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# It all started with Kelly



In 1981, when she was 8 years old, Kelly Northey was diagnosed with a brain tumour.

With little support or research for brain tumours, Kelly fought for six months

before passing away in January 1982. However, her legacy lives on through Brain Tumour Foundation of Canada, founded by Steve Northey, Rolando Del Maestro, a neurosurgeon, and his wife Pamela, a neuroscience nurse.

Learn more about our story at www.braintumour.ca/about-us.

#### **MESSAGE FROM THE CEO**

I was honoured to join the Brain Tumour Foundation of Canada team early in the year and work alongside so many incredible people to create the meaningful impact that we saw in 2022. We couldn't accomplish all that we have without the generosity of donors, and the dedication of our volunteers, health care professionals and BTFC staff. Despite the challenges we continued to face from the COVID-19 pandemic and the unanticipated challenges of 2022, our tight knit and loyal community were resilient and continued to advance our mission. I want to express my deepest gratitude to those who welcomed me so warmly to the team and who showed me what it means to be a part of this amazing community. I look forward to working together in 2023 to make an even more positive impact in the lives of those affected by a brain tumour.

With heartfelt gratitude,



Shannon LaHay Chief Executive Officer

Shannow Tadlay

#### **MESSAGE FROM THE CHAIR**

In all the years that I have had the privilege of being involved with BTFC, I have witnessed incredible resiliency and 2022 was no exception. This Hope in Action Impact Report is filled with examples of the incredible achievements that we have made together with hard work, dedication, creativity, and passion.

2022 was also a year of celebration for Brain Tumour Foundation of Canada. Forty years earlier, our co-founders sat around a kitchen table and made a commitment in honour of 8-year-old Kelly Northey. For 40 years, Kelly's legacy has been guiding our work to find the cause of and cure for brain tumours while improving the quality of life for those affected. In our 40th anniversary year, we celebrated our past, were thankful for the present, and we looked ahead to the difference we can make in the future. No matter when you joined us on this 40-year journey, we would not be here without you.

With sincere appreciation,



Phyllis Retty Chair, Board of Directors

Phyllis Rety

### **OUR BOARD OF DIRECTORS 2022**

Brain Tumour Foundation of Canada welcomed two new members to its Board of Directors in 2022:



#### **Dela Avle**

Dela Avle is General Counsel at Bruce Power, managing the legal and administrative staff in the Law Division. Dela shared his need to be involved

in an organization where he can see tangible benefits to the community and one that could benefit from his skills, experience, and time. He feels Brain Tumour Foundation of Canada does impressive work in the critical area of support for people affected by brain tumours and is glad to be able to support its mission.

In addition to the Board of Directors, Dela is a member of the Brain Tumour Foundation of Canada's Board Governance Committee.



#### **Bill Walker**

Bill Walker is the President and Chief Executive Officer of the Organization of Canadian Nuclear Industries (OCNI), supporting dedicated staff and volunteers and a

membership of 230+ companies with a vision to drive and strengthen a thriving Canadian nuclear supply chain through innovation and leadership. Bill recently retired as MPP for the riding of Bruce-Grey-Owen Sound after a 10-year public service tenure.

Bill's interest and commitment to supporting our organization is a way of giving back, as his son is a brain tumour survivor. His philanthropic spirit extends beyond his role on our board; he has volunteered in various positions with many charitable and not-for-profit organizations over his lifetime. He is also an amateur auctioneer, a practicing marriage officiant, and an avid sports fan.

In addition to the Board of Directors, Bill is a member of the Brain Tumour Foundation of Canada's Advocacy Committee and Marketing & Fund Development Committee.

Meet all our Board of Directors members at www.braintumour.ca/board.

### **Stories of Hope**

Our Stories of Hope give you a glimpse into the personal perspectives of patients and their loved ones as they navigate through the challenges of living with a brain tumour.

Each personal story is unique and a powerful testament to the resilience and determination of the human spirit. Every story serves as a beacon of hope, illuminating the path for others in their journeys of healing and perseverance.



Kristofer

- Remembering and honouring my son, Kristofer Matthew, whose journey ended too soon on April 22, 2022. Kristofer's humorous, generous, compassionate spirit created 21 years of unforgettable memories. Hoping to treat and prevent brain tumours for others, this gift is given in your memory, my Special K!
  - Kindly donated by Katherine



Denis

- Denis would say, "Live in the moment" and "Allow yourself to be happy." Diagnosed with a glioblastoma in May 2013, he never stopped living and inspiring hope in others throughout his journey. Denis had nine beautiful years with us. Unfortunately, he is gone, but his spirit inspires us daily!
  - Kindly donated by Denis' father, Ken



Lauren

- Lauren fought a battle that no child should ever have to go through, and at 12, she lost that battle. Throughout her life, she was surrounded by the love and support of her family, but she also gave them strength through her bravery and beautiful smile. Lauren, and her smile, are remembered by so many people every day!
  - Kindly donated by Shannon

## Virtual Programming to Raise Awareness and Educate

#### **BRAIN TUMOUR WEBINAR SERIES**



Our 2022 Webinar Series included 23 speakers and a total of 11 presentations on a variety of topics, including an update on the World Health Organization (WHO) classifications of brain tumours, a special presentation for International Woman's Day, a discussion about caregiver wellness, updates on treatment and research, a talk about the role of cannabis, and many personal stories of hope. Almost 700 participants watched the webinars live, and many others accessed the recordings on our Youtube channel.

Generously funded by Novocure.

#### novœure

I look
forward to these
webinars. It gives me
something practical and
helpful to fill my time on
long-term disability. I feel
more connected to the
brain tumour community,
positively impacting my
mental health.

Thank you
for the work you
do in providing these
opportunities. They
help with understanding
and accepting what's
happening. It's a relief
to know others
understand.

Thank you
to everyone who
puts these together.
They've given me strength,
and getting more involved
with the Foundation has given
me much comfort and hope.
I wish I'd been able to get
involved ten years ago
after my diagnosis.

#### **BRAINWAVE**



BrainWAVE is a support program for families with a child (19 years of

age or younger) with a brain tumour. The program allows parents and their children to connect with other families in a similar situation and obtain much-needed support, information and education.

In 2022, we focused on creating virtual programming to engage our community. Our virtual events included an online magic show, a "make your own stuffie" activity and a virtual Halloween bingo event. We also sent personalized packages with movie and hockey tickets to the families in our program.







#### **MOBILE APP**

In 2022, we launched a bilingual and accessible mobile app to provide a new way for members of the brain tumour community to connect and access support and resources. Over 800 users have accessed the app in the last year to read our resources and documentation. The mobile app is free to download and is available on the iOS and Google Play stores.

Learn more and download our new app at www.braintumour.ca/app.

Generously funded by The Adam Fanaki Brain Fund.





### **DIGITAL STORIES**













In 2022, five young adult brain tumour survivors from our community participated in a storytelling workshop by Digital Storytelling Specialist, Mike Lang, and in partnership with Selectpath, to share their stories in this unique digital format. Stories and conversations were full of wisdom about what

it means to live with, through, and beyond a brain tumour diagnosis. The impact of this experience on young adults was significant, and we look forward to offering this opportunity to more young adult patients and survivors in 2023.

Watch the stories at https://rb.gy/zm3nc.

#### **PECHAKUCHA**



PechaKucha (PK) is a storytelling platform that celebrates people, passion, and creative thought. The PK 20x20 presentation format is a slide show of 20 images, each auto-advancing after 20 seconds. Twelve members of our community, including survivors, caregivers and healthcare professionals, presented on various topics, from "How to make"

the perfect sandwich" to "Sprinting to a stronger self." It was an opportunity for these community members to share more about who they are, what they are passionate about or a cool project they've worked on. We look forward to hosting our second PechaKucha event in Fall 2023.

Watch the presentations at https://rb.gy/dq65o.

#### **PODCAST - COMING SOON!**

Brain Tumour Foundation of Canada will soon launch a podcast by, for, and about the brain tumour community. Listen in as we talk to brain tumour survivors, patients, and caregivers as they share their stories and perspectives on brain tumour treatments,

research, and survivorship. Hosted by Hugh Hill, Support Services Specialist at Brain Tumour Foundation of Canada, tune in to learn more about the organization's resources, programs, and services for people affected by a brain tumour.



My brother-in-law Derek fought an 11-month battle with a grade 4 tumour. He was and is still the bravest and most incredible person I've ever met. Miss you so much, Derek.

#### PRIVATE FACEBOOK SUPPORT GROUPS



Brain Tumour Foundation of Canada has 6 Private Facebook Support Groups which provide support 24/7 to the brain tumour community. Our groups include:

- Adult Brain Tumour Support Group (English and French)
- Pediatric Brain Tumour Support Group (English and French)
- Caregiver Brain Tumour Support Group
- Young Adults Brain Tumour Support Group

In these online communities, individuals gain access to an active group of brain tumour patients, survivors, parents and other caregivers who ask questions, answer members' questions and share their stories of hope.

Join one of our Facebook groups at www.braintumour.ca/care-support/facebook-groups

# **Congratulations to our 2022 Youth Education Award Recipients!**

Survivors of a pediatric brain tumour between the ages of 16 and 30 pursuing post-secondary education are eligible for our annual Youth Education Awards. These awards of up to \$5,000 encourage young brain tumour survivors to pursue their education dreams while recognizing the significant barriers and financial challenges they may face. In 2022, \$40,000 was awarded to eight (8) recipients. Congratulations, and all the best in their studies!



Coen Knockaert from Winnipeg, Manitoba, is pursuing the University 1 Program at the University of Manitoba. He was diagnosed with a CNS germinoma at age 12.

Generously funded by Phyllis Retty.



**Caden Nurse** from Middle Sackville, Nova Scotia, is pursuing a Bachelor of Science at Acadia University. He was diagnosed with an astrocytoma at age 17.

Generously funded in honour of Susan Marshall.



Anonymous, from Mississauga, Ontario, is pursuing their studies at the Ivey Business School at Western University. They were diagnosed with a brain tumour at age 18.

Generously funded by Deys Fabricating.



**Dereck Lau** from LaSalle, Ontario, is pursuing Engineering at the University of Windsor. He was diagnosed with a medulloblastoma at age 10.

Generously funded by Deys Fabricating.



Bailey Edwards from Langley, British Columbia, is pursuing a Bachelor of Environment Engineering at the University of British Columbia. He was diagnosed with an anaplastic astrocytoma at age 21.

Generously funded by Bruce Power.



**Illyria Volcansek** from Hamilton, Ontario, is pursuing a Bachelor of Science at the University of Guelph. She was diagnosed with a CNS germinoma at age 12.

Generously funded by Andrew Campbell Youth Leadership Foundation.



**Garrett Oakes** from Holmesville, New Brunswick, is pursuing a Bachelor of Health at the University of New Brunswick. He was diagnosed with anaplastic ependymoma at age 3.

Generously funded by The Newhouse Family.



Amy Adams from Delta, British Columbia, is pursuing a Bachelor of Science in Nursing at the University of British Columbia. She was diagnosed with a pilocytic astrocytoma at age 11.

Generously funded by R. Angus King Legacy Fund.



2023 represents our tenth year of providing Student Education Awards and our goal is to fund 10 awards. Learn more about our Student Education Awards at www.braintumour.ca/youth-education-awards.

I was unsure if I was even going to be able to attend university after receiving my diagnosis. Knowing that I have the support and assistance from the Brain Tumour Foundation of Canada while pursuing my educational goals means more to me than I could ever express. This award will help me accomplish what I strive to achieve in life.

### 2022 Brain Tumour Walk Weekend



In 2022, the Brain Tumour Walk was held over a weekend instead of one national walk day to better accommodate different time zones, schedules, and weather. We walked united in a common goal: to end brain tumours. Participants chose how and where to make an impact on June 17, 18 and 19, 2022. United in our steps and cause – our community connected nationally, making a difference across Canada.

Read walk participants' stories at www.braintumourwalk.ca/testimonials.

2,785 participants	<b>468</b> teams	26 sponsors	\$1,347,849
33	13,674	350	raised for the 2022 Brain Tumour Walk
Volunteer Coordinators	donations	survivors	



Once again, people affected by brain tumours were determined that a pandemic would not stop them from coming together to find strength, connection, and hope.

With the passion for supporting the brain tumour community and the mission of Brain Tumour Foundation of Canada, in 2022, 468 teams participated in the event. The top team in Canada, with just two members, was team 'Max's Mission' from Winnipeg, which raised \$27,715.53. We were thrilled to present the Team Captain, Max Erenberg, with the 2022 Cup of Hope!

We are thankful for the generosity of Al's Flower Pouch by A.M.A. Horticulture, our proud national hashtag sponsor, for the third year in a row. #BrainTumourWalk hashtags were used all over social media, raising funds and awareness one hashtag at a time.

Novocure also joined our mission to end brain tumours! Novocure is a global oncology company striving to extend survival in some of the most aggressive forms of cancer. We are very grateful for their support of the brain tumour community and for being a national sponsor of the 2022 Brain Tumour Walk Program.



I am walking proudly in honour of my incredible mother and Nana, Linda Yurensen. We still have a long and unpredictable journey, but now it's time to celebrate, experience, and do all your bucket list stuff. My hope for you as a daughter is that our time together is full of fun, laughter, and adventure if we're feeling crazy. But I also want you to be surrounded by hope, dignity, and peace.

### **Generous Donors Make It All Possible**

Brain Tumour Foundation of Canada is empowered by the generosity and support of many individuals motivated to make a difference for the brain tumour community throughout Canada. In 2022, a year where we continued to be resilient and manage the ongoing challenges of the pandemic, as well as significant economic, social and global challenges, our donors continued to support and invest in our community.

#### **COMMUNITY EVENTS**

Funds raised through Community Events are one of many measures of meaningful impact for these events. Indeed, events hosted in locations across the country help raise awareness for brain tumours and for our organization, ensuring that we can reach more patients, survivors, caregivers, and other stakeholders who can benefit from our support and help us fulfill our mission.



Community events raised \$532,869 in 2022 to support our mission. An additional \$66,586 was raised through our "Your Way" fundraising platform through various events and items sold with proceeds supporting Brain Tumour Foundation of Canada.





The use of Facebook Fundraisers continues to demonstrate the creative support of our community. In 2022, 308 Facebook events raised a total of \$78,863.10.

Learn more about Facebook Fundraisers at www.facebook.com/fundraisers.



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.

#### MATCHING GIFT PROGRAMS

Employee giving programs provide an easy way to make a gift to help! Many companies have programs that match financial gifts or volunteer hours. Contact your human resources department and express your desire to make us your charity of choice.

Find out if your company will match your gift at https://rb.gy/amh30

Taking advantage of my employer's matching gift program doubled the impact of my donation, helping to propel brain tumour research forward.

– Donor





Make a lasting impact with monthly giving! Monthly giving is an easy and convenient way to support the work of Brain Tumour Foundation of Canada throughout the year. To pledge your monthly gift, please contact us at www.braintumour.ca/contact-us.

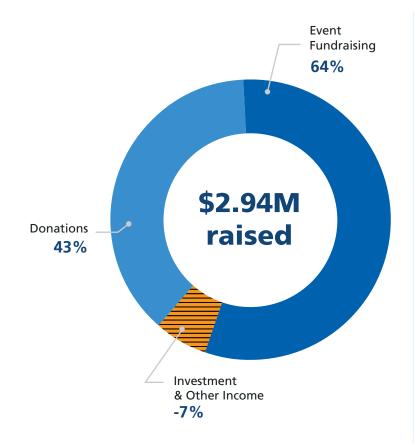
The Brain Tumour Handbook that Brain Tumour Foundation of Canada provided me was invaluable as I navigated my diagnosis and next steps.

Thank you to all our 2022 community event organizers who continued to find creative and impactful ways to put hope into action for the brain tumour community. Find inspiration for your next community event in the fundraising calendar below!

Set the Tone	Share Your Story	Facebook	Garage Sale
Donate to yourself! Others will follow your lead.	Customize your fundraising page. Share why you are fundraising; your story means a lot to others as well.	Share the link to your fundraising page on Facebook and ask for support. Repost often.	Clean your house/closet and have a garage sale or post to Kijiji.
Host a dinner party	Seasonal	Auction	Celebrations
Get your guests to "donate for dinner."	Use the calendar to come up with fun fundraising ideas: Valentine's Day, St. Patty's or the first day of spring or fall!	Auction off tickets to a sporting event or show. Some companies will donate them for your auction.	Having a birthday? Ask for donations instead of gifts.
Empties	Matching Gifts	Change for Change	Host a Paint Night
Collect empty beer and wine bottles from your friends and neighbours.	Ask your boss or HR department for a matching gift to match what you've raised.	Empty your change into a jar at the end of every day for 27 days.	Host a paint night and charge a fee to join.
Game Night	Voicemail and email	50/50 Raffle	Grey for a Day
Organize a Game night and charge a fee to play.	Change your voicemail and email signature to ask for a donation to your fundraising page.	Great for work, church, or school.	Organize a 'Grey for a Day' dress-down event at work and charge everyone to participate.
Local Service Clubs	Name That Tune!	Favourite Restaurant	Potluck
Offer to speak at a local service club or church group. Many donate to charity through volunteer speakers.	Organize a music lunch- hour trivia contest. Charge a small fee to join in and offer prizes.	Do you have a favourite restaurant? Ask management if they will donate a % of sales.	Ask friends and family for a "favourite country" potluck. Ask them to donate the cost of dinner out.
Scavenger Hunt	Pancake Breakfast	Top-Down Car Wash!	Check your fundraising
Invite families to participate in a scavenger hunt. Offer extra tips and hints for different donation amounts.	Large or small – a favourite and a great way to start the day.	Charge \$5 for the car and an extra \$5 to do the roof/top!	Reach out to the contacts that haven't donated to you!
Bake Sales	Treats	5 for 5	Host a Kids' Art Sale
Bake sales work every time! Workplaces, craft nights, kids' sports, etc.	Ask a local Frozen Treat company to donate \$1 for every treat sold on a designated day.	Ask five people for \$5 – very quickly, you'll have \$25!	Have kids submit their artwork. Then, host a hot chocolate art sale for them and their parents.

For more information about fundraising, community events and how you can help Canadians affected by a brain tumour, visit www.BrainTumour.ca or call us at 1-800-265-5106.

### You gave...



#### **ANNUAL PROGRAM:**

# \$1,293,149 through our annual program, as follows:

- \$460,198 through general donations and campaigns
- \$270,742 through grants and sponsorships
- \$468,741 donated in tribute
- \$92,468 through Legacy of Hope bequests

#### **BRAIN TUMOUR WALK:**

## \$1,347,849 raised – 46% of our fundraised revenue:

- 2,785 participants
- 468 teams
- 26 businesses sponsored a Brain Tumour Walk in their community and
- 1 hashtag sponsor!

**COMMUNITY EVENTS:** 

\$599,455 raised by 31 community events including:

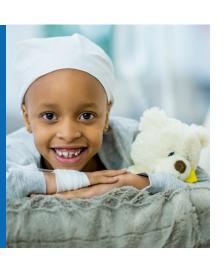
\$66,586

raised through our "Your Way" fundraising platform 308

Facebook Fundraisers raised \$78,863

3,800

Hats for Hope toques raised \$35,500



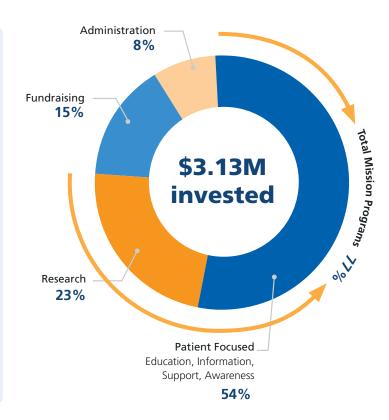
I am walking in memory of Parnian Hosseinpour, a fellow young adult brain tumour patient who passed away in February 2022. Parnian was a force of nature who gave so much of herself in supporting other young adult patients.

- Kaitlyn, Ottawa

### Your impact...

# \$730,461 invested in research, including:

- 1 Research Fellowships
- 2 Research Studentships
- 4 Research Grants (1 Pediatric, 1 Glioblastoma and 2 Brain Metastases Research Grants)
- 4 Feature Grants (2 Pediatric and 2 Glioblastoma Feature Grants)
- 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 Awards



childhood brain tumour survivors were awarded Youth Education Awards	Award for Excellence was awarded (Canadian Association of Psychosocial Oncology - CAPO)	Support groups - 2 in-person, 2 hybrid, and 8 virtual support groups provided support for community members	private Facebook Support Groups provided support to thousands of patients, survivors, caregivers and more
virtual in-services reaching over 70 Healthcare Professionals	<b>693</b> participants attended our 2022 Brain Tumour Webinar Series	participants attended our 2022 French Brain Tumour Conference	<b>91</b> participants attended  our Virtual Healthcare  Professional Symposium
4.7  caregivers attended our  Pediatric Webinar	2,275  handbooks were distributed in both languages	849 mobile app users	38,828 social fans and followers

I belong to a support group. I find it very encouraging and appreciate being able to be real there – not brave like I feel I must be for my husband and children...

## **Expand Funding for Research**

In 2022, Brain Tumour Foundation of Canada's Research program invested \$730,461 through grants, awards, and collaborative projects. This brought our total investment in research to just over \$9.5 million since our founding in 1982.

#### RESEARCH FELLOWSHIP RECIPIENT



Dr. Muhammad Vaseem Shaikh – Postdoctoral Research Fellow at McMaster University, Hamilton, ON Project Title: "Allogeneic, 'off the shelf' CD133 CAR-T immunotherapy for glioblastoma"

Generously funded by the DUNN with Cancer Research Fund.

#### RESEARCH STUDENTSHIPS



Daniel Mobilio – Undergraduate student at McMaster University, Hamilton, ON Project Title: "Uncovering novel small molecule drugs that prevent/block

Generously funded by the Taite Boomer Foundation.



Sami Alrashed – Medical student at the University of Ottawa, Ottawa, ON

progression of brain metastases"

**Project Title:** "Uncovering activation and plasticity of tumour microenvironment in search for novel therapeutic approaches in GBM"

Funded through the generosity of donors.

#### **BRAIN TUMOUR TISSUE BANK**

The Brain Tumour Tissue Bank is located at University Hospital in London, Ontario. Patients with a brain tumour surgically removed at the medical facility can donate some of the tissue to the tissue bank.

Between January and December 2022, the Brain Tumour Tissue Bank collected samples from 73 patients. Of these, 60 brain tumour cases were banked. These cases yielded 300 Snap Frozen specimen vials and 30 OCT embedded vials. Samples were provided to five different research investigators at institutions across Canada.

Learn More about the Brain Tumour Tissue Bank at www.braintumour.ca/research/brain-tumour-tissue-bank.



### BRAIN TUMOUR REGISTRY OF CANADA

The Brain Tumour Registry of Canada was established in 2019 to ensure comprehensive surveillance of all brain tumours across Canada.

Prior to this, the only brain tumour demographic research available to Canadian medical professionals came from the United States. These approximations have been used to guide Canadian research, raise awareness, secure government funding and develop support programs. However, these approximations do not necessarily reflect Canada's brain tumour community.

The various reports produced by the Brain Tumour Registry of Canada comprehensively look at brain tumours across Canada using all-Canadian information. A survival and prevalence report was released in June 2022 and is available on their website, www.braintumourregistry.ca.

# THE PAM AND ROLANDO DEL MAESTRO FAMILY UNDERGRADUATE STUDENT RESEARCH COMPETITION AWARDS

Since 2017, The Pam and Rolando Del Maestro Family Undergraduate Student Research Competition Awards have helped promote scientific innovation among Canadian undergraduate students.

In 2022, the event was held virtually on Saturday, October 1. This event included presentations by the previously awarded Studentship Recipient from the University of Windsor, Dina Dilinaer. Her presentation was entitled "Self-Immolative NanoCapsule - A New Form of Drug Delivery for Glioblastoma Multiforme."

Our Student Research Competition included six teams of undergraduate students from Queens University, Western University, McGill University, McMaster University, University of Montreal, and the University of Newfoundland. The following three teams received monetary awards: Dhruv Patel and Gurdit Sood from Queen's University, Jackie Ve and Rafeh Shahid from Western University, and Neevya Balasubramaniam and Nour Kabbes from McGill University.

#### **RESEARCH GRANT RECIPIENTS**



**Alan Underhill** – University of Alberta, Edmonton, AB

Project Title: "Determinants of KMT5B dysfunction in pediatric glioma"

Generously funded by The Frazer Anderson Pediatric Research Grant, Acuitas Therapeutics Inc.



**Ekaterina Tchistiakova and Nicolas Proquin** – University of Calgary, Calgary, AB

Project Title: "Application of machine learning and diffusion-based radiomics for early detection and treatment response assessment of brain metastases"

Funded through the generosity of donors.



**Jakob Magolan** – McMaster University, Hamilton, ON

Project Title: "Development of Anti-Brain Metastasis Therapeutics"

Funded through the generosity of donors.



**Lisa Porter** – University of Windsor, Windsor, ON

Project Title: "Exploring the Role and the Cancer Activated Microenvironment in the Progression of Glioblastoma: Potential Novel Avenues for Therapeutic Intervention"

Generously funded in Memory of Mackenzie Rigg Brain Tumour Research Grant - Supported by Vikes Kick Cancer.

#### RESEARCH UPDATE

Dr. Raymond Reilly and his team, who received our 2019 Research Grant, have obtained some promising results for their project entitled "Radiation Nanomedicine for Intraoperative Treatment of Glioblastoma Multiforme (GBM)." The treatment consists of gold nanoparticles linked to a radioisotope, lutetium-177, that emits short-range

radiation. The radiation nanomedicine is infused directly and precisely into the brain near the tumour, where the radiation emitted destroys brain tumour cells. It was the first time that radiation nanomedicine was studied to treat glioblastoma tumours implanted into mice at a dose that was found to be safe. The results revealed

that the tumours in the mice's brains were effectively treated with radiation nanomedicine. Further studies are continuing to confirm these early but promising results.

Learn more about Dr. Reilly's research: www.braintumour.ca/blog/q-a-with-dr-raymond-reilly.

#### **FEATURE GRANT RECIPIENTS**



**Sylvia Cheng** – Director of Pediatric Neuro-Oncology, BC Children's Hospital, Vancouver, BC

Project Title: "Radiotherapy and proton beam treatment for childhood brain tumours in Canada"

Funded through the generosity of donors.



Patrick Gunning – Professor, Chief Scientific Director of the Centre for Medicinal Chemistry, University of Toronto, Toronto, ON

Project Title: "Development of Selective Small Molecule Inhibitors as Treatments for Medulloblastoma"

Funded through the generosity of donors.



Melanie Keats – Professor and Affiliated Scientist, Dalhousie University & Nova Scotia Health, Halifax, NS

Project Title: "How people with Glioblastoma view physical activity throughout their palliative journey: A realist study"

Generously funded by the DUNN with Cancer Research Fund.



Silvia Penuela – Associate Professor, Western University, London, ON Project Title: "Inhibition of Panx1 as a novel target for Glioblastoma Multiforme"

Generously funded by the DUNN with Cancer Research Fund and matched by an anonymous donor.

For more information on our Brain Tumour Research Grant Recipients, visit www.braintumour.ca/research\_recipients.

### Raising Awareness One Hat at a Time

On Monday, October 24, 2022, Canada united to support the 5th Annual Brain Cancer Awareness Day.

Hats for Hope is a movement to raise awareness for brain cancer in Canada. Over the years, we have sold thousands of Hats for Hope toques, generating funds and awareness for brain cancer.

Because you purchased a toque, we raised \$30,500 in hat sales in 2022. In addition, our #HatsForHope hashtag sponsor, Novocure, donated \$5,000 to help elevate brain cancer awareness and promote the programs, resources, and support our organization provides to the brain tumour community. Together, we raised an impressive \$35,500.

The #HatsForHope hashtag and other promotional efforts reached millions of people on social media through our posts, ads, and influencers. We received significant support from various Canadian influencers, including our ambassador, the renowned Canadian actor Salvatore Antonio, whose personal story touched so many. In addition, we are grateful to other prominent individuals, such as astronaut Chris Hadfield, singer Vivian Hicks, actor

Paul Sun-Hyung Lee, comedian and TV Show Host
Stewart Reynolds, and sportswriter and sports commentator Jesse Pollock, among others, for their participation.

We are grateful to
everyone who joined our
Hats For Hope movement
on October 24, 2022. By coming
together and wearing our toques,
we were able to show those affected
that they are not alone.

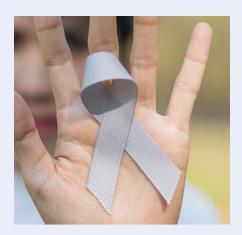
Over the past five years, Hats for Hope toques have transcended their functional purpose and have become a powerful symbol of community, resilience, and remembrance.

Watch for our 2023 Hats For Hope campaign later this year as we introduce a new way to continue to raise awareness for brain cancer and bring hope to those affected.

For more information, please visit our website at www.hatsforhope.ca.



#### **HELP RAISE AWARENESS FOR BRAIN TUMOURS!**



You can help raise awareness for brain tumours throughout the year in multiple ways.

Brain Tumour Awareness Month:
May is Brain Tumour Awareness Month
in Canada. Help us #TurnMayGrey in
2023 to #EndBrainTumours.

World Brain Tumour Awareness:
Day: June 8 is World Brain
Tumour Awareness Day. Follow
@BrainTumourFdn on social media for
awareness-raising social media activity.

#### **Brain Cancer Awareness Day:**

October 24 is Brain Cancer Awareness Day in Canada. Please help us raise awareness by participating in our #HatsForHope campaign.

### www.hatsforhope.ca

International Brain Tumour Awareness Week:

The 16th International Brain Tumour Awareness Week will occur from Saturday, October 29, to Saturday, November 5, 2022.

Learn how to get involved at www.braintumour.ca/get-involved/raising-awareness.

# **Volunteering Weaves Us Together and Connects Us**

#### **2023 VOLUNTEERS OF DISTINCTION**

Volunteers make a difference in the lives of brain tumour patients and families every day. Brain Tumour Foundation of Canada's Volunteer of Distinction Awards are given annually to volunteers who embody the spirit of volunteerism. They are leaders and ambassadors who give freely of their time and energy to help reach Canadians affected by a brain tumour through Advocacy, Research, Information, Support, and Education.



#### Elizabeth Gyuk - Belleville Brain Tumour Walk Coordinator

"As the Belleville Brain Tumour Walk Coordinator, I discovered something special the first time I participated in the event... I realized we were maybe going to do something extraordinary that day. It wasn't because of us. It was because we had the privilege to be there and be a part of this."

"Whether survivors or volunteers, any link to the brain tumour world gives us a common thread and connection. One that crosses boundaries and gives you the liberty to cut to the chase and make that special connection."



#### Shreya Gandhi – Member of the Brampton Brain Tumour Walk Committee, Co-founder of the Youth Brain Tumour Awareness Campaign Project X-Never and SuperKids Committee Member

"Volunteering and sharing our stories with others allows us to open our hearts to those around us and nurture a bond built from a mutual understanding of the other person's adversities. I have met many awe-inspiring people through BTFC, many of whom are now great friends of mine. We are all connected through a similar desire to bring change for those around us. Volunteering has allowed us to cross each other's paths and now walk as a team towards a similar cause - to cure brain tumours once and for all."



#### Visale Balarajah – Member of the Brampton Brain Tumour Walk Committee, Co-founder of the youth brain tumour awareness campaign Project X-Never and SuperKids Committee Member

"Volunteering is the key to bridging the knowledge gaps in society, allowing us to seek and support others through multiple forms. It brings together communities across boundaries to share their knowledge and break stigmas and stereotypes. With the internet, miscommunication and social media playing a large role in our lives in this age and time, this support is much needed and can reach people anywhere in the world."



#### Yasmina Mashmoushi – GTA Support Group Facilitator

"Volunteering continually reminds me that we are working towards the common human goal of attaining a more equitable and prosperous global community. The COVID-19 pandemic has shown us how inextricably linked people across the country and globe are and has affirmed that we must each do our part if we want to dream of a more auspicious future. Volunteering is a way to do my part to help carve out the future. Volunteering is our collective fight for the changes we believe in-changes that make our community a more prosperous place for everyone regardless of ethnicity, gender, or ability."

#### 2023 DAVID KELLY AWARD

The David Kelly Award for Community Service is awarded annually to one individual who exemplifies the spirit of community service supporting the brain tumour community in Canada. This award, previously the Chair's Award for Community Service, has been renamed in honour of brain tumour advocate and fundraising leader David Kelly, from Fredericton, New Brunswick, who passed away in October 2014.

### **The Dunn Family**



The Dunn family began collaborating with our organization following their daughter Allison's glioblastoma diagnosis. Allison's brother Brian had an idea for an awareness run because of Allison's love of running. Before her passing, she was aware of a planned run in her honour and supported it, knowing she would possibly be helping others. The Dunn family pulled the event together in a matter of mere months, a fitting tribute to their decades of charitable experience in the community. The event, Dunn with Cancer, held in Springbank Park, London, is entering its fourth year and has become a way for friends and family to come together in

"A Movement of Hope." In partnership with our organization, all funds raised from the event go to important glioblastoma research.

An event like this does it all. Other families, unfortunately, will go through what our family has, so the more people who get involved, bringing communities and generations together, the more successful we will be with glioblastoma research. It's not just about the funds raised; it is about awareness, coming together and supporting each other.

# **Stories of Hope from our Community**

These stories of perseverance are personal perspectives on how brain tumour patients and families find hope, support, strength, and inspiration. **Read the full stories at www.braintumour.ca/category/stories.** 

#### **RELAYING A MESSAGE - Chelsea Medcalfe**



"Brain Tumour Foundation of Canada offers support in many ways, but most of all, they give hope! There's such great information available to anyone on the brain tumour journey."

Chelsea Medcalfe is the President of the Banff-Jasper Relay Society, an organization that raises funds for Brain Tumour Foundation of Canada. Chelsea took over the organization when her father was diagnosed with a glioblastoma. The relay was restarted in 2005 to honour a fellow runner, Garth Huck, who died of a brain tumour in 2004. Since its restart, runners have raised over \$500,000 for Brain Tumour Foundation of Canada.

The Banff-Jasper Relay is run over a 250-kilometre course. The race is divided into North and South teams that start on opposite ends of the trail during daylight and finish with a large celebration at twilight. The relay is limited to 60 teams. Each team can have 15 members, totalling 900 active participants. The relay challenges runners' endurance and allows the community to unite, share personal experiences and connect.

#### A MEANINGFUL LIFE AFTER ANY BRAIN TUMOUR - Nicole Abouhalka



"For four consecutive years, I had headaches. Then, I was finally diagnosed with a brain tumour and had surgery to remove it.

I relearned to live, drive my car without feeling submerged by the traffic, and tolerate noises, bright colours, and even electric lights. For the first time, I enjoyed watching a flower bloom and a spider weave its web. I have learned to convey my needs to the wonderful people who have walked me through my recovery.

I travelled again, entertained friends, wrote letters

to newspapers, and often addressed the Municipality Council in Guelph, Ontario, and other institutions. I have also participated in many Brain Tumour Walks and every Support Group meeting because only survivors can appreciate our ordeal.

In brief, my life is again full of happiness and sorrow, successes and failures. I keep reviewing my values after each hardship and try hard not to let myself down for my sake and the sake of my loved ones. Bon Courage. Good Cheer. You will succeed."

#### **REDEFINING - Sarah Blanchard**



At 21 years of age, Sarah was diagnosed with a pilocytic astrocytoma. A biopsy was performed on the tumour, which proved to be non-malignant. However, surgery was still needed. The first operation was completed in October 1996 by one of the only four female neurosurgeons nationwide.

After this operation, an ICP tube was put into her brain by drilling a hole through the skull. Even though the wound has healed, Sarah still feels pain, "it feels like an ice pick is being driven into my head. When the weather changes, I feel it. Much like a person with arthritis does."

It was also then that Sarah began researching brain tumours. She received the third edition of the Adult Brain Tumour Handbook, published by Brain Tumour Foundation of Canada.

She continues to learn from herself, others, and the folks at Brain Tumour Foundation of Canada to empathize, educate, and engage with people with similar conditions. Sarah remains positive and upbeat and continues to find quality time to live life to its fullest.

### **CAMINO FOR A CAUSE - Carol Webster Simmerling**



In 2016, Carol's close friend Janet was diagnosed with a brain tumour. It was discovered as suddenly as it had appeared in the form of a seizure. Janet is the major influence and inspiration behind Carol's decision to create a fundraiser: Camino for a Cause. Janet was the one who referred Carol to the team at Brain Tumour Foundation of Canada.

She was moved by the kindness and enthusiasm the organization promotes through a dedicated team of volunteers, survivors, patients, family members, healthcare professionals and staff.

"Janet had spoken so highly of them and how they had made a difference for her and her loved ones. I am impressed by what they do. My relationship with Brain Tumour Foundation of Canada was beneficial," she says.

# **HOW I ENDED MY TOXIC RELATIONSHIP WITH A MENINGIOMA!**- Sophie Lyne Zaretto



"The relationship I had with my meningioma was unhealthy. The sadness, negative emotions, and anxiety I was experiencing following my diagnosis led me to believe that I had to make difficult choices to improve my physical and mental condition. I had identified the cause of my ailments, and now I had to find a cure.

I then contacted the Brain Tumor Foundation of Canada and obtained a list of available resources. I also did some research and spoke with other people who had been diagnosed with meningiomas. Several people suggested I contact a neurosurgeon specializing in skull base surgeries. This is precisely what I did.

On March 17, 2022, I underwent a nine-hour-long bi-frontal craniotomy at the Jewish General Hospital in Montreal. Thanks to the outstanding talent of the neurosurgeon, my meningioma was removed. I had always been afraid of hospitals and surgeries, but I found the strength and the courage to undergo surgery. I had fantastic support from my husband, my mother, and my friends. I also had great trust in my neurosurgeon.

A friend who also had brain surgery shared her mantra with me. It is from Michael Rosen: 'We're going on a bear hunt. Can't go over it, can't go under it, can't go around it, got to go through it.'

I repeated this personal mantra several times to create a state of relaxation and a tranquil mind and to develop my confidence to prepare for the surgery and thus end the toxic relationship with my meningioma."

#### **BAILEY'S STORY - Sharna Collier**



Theatrical, spunky, and strong only begin to describe this energetic six-year-old. "People are always happy to see her, and she makes many friends. Bailey lights up the room!" beams Sharna Collier, Bailey's mom.

In September 2017, at the age of 19 months, she was rushed to McMaster Children's Hospital after hitting her head on a sprinkler at a splash pad. She was sent for an MRI and diagnosed with a grade one pilocytic astrocytoma on her cerebellum.

Sharna and her family are grateful to McMaster Children's Hospital for the connection to Brain Tumour Foundation of Canada. Since 2018, Team

Bailey has been participating in the Kitchener-Waterloo Brain Tumour Walk, having raised over \$1500 in 2021.

With Bailey as captain, the team participated in the Kitchener-Waterloo walk in Paris with friends and family in 2022. "Brain Tumour Foundation of Canada is an excellent organization that has access to resources for survivors, loved ones and family but most of all hope!" advocates Sharna.

Bailey's family follows her achievements with pride. Every step Bailey takes brings her one step closer to her to gaining independence in her life.

#### **BRAVE LIKE SCOTTY - Aimee Easton**



Scotty was diagnosed with a slow-growing glioma in September 2021. At the onset of Scotty's diagnosis, Aimee, Scotty's mom, connected with Brain Tumour Foundation of Canada. She found many valuable educational resources for patients and their families on a brain tumour journey. "You become part of the brain tumour community, which offers strength, courage, sharing your experience and hope," Aimee affectionately expresses.

"We couldn't be prouder of the bravery Scotty has demonstrated. He stays brave for me, his dad, himself, and especially for his younger sister Ruby, who has a heart condition. Scotty teaches her how to be brave; no matter what, you must endure. To us, this walk celebrates his grit and determination through such a difficult year and accepting a lifelong condition," praises Aimee.

Team Brave Like Scotty participated in the 2022 Brain Tumour Walk on June 18 in Gananoque, Ontario. "We hope to continue to contribute to research, which could eventually impact Scotty as he continues this journey to help find a cure to end brain tumours."

Read the full stories at www.braintumour.ca/category/stories.

### YOU NEVER KNOW WHAT CAN HAPPEN! - Max Erenberg



"My world was rocked when I got a call back from my doctor and was told, 'We aren't quite sure what it is yet, but there is an abnormality in your head,'" says Max Erenberg. He was rushed to the emergency room and spent four to five days in the neurosurgery ward. Max endured numerous MRIs, CT scans, rounds of bloodwork, and an angiogram. Finally, he was diagnosed with a pilocytic astrocytoma, a low-grade benign tumour.

Max is very grateful to Brain Tumour Foundation of Canada and acknowledges the staff working tirelessly to assemble their social media, fundraising efforts, and many events. The Brain Tumour Walk is more than just a walk for him, but a cause to show support in numbers—for those whose battles are ongoing, have ended, or have not started. During the 2022 Brain Tumour Walk, his team raised the most donations, with over \$27,000, thus winning the Brain Tumour Walk's Cup of Hope.

His words are encouraging. "Put yourself out there. You never know what can happen. It's about helping people feel supported throughout their journey; you know you're giving that. You can relate, so you're making a difference that way. Just be confident, and don't be shy."

### MY STORY WITH A HORMONE SECRETING TUMOUR - Megan Cavender



In 2018, Megan was diagnosed with a large pituitary tumour and Cushing's disease. She had surgery to remove the tumour, and her recovery has been "going great" since then. Megan is grateful to her family and the medical team, who demonstrated exemplary care.

Feeling the need to give back to the community, and with the COVID pandemic at its height, Megan noted that there were no specific Brain Tumour Awareness masks available to wear. "I used my creativity and designed four different printed masks that I brought to the brain tumour community," she explains.

These masks were double-layer cotton, featuring a pocket for a replacement filter, a metal nose clip, adjustable ear straps, and shaped for breathability

and comfort. "Over 150 people purchased them across Canada, totaling over 400 masks made and all the profits were donated to the Foundation," Megan proudly states.

"The following year, I created a crocheted Brain Bunny. It is wearing one of my printed masks, a blue knit 'Survivor' walk t-shirt, and a knit hope hat. These bunnies have been selling the moment I have another one made." Those generously pledged have gone to pediatric warriors still battling or surviving a brain tumour or brain cancer. They give comfort when needed most. Megan's Brain Bunnies are also a fundraising incentive item for our 2023 Brain Tumour Walk.

### A MIND OVER MATTER - James Rolph



In August 2017, while working with a neurologist to find the cause of his migraines, James was diagnosed with a brain tumour. At the time, he and his wife, Julie, were raising a two and three-year-old, and he was worried about how the diagnosis would impact his life and career; how would he tell those closest to him? He would also need time off from work.

James describes the experience as surreal and a "huge shock." A series of MRIs followed, and the decision was made to remove the tumour that November surgically. However, shortly after, he learned he had a hemangioblastoma, a rare, non-malignant brain tumour.

In 2018, James and Julie – Team Mind Over Matter – embarked on their first Brain Tumour Walk in London, Ontario. Initially, he was very private about his condition and did not publicly fundraise. "Because my tumour was non-malignant, it felt weird, and I didn't know anyone else with one. So when I saw other people like me in blue shirts and stood with them in the group picture, I was just overwhelmed with emotion," he reflects. "I understood these men, women, and children have been through something. For this reason, I have been walking every year since and will continue to do so."

### **PAPA'S PEOPLE - Jenn Radovitzky**



On February 1, 2022, Jenn Radovitzky's father, aged 80, was diagnosed with a brain tumour. Three weeks prior, Jenn's parents had been vacationing in Costa Rica with her and her husband for two weeks. "Dad hiked the rainforest, rode a horse, drove an ATV, and swam in the ocean. He lived life to the fullest!" Jenn exclaims. She describes this experience as the toughest and the most emotionally gruelling time of her life.

Her father's cancer turned out to be brain lymphoma. While he is still in the beginning stages of treatment, the family has already learned there is a desperate need for a cure. Jenn was proactive in searching for resources that would benefit her father. "It was a quick Google search of 'Is there a brain cancer foundation in Toronto?' I saw there was a walk, and it was associated with Brain Tumour Foundation of Canada. There is nothing we wouldn't do for our dad and papa," she advocates.

Brain tumours have now become a part of Jenn and her family's life, which is her connection to the foundation. So, on Father's Day weekend of 2022, the 20 team members of Papa's People set off on their inaugural virtual 5K walk, raising over \$21,000.

#### **TEAM YIPPEE HAPPY LIVELINESS - Chris Moore**



"He was larger than life; in stature, personality, and his impact on others, and is deeply missed by his family, colleagues and friends," Sarah Orsini lovingly remembers of her husband, Chris Moore. In January 2017, after suffering increasingly intense headaches, he was diagnosed with glioblastoma, a terminal brain cancer. He was given nine to fourteen months to live.

"Telling the three boys that their dad would die soon was the hardest thing I've ever had to do. I felt sick to my stomach and could barely get the words out. Then, Chris and I told them together. It was heartbreaking." During those last few months, Sarah learned to be a personal support worker for Chris as he steadily declined. She devoted countless hours to maintaining Chris' comfort and dignity.

"I believe in the power of positivity and the human spirit pulling us through, even in the face of huge obstacles. It was an absolute honour to care for him at the end of his life, and I wouldn't have had it any other way," Sarah states.

At Chris's first oncology appointment, his doctor gave him and Sarah many resources. He was the first to have heard of and connected with Brain Tumour Foundation of Canada.

"Of course, we jumped in and tried them all out. That was the kind of person Chris was; he investigated all the resources and took what he could from each of them," says Sarah. His parents greatly benefited from Brain Tumour Foundation of Canada, especially the monthly support group meetings.

#### **AVA'S ALLIANCE - Ava Broomes**



"My cousin Ava Broomes continually experienced excruciating headaches daily. She was finally diagnosed with high-grade glioma," explains Savannah Swift. After her diagnosis, Ava often missed school and could not attend social gatherings. "It's been tough on her. I think the hardest part was seeing a 12-year-old go through this journey. They should be enjoying their childhood worry-free," expresses Savannah.

"The first time I'd ever read about the foundation, I knew I would be coordinating my first fundraiser event." Throughout Ava's harrowing journey to recovery, she has shown tremendous strength

and courage! Her family and friends - AKA "Ava's Alliance" - will be with her every step of the way!

"I decided to participate in the Brain Tumour Walk, and I thought just to give this a go and see what happens. This first one hit home because she is my cousin. I wanted to do something special for her," states Savannah. Her experience of the walk is connecting with the brain tumour community; by giving support, sharing stories, and raising funds so they do not feel alone. She plans to make the walk an annual event. Savannah hopes to bring awareness while raising funds for research and needed care for those affected by a brain tumour.

Read the full stories at www.braintumour.ca/category/stories.

## **Looking Ahead...**

Brain Tumour Foundation of Canada will continue its efforts to improve treatment access and remove barriers to care. In addition, we will grow the impact of our investment in research through collaborations and partnerships and leverage the findings of the Brain Tumour Registry of Canada.

The past few years have been a challenging experience for many of us as we learn to "coexist with COVID-19". While virtual events have provided a valuable way to stay connected to our community during the pandemic, there is no substitute

for the connection and energy of an in-person event. As a result, we look forward to bringing back in-person events this year and allowing our community to connect with others who understand their experiences.

HOPE is a word that carries immense significance for each one of us. At Brain Tumour Foundation of Canada, we strive to bring hope to those affected by a brain tumour. Through an unwavering commitment to Advocacy, Research, Information, Support, and Education, we seek to provide a glimmer of hope for others in their darkest times.



### **Advocate for Fairness**

As we continued to navigate through the ongoing after-effects of the pandemic, we wanted to ensure that patients, caregivers, and families could count on Brain Tumour Foundation of Canada to continue to recognize and respond to the advocacy needs of the brain tumour community. With the help of our Advocacy Committee, we have worked hard to ensure our advocacy priorities and activities are relevant and meaningful to the brain tumour community. Some impacts of these advocacy efforts:

- We were pleased to be able to share with our community that following a meeting between representatives from our organization and Bristol-Myers Squibb, BMS extended the discontinuation of lomustine from June 2023 to March 2025. We are continuing to work towards solutions to mitigate the impact of this situation on the brain tumour community.
- We partnered with like-minded organizations, including CanCertainty, Neurological Health Charities Canada (NHCC), and Best Medicines Coalition (BMC), by sharing petitions and information on our website and social platforms, assisting with the development and revision of advocacy documents and submissions, attending meetings with stakeholders, and taking part in working groups to tackle specific issues.

#### **Vision:**

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



#### Mission:

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

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Registered Charitable Number: BN118816339RR0001

#### Values:

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



Hope, Caring, Integrity, Accountability and Collaboration

Connect with us on social media @BrainTumourFdn











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