

# Hope *in* Action

YOUR ACTION AND IMPACT PROVIDING HOPE FOR THE BRAIN TUMOUR COMMUNITY



FALL  
2020



# Message from the CEO

This year has not turned out as we had planned. For us, or anyone else. While the world has fundamentally changed, this is our opportunity to celebrate the successes of 2019 and update you on the accomplishments of 2020 so far.

Our community inspires us in so many ways. Thanks to your fundraising, you empower us to advocate for fairness, expand funding for research, increase awareness and education, while fostering the brain tumour community across Canada.

A pandemic isn't going to stop brain tumours, and it won't stop us either. In this publication, we will show you just some of the ways we have reimagined and pivoted our programs so that together we can put Hope into Action, ensuring patients and survivors live longer, better, and with hope. We remain your Brain Tumour Foundation of Canada.

With heartfelt appreciation,



**Susan Marshall**  
Chief Executive Officer  
Brain Tumour Foundation of Canada



Connect with us on social media...



@BrainTumourFdn

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# Because of a pandemic...

In March, we closed our office doors, cancelled in-person events such as support group meetings and BrainWAVE gatherings and began working from home. Despite a pandemic, our mission, to reach every Canadian affected by a brain tumour with support, information, education, and research, continues...

Determined to support the brain tumour community, we relied heavily on our existing virtual platform, while exploring new ways to bring support to the brain tumour community. The result: #SupportAtHome, our new way to connect Canadians while at home.



## Here's how:

- Community call-ins that offer real-time contact with our support staff
- A concert series featuring a variety of up-and-coming and well-known musical acts
- Fun stay-at-home activities for kids and families
- Expanding the reach of our virtual support groups
- Educating through the monthly webinar series

#SupportAtHome will continue throughout 2020 as we have cancelled all in-person events this year. We don't know what next year will bring, but we know that we cannot imagine how we will service our community without your continued support and investment.

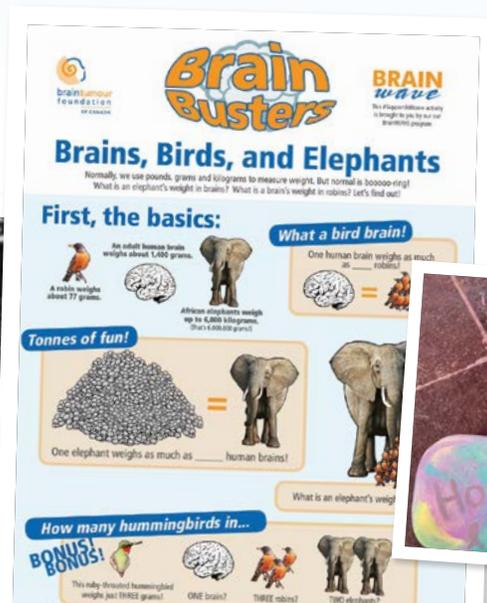
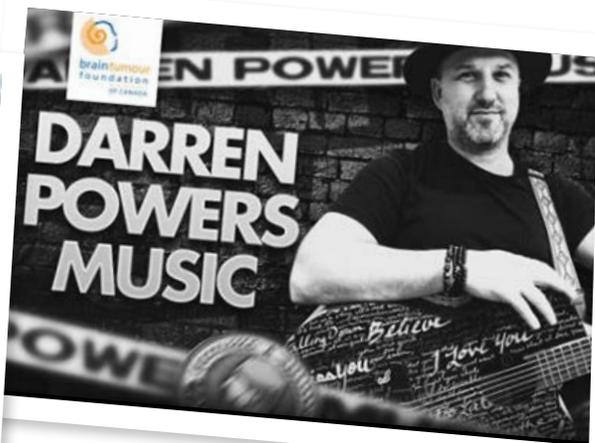
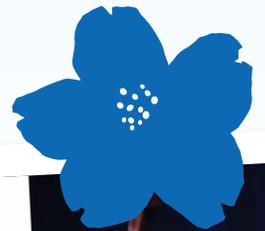
We know that our annual Brain Tumour Walk program is our biggest support group providing our community with the opportunity to come together to celebrate, support and remember. While we were pivoting our support programs, we did not lose sight of the important role that the Brain Tumour Walk provides, and we quickly pivoted our physical walk events, reimagining a national Virtual Brain Tumour Walk connecting our entire community from coast to coast to coast on one day, June 27, 2020. We owe a debt of gratitude to our participants, sponsors, and donors for embracing this change in a year already fraught with flux. Read on to find out more...

We're grateful to The Adam Fanaki Brain Fund for their support of #SupportAtHome and patient handbooks.



**THE ADAM FANKI  
BRAIN FUND**

[www.braintumour.ca/support](http://www.braintumour.ca/support)



# Because you took steps...



## 2020 Brain Tumour Walk Goes Virtual!

Because even a pandemic can't stop our community from ensuring no one affected by a brain tumour walks alone!



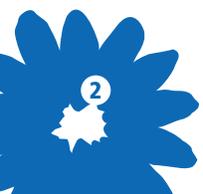
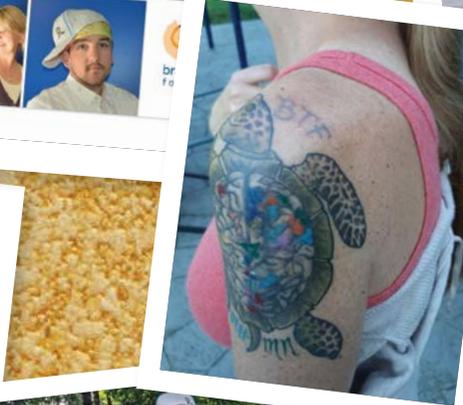
Living in a pandemic changes everything for everyone and this year's Brain Tumour Walk was no exception. We could not have predicted the circumstances leading to our first Virtual Brain Tumour Walk, but the support we received from more than 3,600 participants was incredible.

Because of your unwavering support, an incredible \$1.1 million was raised with donations still coming in. Your generosity and participation in the 27 Canadians Challenge has beaten all expectations and will allow us to continue our commitment to providing emotional support, credible information, empowering education and hope through the funding of brain tumour research.

To everyone who tuned in to our opening ceremonies streamed Saturday, June 27, 2020, thank you for sharing your moments of celebration and solemnity. Thank you as well to our wonderful host, Alan Cross, for getting us ready to venture out and take our steps.

We have taken so much heart and inspiration from your many, MANY posts using the hashtag #VirtualBrainTumourWalk on June 27.

View the opening ceremonies:  
[www.youtube.com/braintumourfdn](http://www.youtube.com/braintumourfdn)



Seeing all of you, from all parts of the country walking, smiling, being together with friends and family was incredibly inspiring and ensured us that no one affected by a brain tumour walked alone.

We could feel the love with each shared comment, like and post you made. So did Al's Flower Pouch by A.M.A. Horticulture, who donated \$5,000 to Brain Tumour Foundation of Canada as our first ever hashtag sponsor.



## Cup of Hope

The Cup of Hope is awarded to the Team that raises the most funds during the annual Brain Tumour Walk program. In October 2019, Candice Petrovic, team captain of Team Hayden was presented with the award, having raised \$45,708!

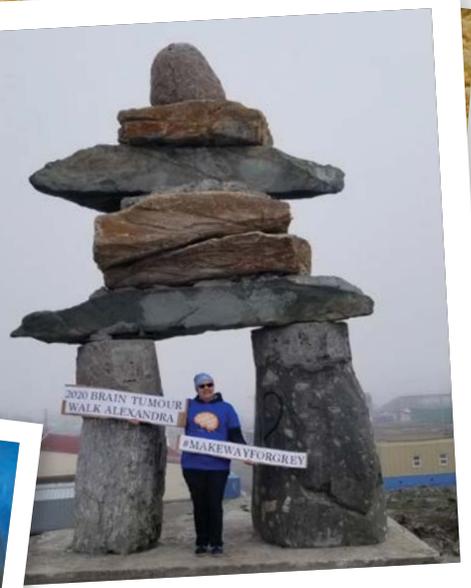
Walking in memory of her little girl Hayden, Candice writes, *"I will continue to fight and advocate for each and everyone of us, and for the future of brain tumour patients. We are here because of brain tumours, and although we know that there are treatments that sometimes are successful, there is still so much work to be done."*



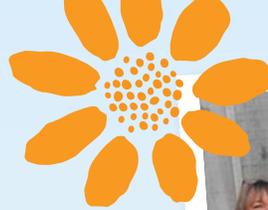
Candice has passed the Cup of Hope to Kyleigh Provenzano from Sault Ste Marie, as her team, the Brain Stormers, raised \$39,175 in 2020!

Thank you to everyone on Team Hayden, all the Brain Stormers, and everyone who participated, for putting hope into action!

[www.braintumourwalk.ca](http://www.braintumourwalk.ca)



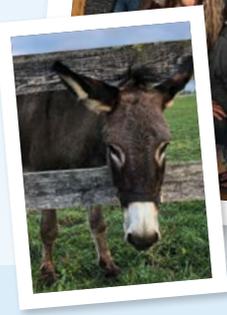
# Because of your creative fundraising...



In 2019 over \$466,000 was raised through events held in communities across Canada. In 2020, your creativity continues. Here are some examples...

## Barn Party

When a loved one of the Janzen family heard the words, “you have a brain tumour”, the entire family was affected by a flood of emotion and the desire to do something to make things better. So what did they do? They hosted a “Barn Party”! Hundreds of friends and family came out to enjoy an evening of fun, food, fellowship, music, dancing and fundraising. Truly a hope-filled event raising over \$22,000 for brain tumour research! Thank you to the Janzen Family for putting hope in to action for the entire brain tumour community.



## Dance of Thrones

Rochelle’s world was turned upside down Good Friday, 2019 when she had a seizure while driving. The seizure was caused by a brain tumour, glioblastoma. An active member of the dance community in Canada, she was determined that her dance students would complete their year-end recital. Rochelle even took part in the recital, then had brain surgery just three days later. Chemo, radiation, and MRIs followed, but that has not stopped her. Determined to give back, Rochelle has since held two ‘World of Dance’ inspired events in Calgary, AB, the most recent event raised \$14,200 for brain tumour research. Thank you, Rochelle. We are sending you positive energy.



## 3v3 Kumar Classic

Jay Kumar was a bright 13-year-old, loyal friend, and rising basketball star. Jay died just nine (9) days after being diagnosed with Diffuse Intrinsic Pontine Glioma (DIPG). In his memory, Jay’s coach and his family started a 3v3 basketball tournament, which is now Ontario’s largest charity 3v3 basketball tournament. Since the inaugural tournament in 2013, the Kumar Classic has raised more than \$20,000 for Brain Tumour Foundation of Canada, even raising \$1,500 in the Virtual Kumar Classic 2020!



## #KickBobToTheCurb

It's not rude, Bob is Kelsey's brain tumour, and he's got to go. A friend offered to paint their header wagon a distinctive colour if more than \$1,000 was raised. We are grateful for this creative fundraising.



## Kelowna SUPERKIDS run

In memory of Sevanah, who died five months after her DIPG diagnosis, Angelina continues to fundraise. In 2019 she raised more than \$6,000 with a SUPERKIDS run at a school in Kelowna, BC. Thank you Angelina!

## MacNeill Edmundson Golf Tournament

To all who support us through Golf Tournaments and other events, we are so very grateful. Thank you!



## A.M.A. Horticulture raises over \$100,000 from the sale of AI's Flower Pouch

*"Since my own brain tumour diagnosis, I've felt that getting information into patients' hands is important. Knowing our Flower Pouch is seen across Canada, it offers a good opportunity to put Brain Tumour Foundation of Canada's name in front of thousands of people for virtually no cost. Using the pouch to raise funds was a logical next step. We hope to take many more steps. In 2020, we became the Foundations' first-ever hashtag sponsor for the #VirtualBrainTumourWalk program. We're proud to be a part of the Brain Tumour Foundation of Canada family."*



## Beautiful bracelets #TurnMayGrey:

*"We helped #TurnMayGrey by selling over 800 bracelets made by Angel Jewelry by Anastasia, raising both awareness and a total of \$40,600 for brain tumour research." - Danielle*

[www.braintumour.ca/communityevents](http://www.braintumour.ca/communityevents)





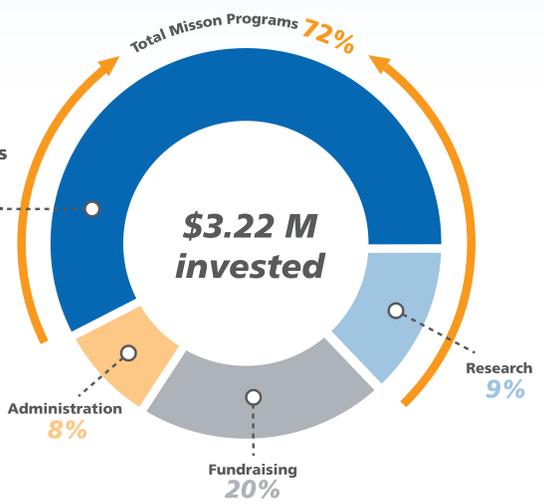
# Your 2019 Hope in Action



## Your Impact:

- 1 Fellow, 2 Quality of Life Feature Grants, 2 Research Grants, 1 Research Studentship, The Pam and Rolando Del Maestro Family Undergraduate Student Research Competition Awards in which 5 teams took part
- \$86,152 to fund the Brain Tumour Tissue Bank supporting 9 research investigators across Canada, and the United States
- \$125,000 invested to fund year five (5) of the Pediatric Brain Cancer Impact Grant
- Brain Tumour Registry of Canada – launched in 2019
- 5 childhood brain tumour survivors were awarded Youth Education Awards
- 3 Health Care Professional (HCP) Professional Development Awards
- 15 in-service presentations reaching over 255 Health Care Professionals
- 230+ Support Group meetings
- 3,355 handbooks were distributed in both languages
- 16 BrainWAVE events
- 1,008 participants either in person or online joined the 3rd Brain Tumour National Conference in Toronto and Montreal
- 2 Young Adult Retreats
- 3 Caregiver Wellness Days

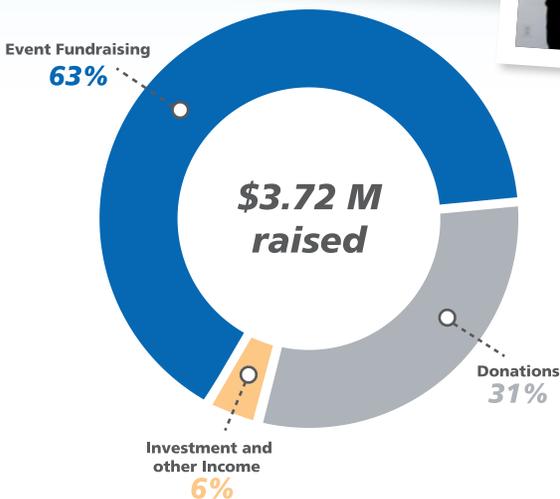
Patient Focus  
Education,  
Information,  
Support,  
Awareness  
**63%**





## You Gave:

- \$1,163,778 donated through our annual program
- \$262,331 received through grants and sponsorships
- \$241,016 donated in tribute
- 10,110 participants walked in 22 Brain Tumour Walk events and fundraised \$1,863,858 – 53% of our fundraised income. 149 businesses sponsored a Brain Tumour Walk in their community
- \$466,405 raised by 64 Community Events
- 30,573 social fans increased awareness of brain tumours
- 1,192,683 page views of braintumour.ca (which was revamped in December 2019)
- Over 700 volunteers supported activities



*Thank you*

# Because you wore a hat...

Every fall, we pull on a hat to raise awareness of brain tumours across Canada. In 2019 people across Canada took selfies and posted with the hashtag #HatsforHope.

## Hats for Hope by the numbers:

- 3,000 hats sold!
- \$20,000 raised in 446 different communities across Canada, and 12 US communities
- 3 public schools held fundraisers
- 2,000+ social media posts
- 4,000,000 people reached online

## Hats off to all of you!

Alli Walker, Musician



Paul Sun-Hyung Lee, Actor



Chris Hadfield - Astronaut



A huge thank-you to New Era Grafix, for their support in selling and distributing our toques. Because of them (and you!) we raised \$10,000 in proceeds from the sale of these hats.



Cheque presentation at Sir Arthur Carty, the school attended by Kelly Northey at the time of her diagnosis, with one of our co-founders and other members of the Northey Family.

## Join us today!

Purchase, pass and post for hope! Here's how:

[www.braintumour.ca/hatsforhope](http://www.braintumour.ca/hatsforhope)

Regina Pats, Hockey Team



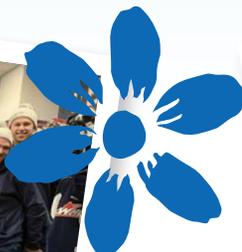
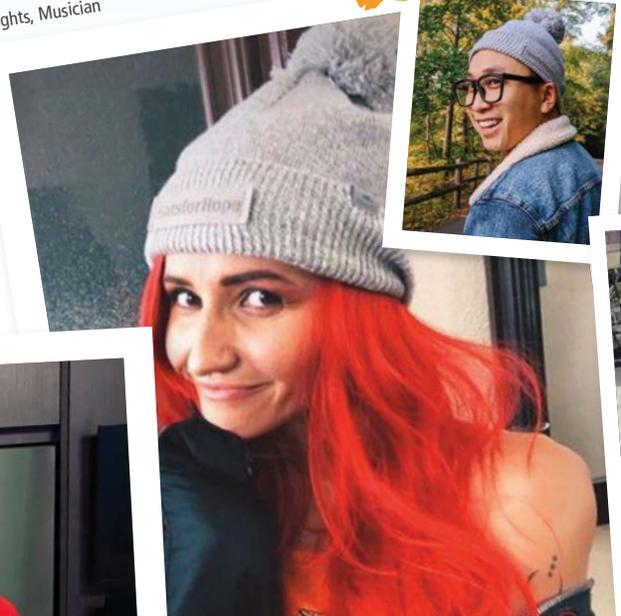
Max Kerman, Musician



Andrew Gunadie, Internet Personality



Lights, Musician



CTV Television Hosts



Piper Gilles, Olympic Ice Dancer



Brain Tumour Foundation of Canada Staff



# Because we need to pursue our dreams...

There are few feelings greater than seeing a pediatric brain tumour patient overcome their diagnosis and pursue their life goals. It exemplifies hope, and the promise of bigger and better things.

## Congratulations to the eight young adults going back to school with a Youth Education Award:



**Hope Edwards,**  
Kelowna, BC  
*Generously funded by:*  
Deys Fabricating



**Adam Pike,**  
St. John's, NL  
*Generously funded by:*  
Phyllis Retty



**Rosstin Saniei,**  
Thornhill, ON  
*Generously funded by:*  
Deys Fabricating



**Alissa Lozhkin,**  
Toronto, ON  
*Generously funded by:*  
Bruce Power



**Tobin Haas,**  
Brampton, ON  
*Generously funded by:*  
Newhouse Family



**Carolyn Cowan,**  
Toronto ON  
*Generously funded by:*  
Rigatoni for Research



**James Wang,**  
Mississauga, ON  
*Generously funded by:*  
R. Angus King Legacy Fund



**Katie Phipps,**  
Mount Albert, ON  
*Generously funded by:*  
Deys Fabricating & Phyllis Retty

Liam Newhouse



Our newest funder to the list above is Liam Newhouse's family in Brampton. Liam was featured in the 2018 Hope in Action after he participated in the Brampton Brain Tumour Walk. We are delighted that his family have since chosen to fund one of these Youth Education Awards.

***"It is our pleasure to fund these awards that bring so much hope to young people affected by brain tumours. Our son is still years away from being able to apply for an award, but it's so reassuring to know that the awards are there for young people across Canada."***

- Newhouse family

# Because of your investment in research...



## Raymond Reilly

Brain tumour patients deserve a gold standard treatment, but if a brain tumour research grant recipient is successful, gold might in fact be a future treatment for people affected by glioblastoma!

Raymond Reilly, PhD, of the University of Toronto, received funding from us in 2019 for his project: 'Radiation Nanomedicine for Intraoperative Treatment of Glioblastoma Multiforme (GBM)'. This innovative study is expected to lead to a new radiation nanomedicine, composed of gold nanoparticles linked to a radioisotope, which could be infused near the tumour during surgery to prevent tumour recurrence in patients with glioblastoma, one of the most common and difficult to treat brain tumours. We provided two years worth of funding to kick start the project.

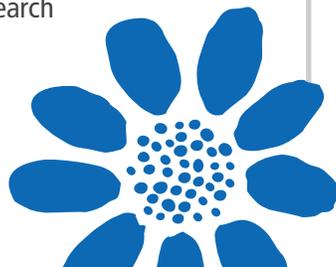
Raymond has recently told us:

*"We had some very good news recently in that we have received a two-year Innovation Grant from the Canadian Cancer Society to continue and extend this project. The preliminary work supported by Brain Tumour Foundation of Canada led to this successful grant funding, which will allow us to make significant progress going forward. One of my graduate students recently transferred to a PhD program to work exclusively on this project. Naturally, I will emphasize the funding from Brain Tumour Foundation of Canada in my presentation, which has and continues to support this research".*

Raymond has been so grateful to us for funding his grant, that he has in turn generously donated to help fund further brain tumour research!

If you want to propel brain tumour research forward, please donate!

[www.braintumour.ca/donate](http://www.braintumour.ca/donate)



Thank you MetaLab Design for partnering with us to establish the Liedke MetaLab Research Fund to invest in research with a glioblastoma focus. Your \$100,000 gift is putting hope into action.



**MetaLab**

Learn more about this project, as Raymond is one of the speakers at the Research Symposium and Student Competition, which will be held online on October 3, 2020. Register now. Spaces are limited.

[www.BrainTumour.ca/ResearchSymposium](http://www.BrainTumour.ca/ResearchSymposium)

## Because brain tumours need to count...

In May 2019 we launched the Brain Tumour Registry of Canada, the first ever registry to count both malignant and non-malignant brain tumours. The first report looked at the incidence rates across 70% of the population.



One year later, on May 14, 2020, we launched the second report on survival data for the same population base.

A pan-Canadian report will be released later in 2020, using comprehensive national data on incidence and survival rates. Our goal is to ensure that every brain tumour in Canada is routinely counted, to make sure every brain tumour counts.

[www.braintumour.ca/registry](http://www.braintumour.ca/registry)

# Our research investments...

From **1985-2019** we have committed **\$7,687,508.50** to research **261 opportunities**.

We funded the **Brain Research Laboratory** from **1986-1990** and provided **\$197,726.00** in support.

In **1991** this was renamed the **Brain Tumour Tissue Bank** and since then we have since provided **\$1,590,619.59** in funding.

Since **1988** we have provided **99 Research Grant Awards** which total **\$2,169,080.03**.

From **1989-1992** we funded **Fellowships** and gave out **7 awards** that awarded **\$198,643.00**. This program was reintroduced in **2010** and since then we have provided **10 awards** that have awarded **\$1,000,000.00**.

In **2011** we began a feasibility study to see if a **Brain Tumour Registry** was possible and since then have supported **\$392,193.00** to this project. The Brain Tumour Registry of Canada **officially** launched in **2019** and there have been **2 reports** since.

In **2013** we awarded our first **Education awards** and since then have given out **31 awards** which total **\$166,675.38**.

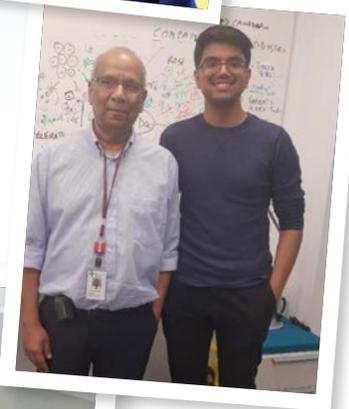
In **2013** our **Studentships** were introduced and since then we have provided **26 students awards** totalling **\$260,000.00**.

Since **1988** we have helped support various **Scientific Conferences** and provided funds to **23 meetings** totalling **\$107,660.00**.

Since **2006** we have partnered with the **Brain Tumour Funders Collaborative** to contribute **\$269,957.50** to brain tumour research.

For all our research grants, opportunities, and initiatives, please visit:

[www.braintumour.ca/research](http://www.braintumour.ca/research)

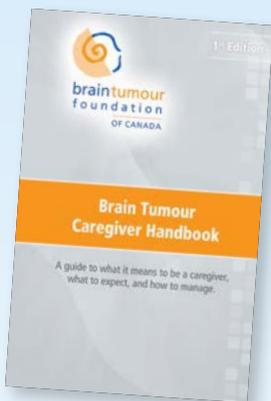


# Because caregivers need care too...

*"The symptoms of what a person goes through when they have a brain tumor is nothing like what we've ever been through with her cancer before"*

– Taylor Swift on her Mother's brain tumour diagnosis.

To order your copy, please visit [www.braintumour.ca/requestinfo](http://www.braintumour.ca/requestinfo)



*"Being a caregiver is hard. Being a caregiver of someone affected by a brain tumour is even harder."*

In 2017 we surveyed our caregivers and were grateful for all the responses which helped bring a Brain Tumour Caregiver Handbook into fruition. This new handbook was launched in December 2019.

*"I have started reading the caregiver handbook and although not far into it I have had tears. Tears for families I have seen go through the brain tumour experience. Tears of joy that we now have more to offer patients and families with this resource."*

– Patricia Randall, Registered Nurse  
Clinical Neurosciences Unit, Foothills Medical Centre, Calgary, AB



More caregiver information:  
[www.braintumour.ca/caregiver](http://www.braintumour.ca/caregiver)

## Support Update

To further support our caregivers, we have added a 5th group to our Virtual Support Groups. Now there are 2 groups that meet online for caregivers.

Thank you also to Dynacare for your support of our caregivers. Not only did Dynacare employees choose to make us their 2019-2020 Lead Charity, they also took part in Hats for Hope, provided gifts for caregivers at Christmas 2019, and participated in the 2020 Virtual Brain Tumour Walk.



# Because you volunteered...



**Support Groups. Brain Tumour Walk events. Governance. National Material Distribution. Fundraising. Awareness-Raising. BrainWAVE. Research.** All of these things can happen because of more than 700 critical volunteers.

Every year, we bring our leadership volunteers together to provide training, and, in 2019 we also hosted a Celebration Dinner to honour and recognize outstanding contributions with the Volunteer of Distinction and David Kelly Award for Community Service.



## Congratulations to the recipients of the 2019 Volunteer of Distinction Awards:

### **Danielle Barclay**

Danielle began to volunteer with Brain Tumour Foundation of Canada in June of 2016 as the convenor of the Edmonton Support Group. A survivor herself, she recognized the importance of providing the brain tumour community with a place to go to share their stories and receive support.

### **Arlette Boghonskhan**

Arlette, from Montreal, QC, has been involved with the organization of the Montreal Brain Tumour Walk for over four years. Her efforts have helped to save thousands of dollars in food, activities and raffle/gifts which are offered to our participants every year.

### **Michele Bliss**

Michele started volunteering as the facilitator of the Burlington Support Group in June of 2017. A brain tumour survivor herself, Michele's unique perspective has been instrumental in helping her mother deal with her own brain tumour diagnosis.

### **Hazel Neely**

Hazel started to volunteer in Brain Tumour Foundation of Canada's London office in November of 2016. Having just recently retired, she wanted to give back. If you have ever called the office for assistance, chances are you have heard Hazel's warm and caring voice on the other end of the phone.

Learn more about all of these award recipients:

[www.braintumour.ca/get-involved/volunteer](http://www.braintumour.ca/get-involved/volunteer)

## Congratulations also go to the recipients of the David Kelly Award for Community Service:



The David Kelly Award for Community Service is awarded annually to individuals who exemplify the spirit of community service in support of the brain tumour community in Canada.

**Mark and Amie Donais**, along with a group of passionate individuals, recognized a need for increased funding in the area of pediatric research. It was out of this need that Rigatoni for Research was born. 15 years, 7 events and \$200,000 later, Mark, Amie and their committee have funded seven \$25,000 research grants and supported three \$5,000 youth education awards.



**In 2015, Barbie Brown and Rob Reichenbacher** lost their 12-year-old daughter Shandy to a brain tumour. Determined to keep Shandy's dream to find a cure for brain cancer alive, they created "Shandy's Dream for a Cure" to raise much needed funds for pediatric brain tumour research. Over the last five years, the small town of Edson, AB has come together every June to support Barbie and Rob and to remember Shandy. It is through their passion and with the support of their community, that they have raised over \$100,000 in support of pediatric research.



# Webinar Series

The Brain Tumour Webinar Series features various free webinars throughout the year which include topics around research, treatment, advance care planning, returning to work after a brain tumour diagnosis, personal stories from brain tumour survivors and caregivers, and more.

## Join us for these last three sessions:

### **Radiosurgery for Brain Metastases: Aggressive Care Through Non-Invasive Means** - Tuesday, October 27, 2020

Presenter: Dr. Hany Soliman, Radiation Oncology, Odette Cancer Centre (Toronto, ON)

### **Dignity Therapy: A Therapeutic Intervention for Individuals with Life-Limiting Illness** - Wednesday, November 25, 2020

Presenter: Dr. Janet Ellis, Psychiatry, Sunnybrook Health Sciences Centre (Toronto, ON), and a Brain Tumour Foundation of Canada Research Grant Recipient

### **When is Too Much? Knowing Your Limits During the Holiday Season** - Wednesday, December 16, 2020

Presenter: Todd Goold, Support Services Specialist, Brain Tumour Foundation of Canada (London, ON)



*"So helpful to hear other people's stories and experiences; that they are just like me and they survived. Nice to hear real stories of success from brain tumour survivors."*

Register now at  
[www.braintumour.ca/webinars](http://www.braintumour.ca/webinars)

**See you online soon!**  
**Connect with us on social media @BrainTumourFdn**

## 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.

## 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.**



205 Horton St. E  
Suite 203  
London, ON  
N6B 1K7

519-642-7755  
1-800-265-5106  
[www.braintumour.ca](http://www.braintumour.ca)

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