their nuclear reactors to support people diagnosed with a brain tumour.

BrucePower
 Innovation at work



Thank you Bruce Power, for putting hope into action!

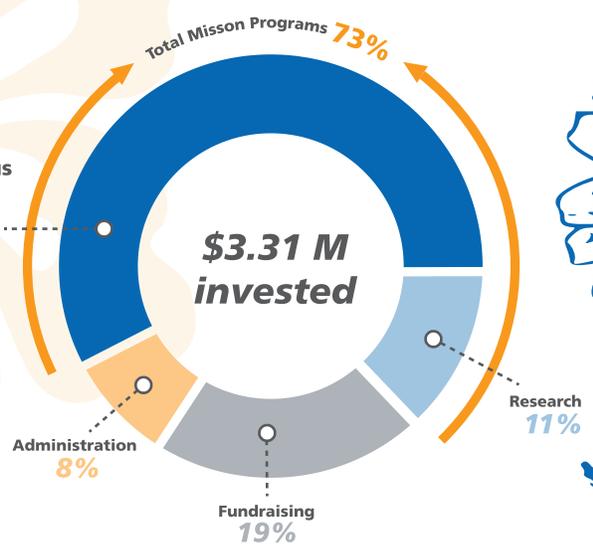


Your 2018 Hope in Action

- ✦ \$353,402 invested in research projects
 - Including:**
 - ✦ 1 Fellow, 2 Research Grants, 3 Research Studentships, The Pam and Rolando Del Maestro Family Undergraduate Student Research Competition Awards in which 8 teams took part
 - ✦ \$85,941 to fund the Brain Tumour Tissue Bank supporting 6 research investigators across Canada, and the United States
 - ✦ \$125,000 invested to fund year four (4) of the Pediatric Brain Cancer Impact Grant
 - ✦ Brain Tumour Registry of Canada
- ✦ 6 childhood brain tumour survivors were awarded post-secondary school scholarships
- ✦ 2 Health Care Professional (HCP) Professional Development Awards

- ✦ 27 in-service presentations reaching over 654 Health Care Professionals
- ✦ 230 Support Group meetings
- ✦ 4,762 handbooks were distributed in both languages
- ✦ 16 BrainWAVE events
- ✦ 1,007 participants either in person or online joined the 3rd Brain Tumour National Conferences in Toronto and Montreal
- ✦ 2 Young Adult Retreats / 3 Caregiver Wellness Days

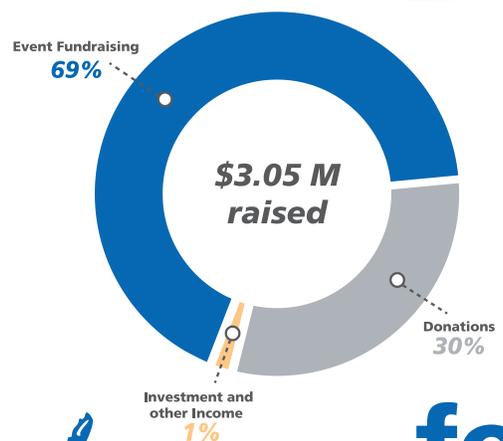
Patient Focus
Education,
Information,
Support,
Awareness
62%





- * \$930,420 donated through our annual program
- * \$232,019 received through grants and sponsorships
- * \$274,552 donated in tribute
- * 10,130 participants walked in 21 Brain Tumour Walk events and fundraised \$1,805,930 – 59% of our fundraised income. 78 businesses sponsored a Brain Tumour Walk in their community
- * \$316,802 raised by 80 Community Events

- * 26,378 social fans increased awareness of brain tumours
- * 1,274,232 page views of www.braintumour.ca
- * Over 700 volunteers supported activities



Thank you
for giving in 2018!



Thank you for your investment in research

Congratulations to the 2018 winners of **The Pam and Rolando Del Maestro Family Undergraduate Student Research Competition Awards**. Undergraduate students from Western and Toronto Universities collaborated on their presentation: Novel Laser-Quantum Dot Imaging-Therapy for Diffuse Astrocytoma to win \$1,000! See this presentation and those of the 3 runners up on our website.

The 2019 Research Symposium will be held in London, ON on Saturday, October 26, 2019, and will include our student competition for 2019. Students unable to compete in person will be live-streamed in. Save your seat now at:

www.BrainTumour.ca/ResearchSymposium



Deejesh Subramanian (Western University), and Syed Mohammad Raza (University of Toronto)



Lab tour hosted by Dr. Michael Taylor

Pediatric Brain Cancer Impact Grant

Thanks to you, in 2015 we embarked on the biggest research grant in our history. The Pediatric Brain Cancer Impact Grant is an investment of \$1.25m for research into medulloblastoma, the most common childhood brain tumour.

Thanks to this grant, in 2017, the research team led by Dr. Taylor at the Hospital for Sick Children, identified twelve subtypes of medulloblastoma and that each subtype is completely different at the time of recurrence.

In 2018, Dr Taylor and his team published a breakthrough study that showed, for the first time, that medulloblastoma can also spread through the blood. Most deaths associated with medulloblastoma are caused by metastatic disease, where the tumour has spread to a new site in the brain. This surprising discovery opens new avenues for diagnosis and treatment. We are looking forward to updating you on the research as it continues. Learn more at:

www.BrainTumour.ca/ImpactGrant



Jax (2008 - 2019) said "Thank You!!"

Our research investments

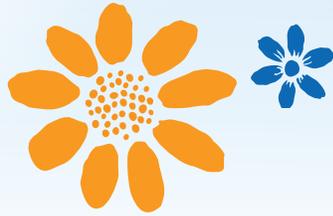
- ✦ From **1982-2018** we have committed **\$7,018,734.70** to research **250** opportunities
- ✦ We funded the **Brain Research Laboratory** from **1986-1991** and provided **\$230,339.00** in support
- ✦ In **1992** this was renamed the **Brain Tumour Tissue Bank** and since then we have provided **\$1,268,854.59** in funding
- ✦ Since **2004** we have provided **74 Research Grant Awards** which total **\$1,847,102.11**
- ✦ In **2010** we began offering our **Fellowships** and have given out **7 awards** since which total **\$700,000.00**



- ✦ In **2011** we began a feasibility study to see if a **Brain Tumour Registry** was possible and since then have supported **\$375,633.00** to this project
- ✦ In **2013** we awarded our first **Education awards** and since then have given out **30 awards** which total **\$142,360.00**
- ✦ In **2013** our Studentships were introduced and since then we have provided **24 student awards** totalling **\$240,000.00**
- ✦ Since **1988** we have helped support various **Scientific Conferences** and provided funds to **21 meetings** totalling **\$85,660.00**



Thank you for counting



Thanks to you, after years in the making, in May 2019 (Brain Tumour Awareness Month), the Brain Tumour Registry of Canada was launched.

The first report, representing 70% of the Canadian population, can be viewed at www.BrainTumourRegistry.ca.

This is not a patient populated registry. Data is collected through institutions where patients are diagnosed, in order to ensure that every brain tumour is counted.

We hope to release a further survival report later this year and, with your support, in 2020 a comprehensive national report will include incidence and survival data for the entire Canadian population.



We will not stop until every brain tumour is routinely counted, as every brain tumour counts! However, we cannot do it without your support. Donate now at:

www.BrainTumour.ca/Registry

Thank you for putting hope into action.



Thank you for supporting our youth



Thank you Rigatoni for Research for putting hope into action by generously funding Christine's Youth Education Award.

Meet Christine



Christine was diagnosed with a brain tumour at the age of 9, an experience that changed her life. The incredible care from the nurses during her year in hospital after brain tumour surgery inspired Christine to become a nurse. Last year, Christine applied for and received a **Youth Education Award for Brain Tumour Survivors**, enabling her to pursue her dream to become a pediatric oncology nurse.

"I would really like to thank Brain Tumour Foundation of Canada for giving me this scholarship. It has been a vital part of my fourth-year experience as a student nurse and has contributed greatly to my success in graduating and passing the nursing national exam."

"At this point in my life, I could say that overcoming childhood brain cancer has been one of the major good things that have happened in my life. Having gone through what was so devastating at that moment in time, but then having victory over cancer, has led me to a life full of grace, opportunity, and love. Being a cancer survivor has shaped my identity for the better, and I am proud to say that I suffered cancer, and that I had the power and strength to defeat it."

Read more of Christine's story at:
www.BrainTumour.ca/EDAwards



...AND
LAST BUT NOT LEAST...

Thank you for volunteering



You help us run events, programs and just about everything!

Congratulations to the 2018 recipient of the **David Kelly Award for Community Service** - Dr. Lisa Porter.

In addition to her role as a Principal Investigator on brain tumour grants, Dr. Porter dedicates a significant amount of time, energy and passion to building a collaborative research community. She believes strongly that great discoveries require many minds and that elevating the work of others will benefit the brain tumour community.

Congratulations also to the 2018 **Volunteers of Distinction** award recipients: Pablo Coffey, Greg Taylor and Christina Hagberg, Kelley Weatherby and Michèle Tirlmont.

Learn more about why these people received these awards and how you can get involved at:
www.BrainTumour.ca/Volunteer

Thank you to everyone of our 700+ volunteers. You put hope into action!

Looking Ahead



Get involved
with us this fall!

Brain Tumour Webinar Series

2019
Brain Tumour
WEBINAR SERIES

Treatments • Resources • Discoveries



To reach you better, we are offering a free webinar series with various online presentations throughout the year. Topics include research, treatment, advance care planning, young adults living with a brain tumour, personal stories from brain tumour survivors and caregivers, and more. These webinars replace the English Brain Tumour National Conference.

Register for these free webinars now and see recordings of previous webinars at www.BrainTumour.ca/Webinars.

Webinars still to
come in 2019:



Webinar Topic:

**Transitioning Between
Pediatric Brain Tumours to
an Adult Setting**



Webinar Topic:

**Brain Tumour Registry of
Canada: Past, Present &
Future**



Webinar Topic:

**Personal Stories of
Hope from Brain Tumour
Patients, Survivors &
Caregivers**



Brain Tumour Research Symposium

Anyone with an interest in brain tumours is welcome to attend the Brain Tumour Research Symposium on **October 26, 2019** in London, ON. Speakers include:

- ✦ A former Brain Tumour Research Studentship recipient, Alexander Rodzinka: "A Novel Approach to Dissecting Brain Tumour Heterogeneity"
- ✦ A former Brain Tumour Research Grant recipient, Qi Zhang: "Gap Junction and Related Proteins in Brain Metastasis"
- ✦ The event also incorporates The Pam and Rolando Del Maestro Family Undergraduate Student Research Competition Awards

There is no cost to attend. Register now at:

www.BrainTumour.ca/ResearchSymposium



Montreal Brain Tumour National Conference



CONFÉRENCE NATIONALE SUR LES TUMEURS CÉRÉBRALES

The Montreal Brain Tumour National Conference will take place on **Saturday, November 2, 2019** in Montreal and will be live streamed across Canada. Presentations will be in French.

Topics include:

- ✿ Advancements in pediatric brain tumour research
- ✿ Treatment of brain tumours
- ✿ The ketogenic diet as a therapeutic tool
- ✿ A patient story
... and more.

Register now at www.TumeursCerebrales.ca/Conference



Celebration Dinner

The English Brain Tumour National Conference might have been replaced by the 2019 Brain Tumour Webinar Series, but we still want to celebrate!

In October, we will bring our leadership volunteers (the wonderful people who run support groups, BrainWAVE programs and key organizers of our Brain Tumour Walk events) together for training. On the Friday night, we will celebrate.

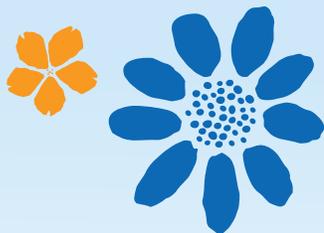
Join us as we announce:

- ✿ The winner of the Cup of Hope (see page 3 for details of the 2018 recipient)
- ✿ David Kelly Award for Community Service and
- ✿ Volunteer of Distinction Awards (see page 11 for last year's recipients)

Everyone is welcome to join the Celebration Dinner, which will take place on **October 18, 2019**, in London, ON. Find out more at www.BrainTumour.ca/CelebrationDinner



Caregiver Resource



“Being a caregiver is hard. Being a caregiver of a loved one with a brain tumour is even harder.”

You told us that the caregiver journey is a challenge because of the nature of the disease. Until recently, we did not offer unique events or resources for the brain tumour caregiver.

In 2018 we launched **Caregiver Wellness Days**, where caregivers came together to support each other and reinforce the message that when a caregiver takes care of themselves, they can in turn, take better care of their loved one.



Later this year, we will launch the very first **Caregiver Brain Tumour Handbook** that will include information such as adjusting to a new normal, managing emotions and expectations, practicing self-compassion and suggestions on how to manage cognitive effects of treatment. Like all our resources, it will be made available free of charge across Canada. Until then, see all the ways caregivers can gain support at www.BrainTumour.ca/Caregiver.

Thank you to the caregivers and those who supported this initiative. You put hope into action.

Vision:

To find the cause of and a cure for brain tumours while improving the quality of life for those affected.

Mission:

To reach every person in Canada who is affected by a brain tumour through support, education, information, and research.



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1.800.265.5106
www.braintumour.ca

Registered charitable number: BN118816339RR0001

Values:

These values inform everything that we do to create impact and meaning for the brain tumour community in Canada:

**Hope, Caring, Integrity,
Accountability, and
Collaboration.**

Connect with us!



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