



braintumour
foundation
OF CANADA

HOPE IN ACTION

2023 IMPACT REPORT TO THE COMMUNITY

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A MESSAGE FROM THE CEO



As I look back on 2023, I am grateful to reflect on another impactful year with Brain Tumour Foundation of Canada. Joining the team in 2022 during the organization's 40th anniversary was an honour, and witnessing the resilience and dedication of our community throughout the past year has been incredible.

One of the highlights of 2023 was our renewed focus on research funding. This continued investment underscores our dedication to driving progress in understanding and treating brain tumours.

Our advocacy efforts accelerated in 2023, as we engaged in new initiatives and continued to champion equitable access to treatments and resources for individuals living with brain tumours.

The Brain Tumour Walk Program, Hats for Hope, Power of Hope, and Community Events all contributed in a meaningful way to our ability to drive our mission, through awareness and fundraising.

As we look ahead to the future, I am filled with gratitude for the enduring support of our donors, fundraisers, volunteers, healthcare professionals, and dedicated staff. Together, we have made remarkable strides in advancing our mission, but there is still much work to be done. In 2024 and beyond, I am committed to continuing this journey alongside our incredible community, making a positive impact on the lives of those affected by brain tumours.

With heartfelt gratitude,

SHANNON LAHAY

Chief Executive Officer

A MESSAGE FROM THE CHAIR

Throughout my years of involvement with Brain Tumour Foundation of Canada, I've had the privilege of witnessing remarkable resilience and achievements. Together, through hard work, dedication, creativity, and passion, we've accomplished incredible feats.

For more than four decades, Brain Tumour Foundation of Canada has sought the causes and cures for brain tumours while enhancing the lives of those affected by them.

We are committed to honouring our past, being thankful for the present, and eagerly striving toward positive changes we can bring about in the future. Whether you joined us recently or have been with us from the start, your financial support has been vital on this journey.

With profound gratitude,



FAITH DAVIS
CHAIR, BOARD OF DIRECTORS



BOARD OF DIRECTORS

The Board of Directors of Brain Tumour Foundation of Canada (BTFC) holds the primary responsibility of advancing the organization's mission, overseeing its management, and ensuring its strategic direction. The board is responsible for making policy decisions, ensuring financial stability, selecting and evaluating the CEO, and monitoring the organization's work.



Faith Davis, PhD, FACE, FCAHS, Chair

Faith Davis, a cancer epidemiologist with over 40 years of experience, chairs the BTFC Board. Retiring from the University of Alberta in 2018, Dr. Davis passionately advocates for an innovative, multidisciplinary approach to enhance care and support for brain tumour patients and caregivers in Canada.



Bill Walker, Vice Chair

Bill Walker is the president and CEO of the Organization of Canadian Nuclear Industries (OCNI) and a BTFC board member. He recently retired as MPP and is a brain tumour advocate in honour of his son.



Kristy Allen, MPH

Kristy Allen, MPH, is a knowledge translation and implementation co-ordinator at the Waypoint Research Institute, within the Waypoint Centre for Mental Health Care in Penetanguishene, Ont.

As a BTFC board member and member of the Advocacy Committee, Kristy contributes her professional expertise in public health, knowledge translation and community engagement.



Dela Avle, Secretary and Chair of Governance Committee

Dela Avle, general counsel at Bruce Power, serves on BTFC's Board Governance Committee. His involvement is motivated by his belief in the organization's vital work and his desire to contribute his skills and time to support its mission.



Shreya Gandhi

Shreya Gandhi, an aspiring clinician-scientist, is a graduate student researching at the MacFeeters-Hamilton Center for Neuro-Oncology Research at Princess Margaret Cancer Research Tower. In addition to her role as director on BTFC's Board of Directors, Shreya chairs the BTFC Advocacy Committee.



Rebecca Harrison

Rebecca Harrison, MD, a neuro-oncologist at BC Cancer, joined the Board of Directors to support its work in neuro-oncology research and advocacy, with a focus on improving outcomes for brain tumour patients and their families.

**Sarah Ironside**

Sarah Ironside, a neuro-oncologist at Horizon Health Network, holds academic positions at Dalhousie University and Memorial University. She has a diverse medical education, specializing in neurology and neuro-oncology, with a particular interest in improving outcomes and care accessibility for brain tumour patients.

**Adam Lakusta**

Adam Lakusta, a Calgary-based lawyer, actively participates in the organization's initiatives, driven by a personal connection as a brain tumour survivor. His diverse education and Western Canada experience bring a unique perspective to his contributions to the organization.

**Daniel Mendelsohn, MD, MSc, FRCSC**

Daniel Mendelsohn, a neurosurgeon at Lion's Gate Hospital, serves on BTFC's Board and its Information, Support, and Education Committee. His involvement is driven by his work in brain tumour operations, and he aims to improve patient experiences in dealing with these diagnoses.

**Mike Mutrey**

Mike Mutrey, a marketing and business development professional, joined BTFC's Marketing Committee in 2022. Inspired by his father's battle with gliosarcoma, he aims to help the organization achieve its education, awareness, and support goals as a board member.

**Mary Lou Robertson, BA, BSW, RSW**

Mary Lou Robertson, a registered social worker with nearly 25 years of experience in health care navigation, covers oncology, mental health, geriatrics, and neurology. As a board member and Advocacy Committee member, she brings her health care expertise and extensive knowledge of drug and treatment access policies in Canada to the organization.

**Russell Smith, Treasurer and Chair of Finance Committee**

Russell Smith is the director of Internal Audit at City of Dreams Manila, leveraging more than 30 years of CPA and CGA experience. He joined BTFC in 2006, due to his daughter's brain tumour diagnosis. After her passing in 2011, he continued to volunteer and joined the Board in 2019.

**Arun Thomas**

Arun Thomas, CIO at Dynacare, is a dedicated Board member and Finance Committee contributor. He also serves on the board of Rapport Youth and Family Services, a not-for-profit offering counselling and support to youth in the Peel Region of the GTA. His commitment to giving back drives his community involvement.



SUPPORT, INFORMATION AND EDUCATION

Brain Tumour Foundation of Canada exists to bring support, information, and resources to people affected by brain tumours throughout Canada. In 2023, we continued to offer support in a way that has evolved as a result of the pandemic. This means that some of our programming and support took place virtually and required us to be creative and persistent in our efforts to connect and engage with our community. We also saw a return to some in-person support groups and events.



We offer four types of **Brain Tumour Handbooks**, each geared towards a different aspect of the brain tumour experience (adult patients, pediatric patients, those diagnosed with a non-malignant brain tumour, and caregivers) and available in English and French. In 2023, nearly 2,000 handbooks were distributed, either in print or electronically, in both English and French.



Our **children's storybook**, A Friend in Hope, tells the story of a little girl named Hope and her journey with a brain tumour, for our pediatric community. In 2023, we received close to 350 orders of our A Friend in Hope storybook.



In 2023, we continued our adaptive efforts to adapt to the evolving needs of our community. In total, more than 15 in-person, city or hybrid **support groups**, four virtual groups and eight private Facebook groups offered support to patients, survivors, caregivers and family members.



BrainWAVE (GOcervo in Quebec) is our volunteer-led pediatric support program for families with children or teens affected by a brain tumour. In 2023, we were able to return to in-person events for the first time since 2019. We held eight in-person events in Ontario, Vancouver, Edmonton, Montreal and Quebec City. We also sent out two mailings to our GOcervo families, which included water park, national parks and movie tickets for the entire family.



Our **SUPERKIDS education program**, developed by teachers, students, and parents within the brain tumour community, educates students about brain tumours and nurtures empathy and support for those affected by them. Since 2021, these lesson plans have exceeded 200 downloads.



Beyond Brain Tumours is our **podcast** by, for, and about the brain tumour community. Brain tumour survivors, patients, and caregivers share their stories and perspectives on brain tumour treatments, research, and survivorship. Since its launch in May 2023, we've recorded eight episodes which count more than 1,000 downloads.



In 2023, we hosted eight **webinars** on a variety of topics, including caregivers' mental health, updates on treatment and research, brain tumours in adolescents and young adults, awake brain tumour surgery, and personal stories of hope. More than 660 people registered, and 381 participants watched the presentations live. Our French-language virtual conference also reached over 230 participants, including patients, survivors, caregivers, and health care professionals.



In 2023, we continued our collaboration with Mike Lang, a **digital storytelling** specialist, director, and producer, to provide a unique platform for our young adult community members to express themselves through a digital film series. Six young adults shared their digital stories, which were broadcast live on Facebook. The videos have over 4,100 views on social media and YouTube.



We provided **retreats** for caregivers and young adults living with a brain tumour. Young adults aged 18 to 39 attended a retreat at Five Oaks, in Paris, Ontario. Caregivers were also invited to attend two retreats in New Brunswick and Ontario.



YOUTH EDUCATION AWARD RECIPIENTS

Survivors of a pediatric brain tumour between the ages of 16 and 29 who are pursuing post-secondary education in Canada are eligible for our annual Youth Education Awards. These awards of up to \$5,000 are offered to encourage young brain tumour survivors to pursue their dreams of education, while recognizing the significant barriers and financial challenges they may face. In 2023, we celebrated 10 years of providing these awards by granting 10 Youth Education Awards.



Ilya Bigarov (Ottawa, Ont.)
Computer Services Technician,
Algonquin College.
Diagnosed with an ependymoma at
age eight.
*Generously funded by R. Angus
King Legacy Fund.*



Justin Lou (Richmond Hill, Ont.)
Bachelor of Arts in Speech and
Language Sciences, York University.
Diagnosed with a medulloblastoma at
age four.
*Generously funded by Deys
Fabricating.*



Ryan Burris (Campbellton, N.B.)
Pursuing D. des sciences de la
santé, University of Moncton.
Diagnosed with a
craniopharyngioma at age 14.
*Generously funded by Deys
Fabricating.*



Daniel Peters (Waterloo, Ont.)
Fitness and Health Promotion, at
Conestoga College.
Diagnosed with a low-grade glioma at
age 12.
*Generously funded by BTFC in honour
of Susan Marshall.*



Alicia Chenier (Sudbury, Ont.)
Bachelor of Arts in Disability
Studies, Toronto Metropolitan
University.
Diagnosed with a
craniopharyngioma at eight
months.
*Generously funded by Kumar
Classic.*



Haven Raeburn-Gibson
(London, Ont.)
Bachelor of Arts, Kings University
College.
Diagnosed with a medulloblastoma at
age 15.
*Generously funded by Deys
Fabricating.*



Arianna E.-Johnson (London, Ont.)
Undergrad in Classical Studies,
Western University.
Diagnosed with a pituitary
macroadenoma at age 18.
*Generously funded by Deys
Fabricating.*



Sophia Spencer (Winnipeg, Man.)
Bachelor of Science, University of
Manitoba.
Diagnosed with a diffuse low-grade
glioma at age 17.
*Generously funded in honour of Alison
Watts.*



Brett Joseph (Edmonton, Alta.)
Bachelor of Arts, University of
Alberta.
Diagnosed with a pilocytic
astrocytoma at age 13.
*Generously funded by Stone Tree
Golf and Fitness.*



Cassandra Stewart (Fredericton,
N.B.)
Bachelor of Education, St. Thomas
University.
Diagnosed with an astrocytoma at
four months old.
*Generously funded by BTFC donors
and Rigatoni for Research.*

BRAIN TUMOUR WALK PROGRAM

In 2023, communities throughout Canada once again united in celebration and remembrance to honour our heroes. With a shared mission to end brain tumours, we walked, raising funds to advance life-changing research, support programs, information dissemination, advocacy efforts, and, most importantly, hope. Originally planning 25 in-person events throughout June, our plans faced unexpected challenges when wildfires swept through certain regions. Four events were canceled to prioritize the health and safety of our vulnerable community members.

\$1,832,884

RAISED FOR THE 2023
BRAIN TUMOUR WALK

5,527

PARTICIPANTS

645

TEAMS

19,032

DONATIONS

41

SPONSORS

475

SURVIVORS

28

VOLUNTEER
COORDINATORS

CONGRATULATIONS TO OUR 2023 CUP OF HOPE CHAMPIONS!

Hope is the common thread that weaves the brain tumour community together. Each year, we celebrate hope by awarding the coveted Cup of Hope to our top team and individual fundraisers from the Brain Tumour Walk.



Brain tumour survivor **Dave Fleischer** of Kitchener, Ontario, received this year's individual Cup of Hope for raising an incredible \$30,000 during this year's Kitchener-Waterloo Brain Tumour Walk.

"I never put it out there to be the top fundraiser, but I'm pretty happy and proud that we were able to contribute what we did." – **Dave Fleischer**



Mal Chamberlain's #1 Fans scored this year's team Cup of Hope, surpassing their \$40,000 goal and raising more than \$46,250 through their participation in the London, Ontario Brain Tumour Walk.

"After tiring weeks of treatment and managing symptoms, the Walk was such an inspiring and encouraging event from start to finish." – **Mal Chamberlain**





OUR GENEROUS DONORS

Community events remain a key component of our fundraising program and represent the commitment of our community to make an impact. These events are hosted throughout the country by individuals, businesses, schools, and organizations.

Funds raised are not the only measure of meaningful impact for these events. Having events hosted in locations across the country raises awareness and the profile of BTFC, ensuring that we are able to reach more patients, survivors, caregivers, and other stakeholders who can benefit from our support and help us fulfill our mission.

Thank you to all our 2023 community event organizers who continued to find creative and impactful ways to put hope in action for the brain tumour community!



Community events raised \$433,541 in 2023 to support our mission. An additional \$88,327 was raised through our "Your Way" fundraising platform, which saw various events and items sold with proceeds supporting Brain Tumour Foundation of Canada.

facebook

The use of Facebook fundraisers continues to demonstrate the creative support of our community. In 2023, 308 Facebook events raised a total of \$44,411.

BrucePower™

Thanks to our committed partner Bruce Power, donors were able to double their impact up to \$100,000 when they donated to our Power of Hope Campaign.



“

My name is Georgie Maguire and I am a medical student at Queen's University. Following my second year in medical school, I was diagnosed with a malignant brain tumour. This life-changing diagnosis led to a week in hospital, months of treatment and a new perspective on the patient experience. Being a patient is challenging, but there are organizations making tremendous efforts to improve it.

Brain Tumour Foundation of Canada is an organization focused on providing information and support to patients, while contributing to brain cancer research. The research aims to find novel therapies to treat, cure, and improve the quality of life for patients like myself.

I have a lot to thank the Brain Tumour Foundation for. They've enabled me to read deeply personal patient stories, provided a meeting place for fellow brain tumour survivors, and allowed me to learn about my tumour at my own pace. This has given me a renewed sense of hope that I had lost after receiving my diagnosis. I am hopeful when I read about fellow survivors living incredible and meaningful lives.

I am hopeful when I see studentship research opportunities that could lead to a classmate discovering a lifesaving therapy. I am hopeful when I see organizations that continue to support patients, families and caregivers from the day of diagnosis to well beyond. I wanted to contribute to Brain Tumour Foundation of Canada through this fundraiser, to ensure these resources are available for all those affected by this disease.

”

THANK YOU FOR SPREADING HOPE

We want to thank you for showing your support on Brain Cancer Awareness Day. Tuesday, Oct. 24, 2023, marked the sixth year of this important occasion, which highlights the impact that brain cancer has on so many lives.

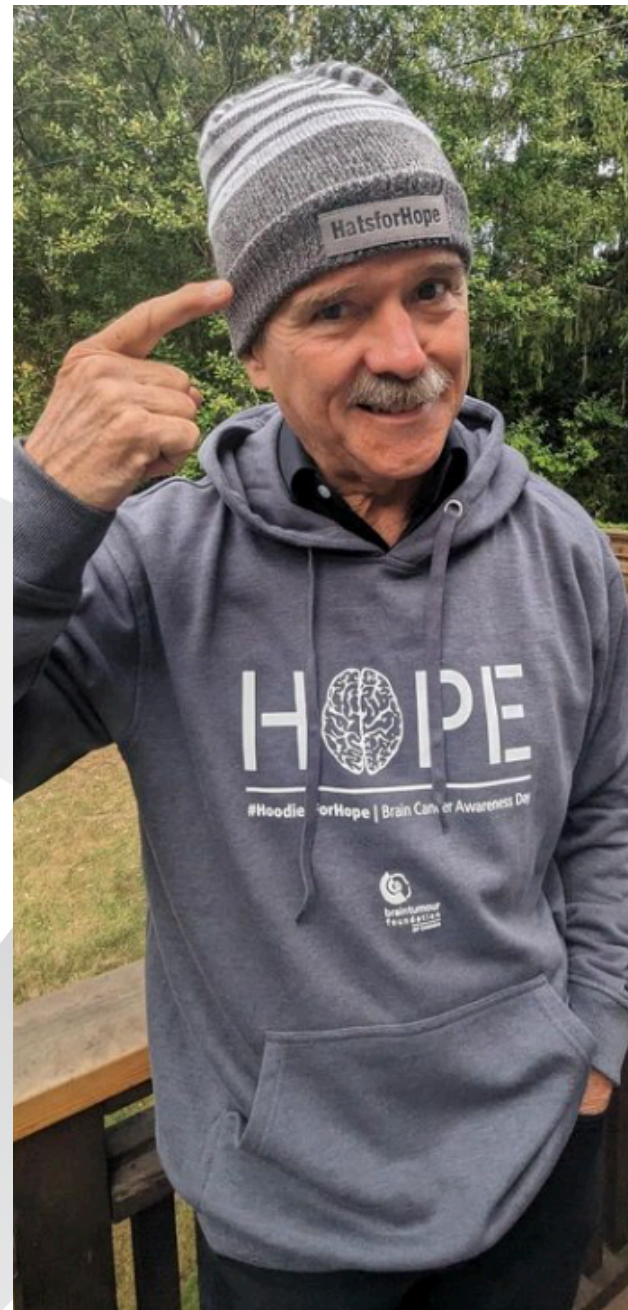
People from all over the country posted photos wearing hats, and our new Hoodies for Hope, with the hashtags #HatsforHope and #HoodiesforHope, in solidarity with those affected by brain cancer.

This year's ambassador was Colonel Chris Hadfield, retired astronaut, author, and space advocate. Along with Col. Hadfield, we were thrilled to have 25 other Canadian celebrities and influencers, who have over 4 million followers on social media, join the Hats for Hope movement, including Paul Sun-Hyung Lee, Stewart Reynolds, Chantal Kreviazuk, Vivian Hicks, and many more!

All proceeds from the campaign go to Brain Tumour Foundation of Canada, helping us advance brain tumour research and support those living with this devastating condition. Close to 1,500 hoodies and 1,000 toques were purchased during the campaign resulting in proceeds of \$35,000 from our partner New Era Grafix. We also received \$8,500 in donations, bringing the total raised to over \$43,500.

The brain tumour community showed its support in other ways as well. We heard stories of an anonymous donor who kindly sent a Hoodie for Hope to a brain tumour survivor and another survivor who met Col. Hadfield at a book signing, where they spoke of their connection to the community.

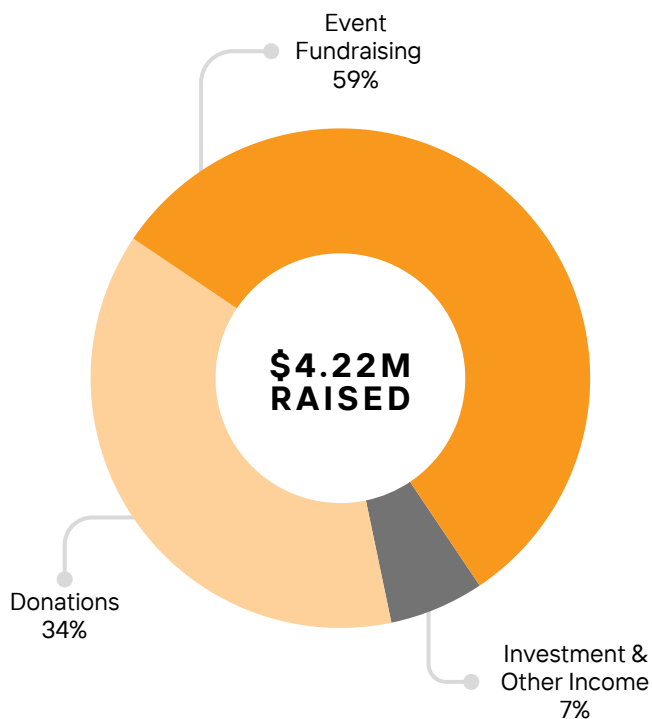
Your impact is strong and far-reaching. Together, we can make a difference in the lives of those affected by brain tumours and bring hope for a cure.



TOGETHER, WE EMPOWER CANADIANS AFFECTED BY A BRAIN TUMOUR TO LIVE LONGER, BETTER, AND WITH **HOPE!**



YOU GAVE



ANNUAL PROGRAM

\$1,514,159 raised through our annual program:

- \$706,394 through general donations and campaigns
- \$230,142 through grants and sponsorships
- \$347,216 donated in tribute
- \$181,812 through Legacy of Hope bequests

BRAIN TUMOUR WALK

\$1,832,884 raised, totalling 43% of our revenue:

- 5527 participants
- 645 teams
- \$12,300 raised from matching gifts
- 41 sponsors totaling nearly \$48,000
- 1 hashtag sponsor

COMMUNITY EVENTS

\$566,279 raised by 31 community events, including:

\$88,327

RAISED THROUGH OUR YOUR WAY
PLATFORM

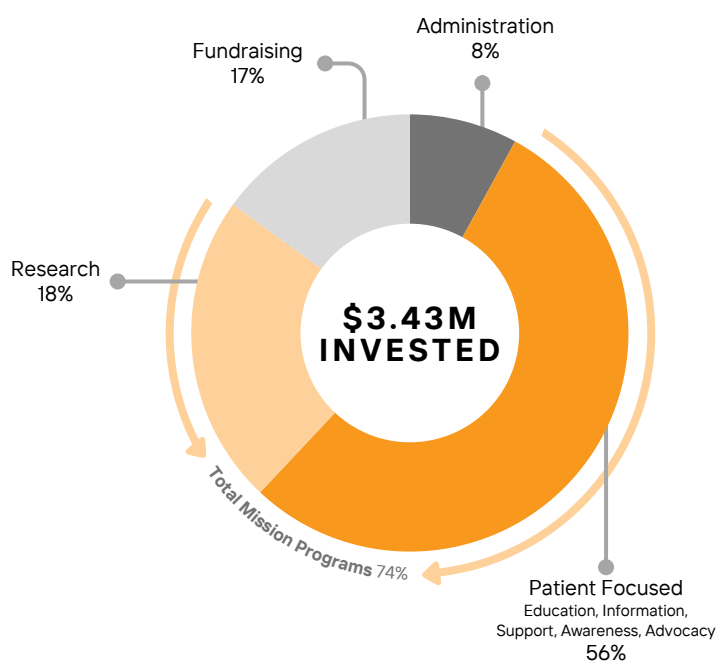
308

FACEBOOK FUNDRAISERS RAISED
\$44,411

RESEARCH IS THE KEY TO ACHIEVING OUR VISION OF FINDING THE CAUSE OF AND A CURE FOR BRAIN TUMOURS.



YOUR IMPACT



\$605,746 INVESTED IN RESEARCH IN 2023, INCLUDING:

- 2 research fellowships
- 1 research studentship
- 2 research grants (1 general and 1 pediatric research grant)
- 5 feature grants (2 pediatric, 2 glioblastoma and 1 quality of life)
- Brain Tumour Tissue Bank
- Brain Tumour Registry of Canada
- Brain Tumour Funders Collaborative Project
- The Pam and Rolando Del Maestro Family Undergraduate Student Research Competition

10

YOUTH EDUCATION
AWARD RECIPIENTS

18

VIRTUAL, IN-PERSON &
HYBRID SUPPORT GROUPS

6

CLOSED FACEBOOK
SUPPORT GROUPS

669

REGISTERED PARTICIPANTS
FOR WEBINAR SERIES

230

REGISTERED PARTICIPANTS
FOR FRENCH CONFERENCE

+1,000

PODCAST
DOWNLOADS

8

IN-PERSON BRAINWAVE
& GOCERVO EVENTS

+2,000

BRAIN TUMOUR
HANDBOOKS ORDERED

10

BRAIN TUMOUR RESEARCH
GRANTS WERE AWARDED

+1,200

REQUESTS FOR
INFORMATION

41,508

SOCIAL MEDIA FANS
& FOLLOWERS

1517

MENTIONS IN
THE MEDIA

RESEARCH: FINDING THE MISSING PIECES OF THE PUZZLE

2023 BRAIN TUMOUR RESEARCH GRANT RECIPIENTS

FELLOWSHIPS



Dr. Lennart Van Winden

University Health Network, Toronto, Ont.

Project title: *Dynamic and niche-specific mapping of the glioblastoma secretome*



Dr. Alberto Delaidelli

University of British Columbia, Vancouver, B.C.

Project title: *Medulloblastoma plasma membrane proteomics to inform optimal-Immunotherapy design*

STUDENTSHIP



Anish Puri, undergraduate student (Anish works with Dr. Sheila Singh)
McMaster University, Hamilton, Ont.

Project title: *uPAR an immunotherapeutic target in recurrent glioblastoma*
This project was generously funded by the Taite Boomer Foundation.

RESEARCH GRANTS



Dr. Stefan Lang

University of British Columbia, Vancouver, B.C.

Project title: *Simulating brain tumour resection to optimize onco-functional balance*



Dr. Vijay Ramaswamy

Hospital for Sick Children, Toronto, Ont.

Project title: *Leveraging therapeutic vulnerabilities of MYC amplified very high-risk childhood medulloblastoma for rational combinatorial therapy*



We strive to help better understand brain tumours and what causes them, to improve current treatments, to move closer to finding new and better treatments, and to enhance the quality of life for brain tumour patients. Our research program is diverse and supports basic science, as well as clinical, translational, and population studies, while providing encouragement to young researchers starting out.

FEATURE GRANTS



Dr. David Hodgson

University of Toronto, Toronto, Ont.

Project title: *From computer to clinic: Deploying artificial intelligence - Assisted radiotherapy planning for brain tumours*



Dr. Hallie Coltin

CHU Sainte-Justine, Montreal, Que.

Project title: *Long-term outcomes of Pediatric low-grade glioma survivors: A molecularly-informed, population-based approach*



Dr. David Schultz

Princess Margaret Cancer Centre, Toronto, Ont.

Project title: *Factors associated with quality of life and neurocognitive function and in patients with brain metastases: Analysis of a prospective longitudinal study*



Dr. Sheila Singh

McMaster University, Hamilton, Ont.

Project title: *Cotargeting ephrin receptor tyrosine kinases A2 and A3 in glioblastoma using bispecific CAR-T immunotherapy*

Dr. Singh's project was generously funded by Dunn with Cancer.



Dr. Federico Gaiti

Princess Margaret Cancer Centre, Toronto, Ont.

Project title: *Epigenetic evolution of glioblastoma cellular states*

Dr. Gaiti's project was generously funded by Dunn with Cancer.



OTHER RESEARCH INITIATIVES

BRAIN TUMOUR REGISTRY OF CANADA

In 2023, the Registry published a peer-reviewed journal article summarizing the previous two surveillance reports from 2021 and 2022, which are available at **BrainTumourRegistry.ca**. The Registry's ongoing work was also presented at the Canadian Neuro-Oncology meeting, at the Canadian Centre for Applied Research in Cancer Control (ARCC), and at the Alberta Central Nervous System (CNS) Tumour Clinical Group annual meeting. Through a partnership with Canadian Cancer Society, the Registry is capturing information on brain metastases and molecular markers for Canadian cancer registries.

UNDERGRADUATE STUDENT RESEARCH COMPETITION

Since 2017, **The Pam and Rolando Del Maestro Family Undergraduate Student Research Competition Awards** have helped promote scientific innovation among Canadian undergraduate students. In 2023, six teams from throughout Canada presented at the event. The following three teams received monetary awards: Ali Haider, Sawsan Haider and Anhadh Law from Queen's University (Ontario), Cedrik Marchildon, Widah Safih and Djessmy Guenieve P. Michel of the University of Sherbrooke (Quebec), and Amna Idris and Deema ElRufaei from the University of Calgary (Alberta).



VOLUNTEER AWARDS

We would like to express our profound gratitude for the tireless dedication of our volunteers throughout the country. Our volunteers create a network of care, compassion, and co-operation that we are honoured to be a part of. Cheers to our remarkable Volunteer Award winners, whose efforts continue to inspire us all!

DAVID KELLY AWARD FOR COMMUNITY SERVICE

The David Kelly Award for Community Service is awarded annually to an individual or group that exemplifies the spirit of community service in support of Canada's brain tumour community. Congratulations to our David Kelly Award for Community Service recipient, **Jason Kaszycki**!

Husband, dad, avid golfer, and brain tumour survivor Jason celebrates the anniversary of his brain tumour surgery each year with a golf fundraiser. Since his first event in 2014, Jason has raised more than \$50,000 towards brain tumour research.



VOLUNTEER OF DISTINCTION AWARDS

Volunteer of Distinction Awards are given every year to volunteers who embody the spirit of volunteerism. Congratulations to the recipients of the Volunteer of Distinction Awards, Stéphanie Morissette, Mary Rawlings and Stu Rawlings!



Stéphanie Morissette

Stéphanie has navigated a road no parent wants to find themselves on, following her daughter's diagnosis with Diffuse Intrinsic Pontine Glioma (DIPG). Though DIPG eventually claimed her daughter's life, Stéphanie continues to fight in her memory.



Mary Rawlings

Mary became a caregiver and advocate for her husband, Stu, through his journey with a brain tumour diagnosis. She found community by participating in a virtual support group for caregivers, eventually taking on a volunteer co-facilitator role.



Stu Rawlings

As Stu recovered from surgery following his brain tumour diagnosis, his challenges included not being able to swallow or speak. He regained confidence and strength through his participation in a virtual support group and became a volunteer co-facilitator soon after.

HEALTH CARE PROFESSIONAL AWARD

The Health Care Professional Award was created in 2020 to recognize individuals in the health care field who have shown exemplary and compassionate care to the brain tumour community. Congratulations to our Health Care Professional Award recipient, **Kelly Bullivant**!



Kelly's care, compassion and knowledge have not only made an impact on the patients and families she helps, but also on young adult brain tumour survivors looking to further their education. As a neuroscience nurse practitioner and long-time committee member of BTFC's Youth Education Awards, Kelly has made a difference in many lives.



CHALLENGES WE ARE FACING

Brain Tumour Foundation of Canada is the only national charity dedicated to finding the cause and cure of brain tumours, whether cancerous, non-malignant, or metastatic. We live with the hope that a cure will be found, but until that day, we will work tirelessly to improve the quality of life for those affected.

Here are some facts to illustrate the scope and impact of this challenge:

- **High Incidence:** Brain tumours are the leading cause of cancer-related deaths in children under the age of 20 and the third leading cause of cancer-related deaths in young adults aged 20-39.
- **Wide Impact:** Brain tumours affect individuals of all ages, from children to the elderly. They do not discriminate based on age, gender, or ethnicity.
- **Limited Treatment Options:** Unlike some other cancers, treatment options for brain tumours can be very limited, and the prognosis can be devastating. Even with available treatments, the survival rates for certain types of brain tumours remain as low as 35.7 percent for patients with a malignant brain tumour.
- **Quality of Life:** Beyond the survival aspect, brain tumours can severely impact a person's quality of life. Survivors often face physical, cognitive, and emotional challenges that require ongoing support and care.
- **Burden on Families:** Brain tumours affect not only the patients but also their families and loved ones. The emotional and financial burden can be overwhelming.
- **Lack of Government Funding:** Despite the significant impact of brain tumours, there is limited government funding allocated to research and support services for those affected.

Brain Tumour Foundation of Canada strives to address these challenges by funding critical research, providing support and education, and advocating for better resources and services. Our work is essential in improving the lives of those affected by brain tumours and ultimately finding a cure.

ADVOCACY AND AWARENESS

NETWORKING & WORKING GROUPS

- In 2023, we participated in all Best Medicines Coalition (BMC) member meetings and working groups, including Drug Supply and Shortages, Pharmacare, Rare Disease Strategy, and Drug Pricing (PMPRB). The issues these groups are working to address are ongoing, and several submissions have been made to stakeholders throughout the year. Our participation in these groups will continue in 2024.
- We participated in all Neurological Health Charities Canada (NHCC) member meetings and have confirmed our support of NHCC's upcoming national survey. The survey will update the findings of the 2014 Mapping Connections Report and provide new recommendations regarding the health needs of the neurological community. Our participation will continue in 2024.
- We are working with Toronto Rehabilitation Institute to develop a brain tumour care pathway for its rehabilitation clinic, which sees a lot of patients for traumatic brain injuries, but also for brain tumours. It has no specific service models or care pathways for assisting patients with a brain tumour, leading to gaps in assessment and treatment. We have provided our resources, infographics and handbooks to the Toronto Rehabilitation Institute so that it may share them with patients. Meetings are scheduled to continue in 2024.



HEALTH TECHNOLOGY ASSESSMENT

- Our participation in Health Technology Assessment processes was new to the organization this year. We worked with a consulting firm to gather input on the brain tumour community's experience with treatments and tumour-treating fields (TTF). We issued a community survey and then completed several interviews in English and French, with the assistance of the consulting firm, to gather important patient and caregiver experiences for our patient feedback submissions to Institut National d'Excellence en Santé et Services Sociaux (INESSS) and Canadian Agencies for Drugs and Technologies in Health (CADTH). While INESSS has issued a negative recommendation, citing cost as a primary factor, CADTH has made a positive recommendation to fund the Optune device. This TTF technology aims to reduce the symptoms of glioblastoma and slow its progression.
- We were also invited to participate in CADTH's Formulary Management Expert Committee (FMEC) pilot meeting where we, alongside a patient representative, shared information on the current brain tumour treatment landscape, in terms of access as well as limited options.

As a result of this meeting and our participation, CADTH's FMEC committee made a recommendation to Health Canada to fund two drugs as a combination therapy (whereas previously they were funded to be used separately), resulting in the potential for a new treatment option to be available for eligible brain tumour patients.

We hope to continue participating in these valuable health technology assessment opportunities in 2024, providing a pathway for interested brain tumour patients and caregivers to share their experiences, improving the care and treatment landscape in Canada, and situating BTFC as a leader in helping to advance treatment options for the community.

DRUG AND TREATMENT ACCESS

We have been following the lomustine discontinuation since 2021. In November 2022, we gave a presentation to the Adolescent and Young Adult (AYA) Tumour Board, outlining the timeline of the discontinuation and our prior activities. This included meeting with the supplier, Bristol-Myers Squibb™ (BMS), to illustrate our concerns and ask questions, and as a result, securing a later discontinuation date, which provided us more time to advocate and to better understand the potential impact of the discontinuation on the health care community and patients.

RESEARCH FUNDING

We submitted an advocacy letter to the Prime Minister, Deputy Prime Minister/Minister of Finance, Minister of Health, and Minister of Science, Industry and Innovation, requesting that they revisit the Canadian Institutes of Health Research (CIHR) funding model, as it is not adequate to keep researchers engaged with the Canadian brain tumour research landscape or allow them to proceed with their studies with confidence and financial security.

ADVOCACY SURVEY & SETTING OUR PRIORITIES FOR 2024

In June, we issued an advocacy survey to the community in both English and French. As a result of that survey, we were able to confirm our advocacy activities and priorities are in alignment with the current needs of the brain tumour community. We hope to work towards these activities and priorities, in collaboration with stakeholders such as government, regulatory bodies, the health care community and the brain tumour community.

Our priorities:

- Timely and equitable access to drugs and treatment (including take-home cancer drugs through Pharmacare and access to radiosurgery, including proton beam therapy, as well as improved processes to address drug discontinuations and shortages);
- Increased and sustainable brain tumour research funding;
- Survivorship and ongoing support, including better understanding and awareness of the care needs of the brain tumour community (such as home care, rehabilitation, palliative care, etc.) and the impact of diagnosis/treatment on daily life and quality of life.



STORIES OF HOPE

These stories of perseverance are personal perspectives on how patients and families find hope, support, strength, and inspiration. Scan the QR code to read the full stories.



Penn The Brave

Coming from a tight-knit family in Calgary, Penn Manabat knew she was dearly loved by her aunts, uncles, grandparents, mother, father, big sister, Paige, and dog, Pepper Potts. She had over 20 cousins. Penn's family nurtured her into becoming a healthy three year old; intelligent, articulate, and she had a one-of-a-kind personality.

"She was mature beyond her years. Even when she was going through so much pain, I know she was thinking a lot about Mom, Dad, and Paige."



Keep On Keeping On

Debbie Slavik is a 50-year brain tumour survivor and is one of the very few from the time of her diagnosis in 1972, when she was only 13 years of age.

"Nobody seemed to pull through or endure a brain tumour accompanied by the gruelling surgeries involved. An adult, maybe, but children rarely survived the journey affected by a brain tumour. I feel as though I am a miracle child of that day and age."



For The Love of Life

Michaela Keech was born and raised in the beautiful city of North Bay, Ont. For the last three years, she and her boyfriend, Kulbir Singh, had been living in the Woodbridge-Vaughan area.

Michaela had consulted her doctor because she was experiencing hearing problems, such as noise sensitivity, as well as things overall not seeming quite normal to her. Although the results of the hearing test seemed fine, her difficulties persisted.



A Cheerful Heart is Good Medicine

"When my sister, Melanie, was first fighting, I remember feeling that the gift of health was something I never wanted to take advantage of again. That inspired me to make the right choices every day and take care of myself emotionally and physically." - Jenn Schatz. Jenn considers Melanie to be a major influence on her appreciation of life.

Scan the code
to read the
full stories.





THE MOMENT IT ALL CHANGED: JEFFREY ALBAUM'S STORY

Jeffrey and Susan's story is about love, gratitude, family, community, strength, and support. Jeffrey Albaum is 61 years old and a "living with" patient. Before December 2022, he was rarely sick.

After having a seizure on December 2, 2022, he underwent surgery in January 2023 to investigate the drastic change in his health. Two weeks after the surgery, the doctors diagnosed Jeffrey with a grade-four glioblastoma. But, unfortunately, the doctors told him and his wife there was no cure. At that moment, everything changed drastically.

Jeffrey and Susan were shocked and devastated as they had never imagined hearing this news. Susan remembers feeling like all their hopes and dreams for a beautiful life together were shattered instantly—individually and in partnership.

After their first marriages ended, Jeffrey and Susan had a long time to find one another. They met in 2017, first dating, then living together. They were finally married on August 23, 2020, in the turmoil and uncertainty of the COVID-19 pandemic. It was love at first sight, and their connection grows stronger every day.



“

That's who he is and why he is absolutely loved. I think the world deserves to know who Jeffrey is. He's everything; loving, strong, smart, talented, passionate, fun, and adventurous. - Susan

Scan the QR code to continue reading this story..





Finding Positivity Through Adversity

It's hard not to smile when speaking with Jeff Wagner. His positivity is infectious, and his desire to better himself, even in the face of adversity, is nothing short of inspiring.

"I'm not afraid of death, and I'm not worried about getting better," he says. "I'm just here to experience life as it is."



Life Beyond the Rough

Will Burleigh's first major setback came at age seven, when he began experiencing frequent headaches. His parents took him to McMaster Children's Hospital, where doctors thought Will might be suffering from a sinus infection. They sent him home, only for the headaches to continue.

"A couple trips to the ER, a couple trips to his family doctor, several calls from the school that he wasn't feeling well. We were at McMaster one day, they sent us home again, and then 12 hours later, we were back. Will was vomiting and screaming in pain. That's when they did his first MRI." - Denise Burleigh



Adalyn's Story of Courage and Community

For Melissa and Evan Funk, Steinbach, Man., is home. It's where they grew up, where they raise their own family—daughters Adalyn, five years old, and Raya, four years old—and where they run a successful serveware company, Lynn & Liana Designs.

Call it a mother's instinct, but Melissa says she could tell something wasn't right with her "bubbly and energetic" daughter, who she describes as having a "big personality."



This Too Shall Pass

Blake and Jessica Cuthbertson were married in 2018. His wife was a well-loved Grade 1 teacher in Brampton's Rowntree Montessori Schools. To this day, Blake admires and adores her selfless dedication to the community.

"She was consistently involved in clubs and teams and joined committees. She was an avid reader of many subjects and stories. Jessica was involved with sports throughout high school, focusing on soccer and basketball. She coached her school and other soccer teams as well."

Scan the code
to read the
full stories.



RAISING AWARENESS

BRAIN TUMOUR AWARENESS MONTH

May is Brain Tumour Awareness Month in Canada. Wear grey, update your social media profile pictures with our #TurnMayGrey profile frame, fundraise and share your story on social media with the hashtag #TurnMayGrey. www.BrainTumour.ca/BTAM

BRAIN CANCER AWARENESS DAY AND HATS FOR HOPE

October 24 is Brain Cancer Awareness Day in Canada. Put your hats on and share photos on social media with the hashtag #HatsforHope! Since 2019, we have sold thousands of Hats for Hope toques, raising funds and awareness for brain cancer. www.HatsForHope.ca

BRAIN TUMOUR WALK PROGRAM

The Brain Tumour Walk is an opportunity to come together across Canada to celebrate and remember. We walk with a united goal – to see an end to brain tumours. It is our largest peer-to-peer fundraising event to fund brain tumour research and support, education and information programs to help brain tumour patients and survivors live longer, better, and with hope.

www.BrainTumourWalk.ca

YOUR WAY TO #ENDBRAINTUMOURS

Our Your Way to #EndBrainTumours platform provides everything you need to be a successful fundraiser. Choose from our list of ideas or create something unique, customize your personal page and start fundraising immediately.

www.EndBrainTumours.ca

MEMORY OF HOPE

"Those we hold closest to our hearts never truly leave us. They live on in the kindness they have shared and the love they brought into our lives." ~ Anon.

You can pay tribute to a loved one with a page that provides hope for others affected by a brain tumour. When you donate in memory of a loved one, you are providing much-needed hope. Hope through support, hope through information and education, and hope through research. Hope for a cure. Learn more at www.MemoryOfHope.ca.



TOGETHER, WE CAN MAKE A DIFFERENCE

In every challenge, unyielding hope and unity empower us to overcome the most formidable obstacles. With the unwavering support of our incredible community, a better future is within reach.

Hope guides us through the darkest times, driven by resilience, determination, and the collective strength of our community. Unity transforms individual efforts into a powerful movement, amplifying our impact and creating a ripple of change.

With hope as our compass and unity as our strength, we bring support to those affected, ushering in a future where these diagnoses no longer hold the same weight of fear and uncertainty. Your support, contributions, and dedication are the threads that drive hope and unity. Through our collective efforts, we will push the boundaries of what is possible and continue the fight for a cure.

Moving forward together, with hope and unity, we can overcome challenges and create a future where brain tumours are but a memory of the past. Thank you for being a vital part of this inspiring journey towards a brighter and more hopeful tomorrow.

MISSION

Our mission is to reach every individual in Canada affected by a brain tumour through advocacy, research, information, support, and education.

VISION

Our vision is to discover the cause of and a cure for brain tumours, all the while enhancing the quality of life for those impacted.

VALUES

At the heart of our organization, five core values serve as guiding principles that shape our every action, creating impact and meaning for the brain tumour community in Canada.

Hope, Caring, Integrity, Accountability and Collaboration.



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