

Hope *in* Action

YOUR ACTION AND IMPACT PROVIDING HOPE FOR THE BRAIN TUMOUR COMMUNITY

Integrity



Collaboration



Hope



Caring



Accountability

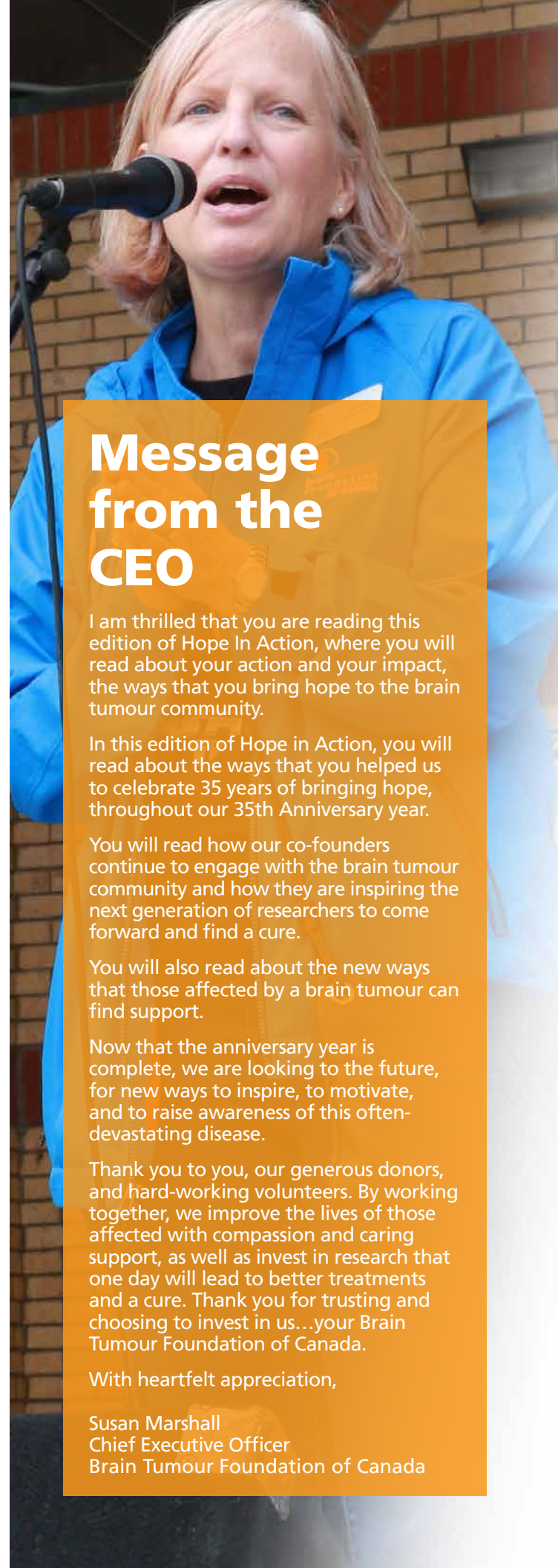
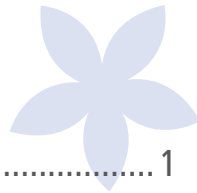


FALL
2018



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Message from the CEO

I am thrilled that you are reading this edition of Hope In Action, where you will read about your action and your impact, the ways that you bring hope to the brain tumour community.

In this edition of Hope in Action, you will read about the ways that you helped us to celebrate 35 years of bringing hope, throughout our 35th Anniversary year.

You will read how our co-founders continue to engage with the brain tumour community and how they are inspiring the next generation of researchers to come forward and find a cure.

You will also read about the new ways that those affected by a brain tumour can find support.

Now that the anniversary year is complete, we are looking to the future, for new ways to inspire, to motivate, and to raise awareness of this often-devastating disease.

Thank you to you, our generous donors, and hard-working volunteers. By working together, we improve the lives of those affected with compassion and caring support, as well as invest in research that one day will lead to better treatments and a cure. Thank you for trusting and choosing to invest in us...your Brain Tumour Foundation of Canada.

With heartfelt appreciation,

Susan Marshall
Chief Executive Officer
Brain Tumour Foundation of Canada



Thank you for celebrating...

It had been 35 years since Steve Northey sat down with his daughter's Neurosurgeon, Dr. Rolando Del Maestro and his wife Pam, a Neuroscience Nurse, to map out the concept of the Brain Research Fund (Brain Tumour Foundation of Canada's original name).

We are proud to still be here, continuing their vision to find a cure for brain tumours and to provide information and support for those affected.



We are thrilled our co-founders are still actively involved with our organization and we had many reasons to celebrate with them, from Steve being the MC for the Celebration Dinner at the Brain Tumour National Conference, to inspiring the next generation of undergraduate students to compete through the inaugural Pam and Rolando Del Maestro Family Undergraduate Student Research Competition Awards (more on pg. 9 in this issue).

Thanks to the generosity of donors and volunteers, Brain Tumour Foundation of Canada has now been making an impact on the lives of patients and families for 36 years. With your support, we will be here until a cure is found.

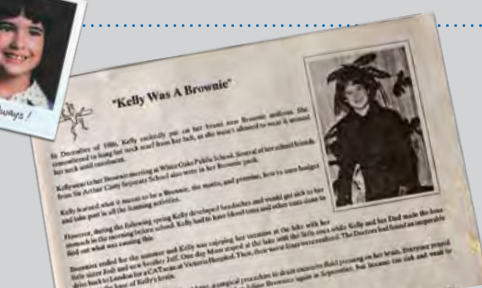
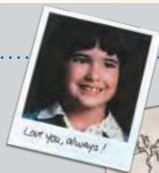
Learn more about the 35th Anniversary activities at <https://www.braintumour.ca/35>



Here's our story...

1982

Kelly Northey Passes away due to a brain tumour; the search for a cure begins.



Kelly's Hat



Thank You For Walking...



...Because those affected by brain tumours should never walk alone.



Liam Newhouse walks as a proud survivor...

Brampton Brain Tumour Walk

"Liam, by way of a routine eye exam on his 9th birthday, was noted to have papilledema (swollen optic nerve) and was sent to SickKids for further assessment. After an MRI the same day, Liam was diagnosed with a Pilocytic Astrocytoma and underwent 8 hours of surgery the following day where they completed a full resection. After some time in hospital and rehab, Liam made a full recovery. Liam has since had a tumour free 1-year MRI and is very proud of his recovery. Within 9 months of his surgery, he and his hockey team went on to win a gold medal with Liam getting 8 goals and 9 assists for the year. Liam is a true miracle and is a proud ambassador for SickKids and the Brampton Brain Tumour Walk. He remains fully and unconditionally supported by his parents, Stephanie and Scott, his brother Ethan, and all his friends and family who all support him on the annual walk." - Stephanie, Liam's Mom



...To bring hope.

1985

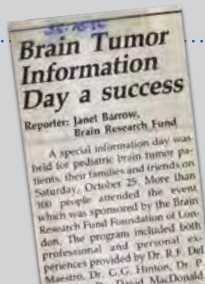
First donation of \$95,000 Cavitron Surgical Aspirator to Victoria Hospital.



2

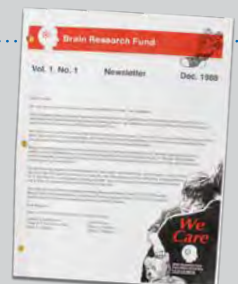
1985

First Information Day conference; a day of hope, support and learning for patients, families and physicians.



1988

First issue of Brainstorm Newsletter; now delivering more than 12,000 copies via email.





...To raise awareness.

...To find a cure.



...To celebrate survivors.



Tammy Farand walks in memory and to raise awareness...

Edmonton Brain Tumour Walk

"In 2017 I registered a team, Farand's – "For the Fight", to walk in memory of my dad, Adrian, and my sister Pat who were both taken by glioblastoma brain tumours. After I participated in my first walk, I knew I had found a purpose to not only continue "the fight" that my loved ones lost but to give hope to others battling a brain tumour diagnosis. Raising awareness, fundraising, and encouraging others to join the movement has become very important to me. I choose to no longer be afraid to talk about brain tumours but instead do my part to try to make a difference.

Those we love don't go away; they walk beside us every day and I know my dad and sister walk with me when I participate in the Brain Tumour Walk. It's a day every year that I can honour them in a beautiful way."



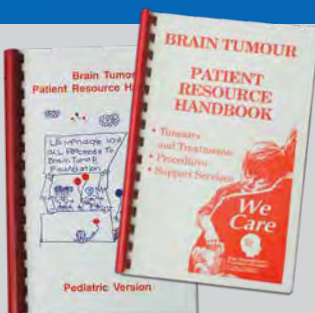
Markella Gionet walks in hope...

Victoria Brain Tumour Walk

"Brain tumours had touched my life three times before I began supporting this event through participating in the annual Brain Tumour Walk. My father was diagnosed with meningiomas when I was 6 months old, and luckily, he has thrived ever since his surgical treatment. My second encounter occurred in 2004 when a dear friend and mentor of mine unfortunately lost her battle to glioblastoma. Later that same year, I was diagnosed with pituitary adenomas. I knew then that I had to get involved and make a difference towards conquering this disease. I took over the coordination of the Victoria Brain Tumour Walk event 13 years ago and it has touched my life in so many positive ways since! I am honored and very proud to be a part of this Foundation that has made a difference in so many lives, including mine."

1989

First edition of the patient resource handbook published; now in its 6th edition.

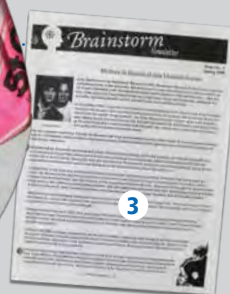


1989

First support meeting; now a network of 26 support groups across Canada.



Nicole Victoria Duffin's Hat



Thank you for raising awareness and funds...

Since his diagnosis in 2011, Connor Thomson has been actively fundraising through **"Birdies for Brain Tumours"**, an annual golf tournament hosted in Brandon, MB. Since its inception in 2012, the tournament has raised over **\$200,000** in support of our research program.



Although he has undergone 5 brain tumour surgeries, multiple rounds of chemotherapy and 30 treatments of radiation, Connor is always willing to share his story and supports activities happening in the Winnipeg area to raise awareness about research for this disease. For his leadership and commitment to funding brain tumour research Connor was awarded the David Kelly Award for Community Service in 2017.



Since then, his long-term friend Jason Earl has taken the helm of Birdies for Brain Tumours and Connor remains involved and eager to play.

There's only one event with a bear plan! It's also one of few road-races to take place in a National Park setting. The **Banff Jasper Relay** involves teams of 15 runners racing a total of 260 km along the Icefields Parkway – in one day!

Blair Shunk has been at the helm of the annual Banff Jasper Relay for more than a decade. Blair, who revived this annual relay marathon in honour of a loved one and avid runner who passed away from a brain tumour in 2004, thought it was only fitting to do so in Garth's honour and, at the same time, to raise awareness and funds to help those impacted by the same disease that took his friend's life.

Since its first year, the Banff Jasper Relay has raised well over \$500,000 for brain tumour research and programs.

In recognition of Blair's commitment and leadership, he was awarded the David Kelly Award for Community Service in 2016.



To learn more about how you can organize an event in your community, visit: <https://www.braintumour.ca/communityevents>

1991

Brain Tumour Tissue Bank created; provides free clinical samples for research projects around the world.



1994

Founding member of the North American Brain Tumour Coalition.



1994

First Pediatric Fun day; now known as the BrainWAVE support program for families.



Brain Tumour Foundation of Canada Develops New **SUPERKIDS** Program!



Caped crusaders, masked heroes, and sidekicks unite to celebrate the **HERO** that lies within us all.
Let's unleash the **POWER** of **HOPE** and conquer brain tumours together!

Grab your capes, pull on your spandex tights and release your inner hero! Come out or host your own fun day in support of pediatric brain tumour research, and enjoy a day featuring activities for all ages!

SUPERKIDS UNITE!



Thank you for hosting...

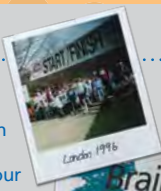
KIDSTOCK – A Quest to End Brain Tumours (Woodstock, ON, Sunday, August 12, 2018)

The idea for the event was born out of tragedy. In less than two years, three families in Woodstock had children die from brain cancer. "The families of those children wanted to do their part and have an event the

community could enjoy as a way to thank them for their support over the years as their children lived with brain tumours," event co-organizer Liz Wismer-Van Meer said. While the focus of the event was to raise awareness and funds, the aim was to keep it entertaining for all involved. A family fun event for kids and kids at heart.

1995

Spring Sprint brand launches and held in one city which raised \$4,000; now known as Brain Tumour Walk, held in 20+ cities across Canada; exceeding 1.7 million raised in 2018.



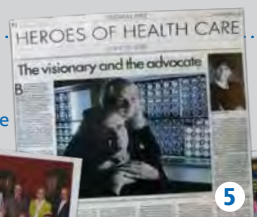
1999

Founding member in creating the Canadian Alliance of Brain Tumour Organizations.



2000

Canadian Neuro-Oncology Scientific Conference sponsorship in honour of Dr. Rolando Del Maestro.



Your 2017 hope in action...

✦ \$479,569 invested in research projects

Including:

- ✦ 1 Fellow, 5 Research Grants, 5 Research Studentships, The Pam and Rolando Del Maestro Family Undergraduate Student Research Competition Awards in which 9 teams took part
- ✦ 93,148 to fund the Brain Tumour Tissue Bank supporting seven research investigators across Canada, Israel and the United States
- ✦ \$125,000 invested to fund year three (3) of the Pediatric Brain Cancer Impact Grant
- ✦ The Canadian Brain Tumour Registry Project

✦ \$277,838 donated in tribute

✦ 8,397 participants walked in 21 Brain Tumour Walk events and fundraised \$1,809,041 – 52% of our fundraised income. 70 businesses sponsored a Brain Tumour Walk in their community

✦ 5 childhood brain tumour survivors were awarded post-secondary school scholarships

✦ 2 Health Care Professional (HCP) Professional Development Awards

✦ 25 in-service presentations reaching over 432 Health Care Professionals

✦ 230 Support Group meetings

✦ 7,240 handbooks were distributed in both languages

✦ 13 BrainWAVE events

✦ 873 participants either in person or online joined the 2nd Brain Tumour National Conference in Toronto and Montreal

✦ 3,297 donors through our annual program



✦ \$405,127 raised by 80 Community Events

✦ 35th Anniversary Golf Classic \$35,014

✦ 23,670 social fans increased awareness of brain tumours

✦ 1,311,058 page views of www.braintumour.ca

✦ 29 landmarks were lit up for Brain Tumour Awareness Month and 11 proclamations were made in 2017

✦ Over 700 volunteers supported activities



2000

First Canadian Association of Nurses (CANN) Award, named in honour of Pamela Del Maestro.



2001

The Province of Ontario declares October to be Brain Tumour Awareness Month; now celebrated in May.

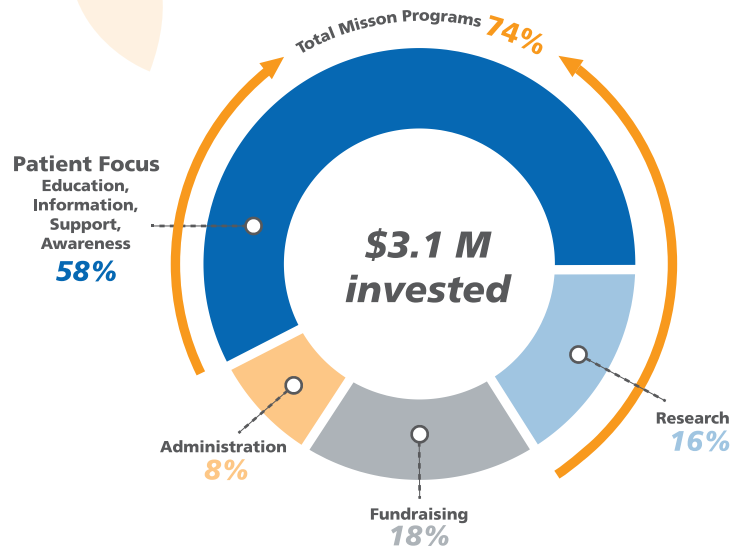
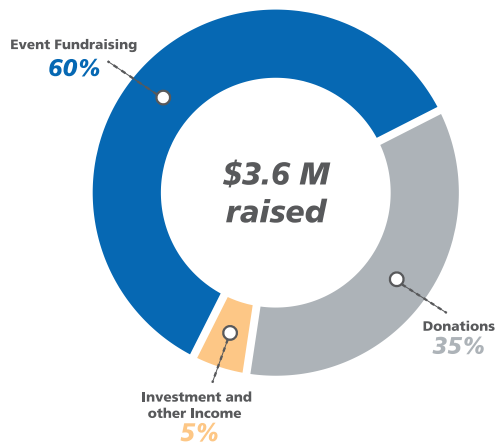


2002

Virtual support centre, patient forums, and online chat features are added to the website.



Thank you for giving in 2017...



Thank you for volunteering...

It was volunteers who first sat around the kitchen table in 1982 to begin the effort to reach every Canadian affected by a brain tumour with support and information and begin the work towards a cure.

In March 2017 we were grateful to attend the Ontario Ministry of Immigration and Citizenship Volunteer Service Awards and honour those three volunteers, our co-founders, with an award to represent their 35 years of service! Also pictured is Dr. Joe Megyesi, neurosurgeon and former Chair of our Board of Directors for his 30 years of service.

As a national organization we could not run our programs, services and other events without the support of more than 700 volunteers. In 2017 we recognized four volunteers with the Volunteer of Distinction Awards; Rick Bradt, Rachel Brown, Diane McFarlane, and Claire Snyman.

Learn more: <https://www.braintumour.ca/volunteersofdistinction>

In addition, there were not one but two recipients of the David Kelly Award for Community Service. This award honours those who exemplify the spirit of community service in support of the brain tumour community in Canada. Congratulations to Jennifer Gouchie-Terris and Connor Thompson.

Learn more: <https://www.braintumour.ca/davidkellyaward>

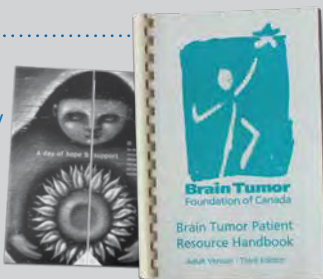


We are looking forward to presenting the 2018 awards at the Brain Tumour National Conference Celebration Dinner on October 19, 2018.

You're welcome to join us at this ceremony. www.braintumour.ca/conference.

2005

First Canadian Association of Nurses in Oncology (CANO) Award presented.



2005

Children's Storybook is produced; now available in English, French and Italian.



2005

North American Brain Tumor Funder's Collaborative is established.



Thank you for Fostering HOPE

Dr. Ugljesa Djuric

Richard Motyka Brain Tumour Research Fellow (2017)

Project: "Systematic proteomic profiling and subclassification of Glioblastoma"

Location: University Health Network, Toronto, ON

"Being awarded the Richard Motyka Brain Tumour Research Fellowship means that I can continue to pursue my passionate career of finding better treatment options for glioblastoma brain tumour patients.

Although genomics-based breakthroughs have made moderate impacts on improving patient diagnosis, overall glioblastoma survival rates have remained stagnant over the last twenty years.

With the generous support of this fellowship I can focus on utilizing the newest available proteomics technologies to further understand this devastating cancer and improve patient outcomes as a result. Indeed, mass spectrometry-based proteomic efforts have shown promise in other tumour types as a superior profiling method to understand abnormal tumour-related biological pathways. Translating this technology has potential in further subdividing glioblastoma tumours into distinct subtypes and thus could uncover previously unrecognizable treatment approaches.

As a medical researcher, I always strive to generate results that can positively affect patient outcomes and I am tremendously grateful for the generosity of the Motyka family and Brain Tumour Foundation of Canada for their continued support of the brain tumour research field".

Learn more:
<https://www.braintumour.ca/udjuric>



Dr. Ugljesa Djuric,
Research Fellow

2008

Canadian Association of Psychosocial Oncology (CAPO) Award is launched to showcase the important work of psychosocial oncology professionals.



Richard A.
Bradt's Hat

2008

First Health Care Professional Symposium; brings brain tumour education to health care professionals and front line staff.



2009

First In-Service held for neuro-oncology and neuroscience teams working with people affected by a brain tumour.



Brent Tyler
Spruce's Hat

The Pam and Rolando Del Maestro Family Undergraduate Student Research Competition Awards

In 2017 our co-founders demonstrated their ongoing commitment to the vision of our organization, by launching The Pam and Rolando Del Maestro Family Undergraduate Student Research Competition Awards to

inspire undergraduate students to begin a career in brain tumour research to find the cause of and a cure for brain tumours. 9 teams participated in the inaugural competition with monetary rewards going to the top three teams. The winning team had this to say about their experience:

"As an individual passionate about brain tumours, this Student Research Competition allowed me to network with like-minded students and gain a broader perspective on the multitude of novel strategies that can be employed to tackle this devastating

disease. Having come first place in the competition, we were given the opportunity to present at the Join the Movement to End Brain Tumours National Conference, where we interacted with children and adults suffering or affected by brain tumours; ultimately propelling motivation and giving our work meaning.

I encourage students interested in brain cancer research to attend and compete in this worthwhile learning opportunity!" - Ashley Adile

Research Grant (2018)



Dr. Pejman Jabehdar Maralani

Generously funded by Venera Fazio, Italian Canadian writer and poet

Project: Advanced magnetic resonance imaging for detection of tumour regions enriched with glioma stem cell niches
Location: Sunnybrook Health Sciences Centre

"Thanks to the generosity of Brain Tumour Foundation of Canada and its donors, I was able to validate the use of an advanced magnetic resonance imaging (MRI) technique called "quantitative blood oxygen level dependent" (qBOLD) imaging in assessing the level of tumour oxygen in patients with glioblastoma. This technique advances the field by allowing clinicians to identify low oxygen content parts of the tumour that are resistant to chemo and radiation therapy prospectively and noninvasively, without any additional risk for patients.

Learn more: <https://www.braintumour.ca/pmaralani>

Studentship (2017)



Ashley Adile

Generously funded in memory of Taite Boomer

Undergraduate Science Student at McMaster University

Project: Small molecule inhibitors targeting self-renewal as a therapeutic option for recurrent childhood medulloblastoma

"Being awarded a Brain Tumour Research Studentship means the opportunity to continue my life motto that "the learning never stops", allowing me to pursue valuable work in medulloblastoma research. This recognition strengthens my commitment towards a career in medicine, in hopes of making a meaningful contribution towards finding a cure for those impacted by this debilitating disease. I am both honoured and humbled by this studentship and sincerely thankful to Brain Tumour Foundation of Canada, its generous donors and patients who nobly donate their tumour samples to make this research possible. I am grateful for the opportunity to work alongside Dr. Sheila Singh and her lab of innovative scientists."

Learn more: <https://www.braintumour.ca/aadile>

Youth Education Award (2017)



Andrew Welsh

Generously funded by West Coast Trail Hike

Pursuing Biomedical Engineering at the University of Waterloo

Diagnosed with a suprasellar craniopharyngioma at age 9

"Having successfully battled a brain tumour, I have experienced firsthand the benefit that biomedical technology has in saving a person's life and want to give back in that area. This award will lessen my financial burden, allowing me to focus more on my studies as I continue my third year of Biomedical Engineering – inspiring me to keep going when the journey gets tough. It will help me reach my goal of helping others who were in situations like me through medical technology."

Learn more: <https://www.braintumour.ca/educationawardees>

2010

Joined the world of Social Media; Introduced our Facebook and Twitter profiles.



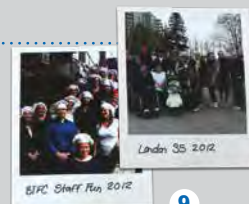
2010

First William Donald Nash Brain Tumour Research Fellowship awarded to Dr. Tommy Alain at McGill University in Montreal.



2012

The Canadian Brain Tumour Registry project was born; Dr. Faith Davis began work on Canada's first and only source of brain tumour data.



Thank you for raising awareness...

May is Brain Tumour Awareness Month and a chance for people across Canada to perform activities to start conversations and raise awareness of this devastating disease.



Some of the ways you can get involved include; lighting up landmarks, having Brain Tumour Awareness Month proclaimed by your local municipality, writing to the editor of your local newspaper, or simply wearing a grey ribbon.

We are also grateful for the support of the Minister of Health, Ginette Petitpas Taylor, for her support and kind

words in a video that was released in May, featuring Chris, a member of the brain tumour community.

The next official opportunity to raise awareness is International Brain Tumour Awareness Week, October 20-27, 2018.

Learn more about what you can do for Brain Tumour Awareness Month at <https://www.braintumour.ca/BTAM>

2012

First Richard Motyka Brain Tumour Fellowship was awarded to Dr. Samuel Lawn at the University of Calgary.



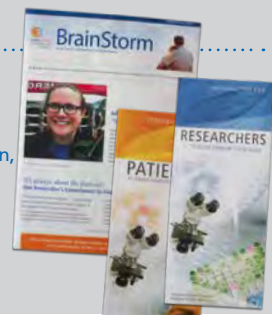
2014

First Stephen Buttrum Brain Tumour Research Fellowship was awarded to Dr. Florence Cavalli at the Hospital for Sick Children in Toronto, ON.



2014

First office opened in Montreal, QC; a second satellite office was established in Edmonton, AB the following year.



Signs & Symptoms Awareness

Brain tumours are more common than people think. Knowing the signs and symptoms can lead to faster diagnosis and better outcomes for the patient as a result. If you could please share the signs and symptoms and encourage anyone who is concerned to talk to their healthcare professional, you could just save a life. Thank you!

Learn more:

www.braintumour.ca/symptoms

Facebook Support Groups

You are never alone on the brain tumour journey. In December 2017, we launched our first Closed Facebook Support Group. A place where brain tumour patients, survivors, caregivers and loved ones can ask questions, share stories of hope and support, and support each other. More than 1,000 people are now members of this group.

Given the success of the first group, we have also opened a group specifically for anyone affected by a pediatric brain tumour. This means that we now offer four groups: General groups in both English and French, and groups for anyone affected by a pediatric brain tumour in both English and French.

Learn more, including how to become a member at:

<https://www.braintumour.ca/closedfacebooksupportgroup>



Our newest awareness poster - Brain Tumour Signs and Symptoms in Children



Brain Tumour Signs and Symptoms poster

Watch our social media for another new opportunity to raise awareness!



2015

First virtual support group introduced; now a part of 4 virtual support groups available to those affected by a brain tumour diagnosis.

Over the next four years, Dr. Michael Taylor and his team will study the most common pediatric brain cancer (medulloblastoma) in an attempt to personalize care for young children with brain cancer.



2016

First HCP Professional Development Grant is launched; provides funding to health care professionals who would like to attend a medical, scientific, or professional development conference or workshop.



Sterling Bacon's Hat

Thank you for supporting new programs...

GOcervo is a support program for families with a child or teenager

Since 1994, BrainWAVE has been making it possible for families in Southwestern Ontario, Lower Mainland British Columbia, and Alberta to have Wild Adventures Everywhere (did you know that's what the WAVE in BrainWAVE originally stood for?).



Early in 2018 this program expanded into Quebec with a new name 'GOcervo'. The GOcervo program has taken families in Montreal to see Disney on Ice and families in Quebec City to the aquarium and is working on new adventures for the fall. See details on all upcoming BrainWAVE events and photos from the previous events at

<https://www.braintumour.ca/gocervo>



Caregiver Wellness Days Support Caregivers

Showing our community, we 'care for the caregivers' we held the inaugural 'Caregiver Wellness Days' in 2018. These days are to inspire the caregiver to be the very best, so that they can continue to give their very best.

So far, these events have been held in Moncton, NB; Edmonton, AB and will be held in Winnipeg, MB in September 2018. If you are caring for a brain tumour patient, watch for similar events in a city near you soon.



2016

First Facebook support group created; more than 1000+ members have since joined the private group.



2016

First Brain Tumour National Conference is held in Toronto, ON.



See our next page to learn more about our Brain Tumour National Conference which is happening in Toronto and Montreal this October.

BRAIN TUMOUR NATIONAL CONFERENCE

TORONTO | SATURDAY, OCTOBER 20, 2018

PLUS: CELEBRATION DINNER - FRIDAY, OCTOBER 19, 2018

Sheraton Toronto Airport & Conference Centre - 801 Dixon Rd, Toronto, ON M9W 1J5



Presentation Themes:

Keynote Presentation:

▶ New Radiation Technologies for Brain Tumours

Dr. Arjun Sahgal, Radiation Oncologist, Sunnybrook Health Sciences Centre

- ▶ Care for Caregivers
- ▶ Life After A Childhood Brain Tumour
- ▶ Support for Non-Malignant Brain Tumours
- ▶ Cannabis
- ▶ Music Therapy
- ▶ Sexuality & Intimacy
- ▶ Personal Stories

PLUS: Top 4 Student Research Competition teams from across Canada will compete for The Pam and Rolando Del Maestro Family Undergraduate Student Research Competition Awards.

Who Should Attend?

- ▶ Anyone affected by a brain tumour
- ▶ Health Care Professionals
- ▶ Volunteers

**“ Loved the conference!
Loved being around people from
all over the country that are going
through the same thing as me. ”**

- Conference Attendee

Supporting Sponsors:



Agenda, Speakers, Live Streaming Options, Registration:

(Also learn about our Montréal Conference on Saturday, Oct. 27)

www.BrainTumour.ca/Conference

We've Moved!

In January 2017 we moved! Having been at the previous location for 13 years, we had outgrown the space and our staff were spread over two floors. Our new office space is on one floor, has technology that enables us to serve you better and, here's the best part, it costs less! As you can see from the photo, we are even able to have signage outside. If you see the signs, please stop in to say hello!

We are open Monday – Friday from 8:30 am to 4:30 pm EST. We hope to see you soon!

Our new address:

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



2017 / 2018 Board of Directors:

Rosemary Cashman	Maureen Daniels
Chris Sullivan	Kristin Danniels
Phyllis Retty	Dr. Thierry M. Muanza
Lynn McRae	Dr. Adrianna Ranger
Jennifer Bell	Robin Urquhart
Ron Craig	Jennifer Wilson

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.

Leaders of Distinction:

Steve Northey, Co-Founder
Pamela Del Maestro, Co-Founder
Dr. Rolando Del Maestro, Co-Founder
Perry Ferguson, Founding Director
David Lucy, Founding Director
Jane Hauser, Leader of Distinction
Phyllis Retty, Leader of Distinction
Melodie Northey, Leader of Distinction
Dr. Joseph Megyesi, Leader of Distinction

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.**



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