



braintumour
foundation
OF CANADA



2011 Report

TO THE

BRAIN TUMOUR COMMUNITY

Sara, pediatric
brain tumour
survivor, and
big sister, Alice

Our Impact

In 2011

Your generous support leads the way for brain tumour patient programs and research, all across Canada. Because of you, in 2011 we reached more people affected by this disease than ever before.



69

Patients who donated brain tumour tissue to the Brain Tumour Tissue Bank at London Health Sciences Centre in London



800

People participated in monthly Adult Brain Tumour Support Groups across Canada



60

Families took part in the BrainWAVE support program in Southern Ontario and British Columbia



4894

Brain Tumour Patient Handbooks (Adult, Pediatric and Non-Malignant) delivered across Canada, to health care professionals and people affected by a brain tumour



1491

Children's storybooks in English, French and Italian delivered to families, children and schools across Canada and internationally



115

Health Care Professional Kits disseminated across Canada



111

Community Events held nation-wide, supporting brain tumour research and patient programs



5858

Participants in the Spring Sprint program in 21 cities across eight provinces



24,000

BrainStorm print newsletters distributed across Canada



9

Brain Tumour Research Grants awarded by Brain Tumour Foundation of Canada



619

People participated in Brain Tumour Information Day Conferences and Education Seminars



1278

Requests for information and one-on-one emotional support



69,913

Unique visitors to Brain Tumour Foundation of Canada's website



250

Health care professionals attended 12 in-service educational presentations



451

Media hits, helping raise public awareness about brain tumours



90

Health care professionals attended four Health Care Professionals' workshops



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Our Mission

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

Our Values

Our Values serve as guidelines for our conduct and behaviour as we work towards our Vision.

HOPE

We strive to empower and engage people affected by a brain tumour through optimism, while inspiring the community to share their time, talent, experience and resources.

CARING

We act with empathy, compassion, understanding and a strong desire to empower and emotionally support those we serve.

INTEGRITY

We are committed to honesty, respect and transparency in our actions and to always do what we promise.

ACCOUNTABILITY

We fulfill our legal, moral and ethical standards with rigour; and we report back to our stakeholders in a timely and accurate manner.

COLLABORATION

We work toward achieving our mission through effective partnerships, alliances and affiliations with volunteers, staff, donors and other members of the brain tumour community.

CREATING A CONNECTED COMMUNITY

We honour and celebrate relationships that help the organization to live and advance its mission and vision. We are stewards committed to long term, mutually supportive relationships that create a vibrant brain tumour community.

Our Vision

Our Vision is to find the cause of and cure for brain tumours while improving the quality of life for those affected.

Every hour of every day, more than one Canadian hears the words, “you have a brain tumour.” This is what drives Brain Tumour Foundation of Canada to continue working diligently to meet the needs of all Canadians living with a brain tumour. It is because of you, our dedicated donors and volunteers, that our mission and vision will be met, and for this we extend our heartfelt gratitude.

This past year was one of transformation for the organization; a year that ushered in several new initiatives to help lift the burden of a brain tumour for anyone touched by this devastating disease. We are urgently pursuing more answers around cures and causes for brain tumours through our Research program as well as collaborative projects across North America. We are stepping up our advocacy efforts to lay the groundwork for future campaigns based around issues recently identified through a community survey: the need for increased funding for brain tumour research, for better patient care through accurate data collection, and for equal access to drugs and treatment. We also had a record-breaking year for Spring Sprint, the largest fundraiser for the brain tumour community. More than \$1.6 million was raised to fund critical research and patient programs.

We welcome you to the 2011 Report to the Brain Tumour Community. Here you'll read moving stories about how you make a difference in the lives of those affected by a brain tumour. These stories echo our values of Hope, Caring, Integrity, Accountability, Collaboration and Creating a Connected Community. They also show how deep the commitment to overcoming this disease runs.

Thank you for your tireless support and determination. Our work is only made possible through your kind generosity.

Together we will change the future of brain tumour research and patient care. Together we will find a cure.



Joseph Megyesi
Chair, Board of Directors



Susan Marshall
Executive Director

Hope

“ You just hope for the best. Hope that someday someone will find a cure and be able to help brain cancer survivors have a really good life. That’s our dream. ” Ruth Motyka



Dan, Richard and Ruth Motyka

When Dan and Ruth Motyka’s son, Richard, was diagnosed with an aggressive grade 3 brain tumour in August 2003, life changed in an instant for everyone. “Our reaction was horror,” says Richard, now 48. While he was unable to return to his job as the vice-president of a Silicon Valley-based hi-tech company, Richard began rebuilding his life with a series of wide-ranging pursuits including supporting Brain Tumour Foundation of Canada.

It became a family effort as Karen, Richard’s wife, their twins Stephenie and Danny, his parents Ruth and Dan, his sister Alison and many others rallied to show their support for Richard and others affected by the disease.

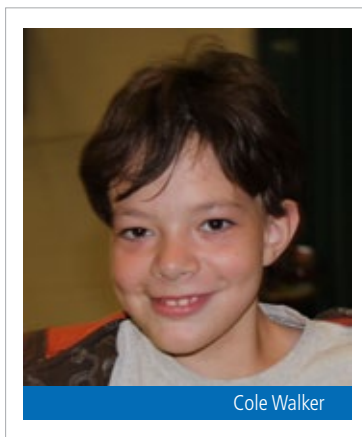
Richard’s sister Alison and her husband Darrell, along with former business partners Howard Crone and his wife Michelle, have played a vitally important role on the financial front in helping the battle against brain tumours: they have made special gifts to fund research into the cause of and cure for the disease. Alison and Darrell have also created the Richard Motyka Brain Tumour Fellowship. The Fellowship supports the critical need for an increased focus on brain tumour research and enables young clinicians and scientists to enter this important field, accelerating studies leading to a cure for brain tumours. 2011 marked the inaugural year the Richard Motyka Brain Tumour Research Fellowship was open for applications, and the first award will be given out in 2012.

Research Program Spotlight

Since 1985, donor support has led to Brain Tumour Foundation of Canada providing \$3 million to support important research into the cause of and cure for brain tumours.

- In 2011, nine Brain Tumour Research Grants were awarded by the organization, for projects that explore diagnostic methods, patient quality-of-life and brain tumour treatments.
- 69 brain tumour tissue cases were provided to the Brain Tumour Tissue Bank, a Brain Tumour Foundation of Canada-led initiative that collects human brain tumour specimens and matching clinical data for neuro-oncology research.
- 14 joint projects, funded through the Brain Tumor Funders’ Collaborative, of which Brain Tumour Foundation of Canada is a founding member, concluded their research. Results from this research will be available in 2012.
- Calls for applications to the William Donald Nash Brain Tumour Fellowship and Richard Motyka Brain Tumour Research Fellowship were open in 2011, with funding to begin in 2012.
- Fall 2011 marked the first period of funding Brain Tumour Foundation of Canada provides for the new, three-year Developmental Neurobiology Collaborative Grants for pediatric brain cancer research. These funds are awarded in partnership with the US-based National Brain Tumor Society.

“ In 2003, I heard the words that no parent should ever have to hear, ‘your four-year-old son has a brain tumour.’ ” Lisa Walker



Cole Walker

When Lisa and her husband, Rick, learned their son, Cole, had a Brainstem Glioma, they were devastated. They say that amid the turmoil of Cole’s diagnosis and the ongoing journey of recovery and coping with treatment side effects, Brain Tumour Foundation of Canada has been there. “When we found out about Brain Tumour Foundation of Canada it was truly a beacon in the night. Just knowing that the information we needed was from a reliable source that wasn’t promoting a specific treatment or option helped greatly. The Pediatric Brain Tumour Patient Handbook has been so very helpful to us.”

In addition to the handbook, Cole and his entire family have found care and support through BrainWAVE, with Lisa saying the program is something for the family to attend together without the pressure that Cole’s challenges and “difference” can create. “It has been so very helpful knowing that there was a group out there that understands what Cole was going through and what I was going through as his caregiver.”

Cole is now 13 and in grade seven, thriving as a young teen and student.

Programs and Services Spotlight

In 2011, thousands of individuals and families found compassion and understanding through our Information and Support Services and Education Program.



- Information Days and Education Seminars welcomed 619 participants. These events bring together speakers from the health care and brain tumour communities to share their expertise and knowledge with an audience of patients, caregivers and other medical professionals.
- Adult Support Groups provided a confidential, inclusive environment for more than 800 people to share their experiences with a brain tumour.
- 60 families took part in BrainWAVE, our volunteer-led pediatric program that offers families the opportunity to connect with others on the journey with a brain tumour.
- Information Services fulfilled 1042 requests for resources and information about brain tumours.
- 4894 Brain Tumour Patient Handbooks were distributed across Canada and internationally.
- Health Care Professionals’ Workshops and In-Service Presentations were provided to more than 300 medical professionals in Ontario, Saskatchewan, Alberta and Nova Scotia. These presentations enhance insight into Brain Tumour Foundation of Canada’s programs and services, and provide up-to-date brain tumour information and resources to health care professionals. This information and awareness helps increase comfort in referring those affected by a brain tumour to Brain Tumour Foundation of Canada.

Integrity and Accountability

During the past year, our donors continued to be generous and support our efforts through all areas of our fundraising endeavours. Our gross revenue in 2011 reached more than \$2.8 million, which represents an increase of 11.9 per cent over 2010. The year ended with an excess of revenues over program expenditures of \$310,592. These favourable financial conditions allowed us to allocate funds to further grow the research program in 2012 and maintain the organization's sustainability fund.

At Brain Tumour Foundation of Canada 73.5 cents of every dollar spent goes directly to support the brain tumour community through research, support, information and education. Fundraising (22.9 per cent) and Administrative

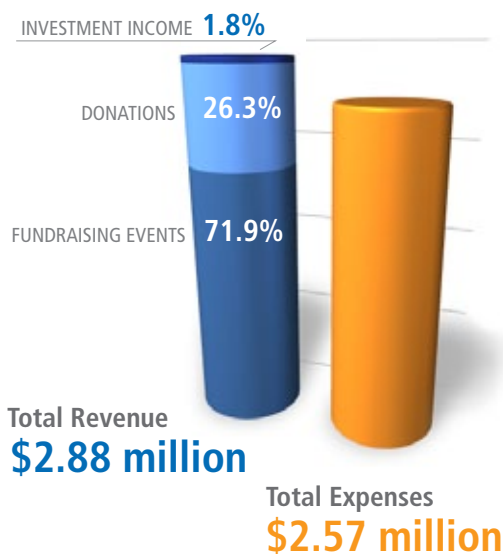
(3.6 per cent) expenses are well managed accounting for 26.5 per cent of total expenditures.

Brain Tumour Foundation of Canada follows the Imagine Canada Ethical Fundraising and Financial Accountability Code. If you are interested in a detailed financial report, please visit www.BrainTumour.ca or contact Susan Marshall at 1-800-265-5106 ext. 222 or smarshall@braintumour.ca.

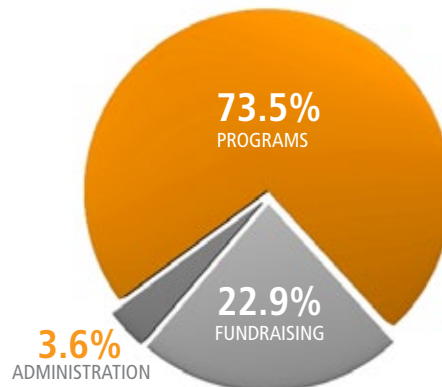


How Your Donations Help the Brain Tumour Community

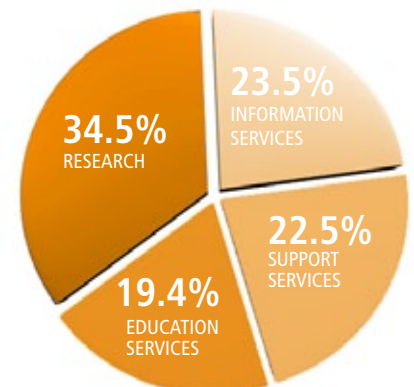
2011 REVENUE AND EXPENSES



OVERALL ORGANIZATIONAL EXPENSES



ALLOCATION OF PROGRAM EXPENDITURES



Collaboration



The cliché goes, “when life gives you lemons, you make lemonade,” and activist Femma Norton brings this saying to life by taking the many lemons she has been given and squeezing the most out of them.

Femma is a brain tumour survivor herself, and has taken on a nurturer’s role when loved ones have also faced their own diagnosis including her father, sister and brother, each of whom passed away from Glioblastoma Multiforme brain tumours. The disease first impacted Femma’s family more than 40 years ago. It was then that she took on her initial activist role. “I was only 22 years old at the time. Back then, it was a diagnosis from outer space.” As little was known at that time, she began to advocate and research potential treatments available.

Since then, Femma has continued to play an active role in the brain tumour community. One issue close to her heart is that of much-needed improved data collection of all brain tumours in a national registry. She has met with Members of Parliament to make them aware of the need, which helped lead the passing of Private Member’s Motion, M-235. This motion directs the development of a nation-wide effort to collect data about all brain tumours. Today she is working to see this direction implemented.

Femma also represents Brain Tumour Foundation of Canada at the Canadian Alliance of Brain Tumour Organizations (CABTO), a union of brain tumour organizations, to exchange information and expertise. She values CABTO’s collaborative structure and is proud to be a part of a group that works effectively together. She adds that, “Whenever I go to their meetings or participate in their conference calls, I feel like I’m helping and giving my time to the cause.”

Femma expresses her gratitude as a volunteer member of Brain Tumour Foundation of Canada’s Advocacy Committee, remarking that, “it’s through the information available that shows they are well-informed and an incredibly worthwhile organization to get involved with.”

Advocacy Spotlight

In 2011, Brain Tumour Foundation of Canada extended its advocacy program with the establishment of the Advocacy Committee. The advocacy efforts of the organization work to ensure those affected by the disease have the information and support to fully participate in all aspects of life. This includes working to change practices and attitudes that are not inclusive of the brain tumour community.

The first-ever survey on advocacy issues for the brain tumour community was conducted in October 2011. This survey, along with other research, led to the establishment of the top issues for Canada’s brain tumour community related to advocacy efforts:

- Awareness about brain tumours among influencers
- Increased brain tumour research funding
- Data Collection - Counting Every Brain Tumour
- Equal access to drugs and treatment

The organization is constantly monitoring research outcomes, tracking media stories and communicating with health care professionals on issues that could impact the brain tumour community.

In addition, as part of the advocacy section of BrainTumour.ca, an Individual Advocacy Toolkit was made available to support the brain tumour community. This package is designed for those working with and/or on behalf of people with a brain tumour, or their health care partners, to help the patient obtain needed services and support, and to help maximize their quality of life.



Connected Community

On a beautiful July 2011 morning in St. John's, Newfoundland, cousins Andrea Senyk and Derek Zwambag approached the last leg of Miles 4 Minds, their cross-Canada bike trek that raised almost \$12,000 in support of brain tumour research and care.

The motivation for Andrea and Derek's coast-to-coast ride drew on personal inspiration: they have two close friends from Highgate, Ontario who have dealt with brain tumours. Andrea's 71 year-old neighbour has been fighting a tumour for ten years. "She's gone through chemotherapy and suffered two strokes but she's never given up," says Andrea. "She's a role model for us."

The tour was also dedicated to the memory of firefighter Bob Van Goethem. The father of three children was diagnosed with a brain tumour in 2006 and passed away last year at the age of thirty-one. "Our whole community misses Bob so much," says Derek. "He showed so much strength as a firefighter and as he fought his tumour. He gave so much to everyone around him and we want to honour him."

Miles 4 Minds kicked off in Port Hardy, British Columbia on April 30 with the duo cycling from the West Coast to the East over the next three months. Along the way, Andrea and Derek connected with survivors, caregivers, loved ones and Canadians of all walks of life who continued to inspire them to reach their goal of raising money towards finding the cause of and cure for brain tumours and to improve the quality of life of those affected.

Admittedly, Derek says he and his cousin had never faced a physical challenge quite like Miles 4 Minds, "but it's nothing compared to the fight we've watched people with brain tumours go through. Our bike ride was for them... we're on the journey toward a cure."

Event Spotlight

Millions of dollars are raised through Spring Sprint and Community Events every year that benefit the 55,000 Canadians living with a brain tumour.

- Spring Sprint had a record-breaking year in 2011, raising \$1.66 million and surpassing the original goal of \$1.5 million. More than 5800 people took part in Spring Sprints in 21 cities across Canada plus the Virtual Run.
- 111 Community Events were held nationwide, raising nearly \$320,000. These events were organized in honour of those affected by a brain tumour.
- Volunteers nation-wide helped raise awareness about brain tumours and the organization through Awareness Displays in local, high-traffic areas such as libraries, shopping malls and community centres. In October 2011, in support of Brain Tumour Awareness Month, 225 Awareness Displays were set up across the country.



Derek Zwambag & Andrea Senyk - Miles 4 Minds

“ Being involved in an event such as the Spring Sprint, seeing the personalities, human spirit and the energy of everyone, is very inspiring. ” Yaron Butterfield

After a diagnosis with a Glioblastoma Multiforme in 2004, Yaron Butterfield began attending Spring Sprint to promote brain tumour awareness and fundraise for research and patient programs.

After a few years as a participant in the annual fundraiser, Yaron was asked to coordinate the 2008 event and has done so ever since. As the Vancouver Spring Sprint Coordinator, Yaron has had the opportunity to “meet new people and help organize a successful event for a great cause.”

Being both a brain tumour survivor and a researcher at the BC Cancer Agency in the Genome Science Centre, Yaron has been able to offer his expertise and skills at Spring Sprint. “It means a lot to me to help put together an event where others affected in some way by the brain tumour experience can get together, meet each other, and have fun,” says Yaron. He especially enjoys the energy of the crowd during the warm-up prior to the event and seeing everyone come back through the finish line.



Yaron Butterfield



2011 Spring Sprint - Vancouver, BC

Volunteer Spotlight

Each year, all across the country, volunteers give of their time and expertise to help lead Brain Tumour Foundation of Canada programs and services. In 2011, more than 700 individuals helped connect the brain tumour community through their volunteerism.

BRAIN TUMOUR FOUNDATION OF CANADA VOLUNTEER OF DISTINCTION AWARDS

A Volunteer of Distinction Award is given to an individual or individuals who embody the spirit of volunteerism and give of their time to support the mission and vision of Brain Tumour Foundation of Canada.

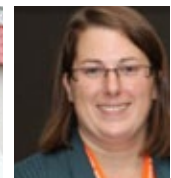
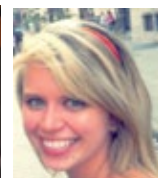
In 2011, the organization recognized six volunteers with this award of distinction:

- Jennifer Quinn of Edmonton, AB, and Jacqueline Huff of Vancouver, BC and Kathy Thornton of White Rock, BC were recognized on October 1 at the Calgary Brain Tumour Information Day Conference.
- Agnes Chick and Christa Kingsley from London, ON were recognized on October 15 at the London Brain Tumour Information Day Conference.
- Joline Leblanc of Moncton, NB was recognized on October 29 at the Halifax Brain Tumour Information Day Conference.

Volunteers of Distinction

Left to Right

Jennifer Quinn, Jaqueline Huff,
Kathy Thornton, Agnes Chick,
Christa Kingsley, Joline LeBlanc



Thank You

Brain Tumour Foundation of Canada extends its deepest gratitude to everyone who makes our work possible. Every gift helps change the future of brain tumour research and patient care. Thank you for being a partner in progress and bringing hope to everyone affected by this disease. Hope through research. Hope through patient support. Hope for a cure.

Special and Major Gifts

Alison and Darrell Jones
Jack Nichol Family Fund, a fund within London Community Foundation
Anonymous Donor

Estate of Anna Alblas
Estate of Lillian Janet Hodgert
Estate of Marjorie Howe
Estate of Phyllis Randall



“ I have chosen to honour Bob through a life insurance policy that will leave a legacy because the Brain Tumour Foundation of Canada was a huge part of my caring for my husband. ” Shelley Fitak

Legacy Funds

The David Bloom Legacy Fund
The Kelly Northey Legacy Fund
The Hannah Patterson Legacy Fund
The R. Angus King Endowment Fund

Legacy Giving

Joseph Barnes	Leendert De Goffau	Carina Jacobsen	Bridget Plumb
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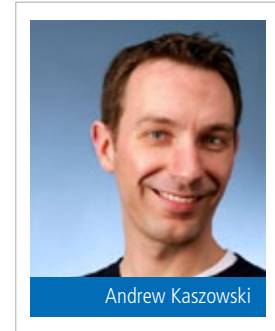
Kelly Society

Chantalle Butler	Alykhan Mamdani	Richard Seewald & Carol Van Evera
Marjory Buttrum	Susan Marshall	Norman Sonnenberg
Pam & Rolando Del Maestro	Heather Mastromattei	Sean & Michelle Taggart
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	Ben Seewald	



Monthly Giving Club

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Dave Allen	Jean Gross	Amitabh Mukerji
Lewis Balsdon	Marie Gwilym	Cora Murphy
Tony & Joan Barton	Betty Haldane	Carolyn Naus
Glenn Bauman	Harry Hall	Catheline Nemeth
Wendy Bethune	Diane Halliwell	Marian Parker
Nick Betik	Bruce Innes	Everett Pope
Iona Bolger	Sheila Jackson	Susan Purchase
Jennifer Bulatao	Carina & Peter Jacobsen	Carolyn Reed
Keith Burling	Leslie Jager	Nancy Rideout
Trice Cameron	Andrew Kaszowski	Carolyn Ross
Erin Chapman	Sarah Keels	Ruth Russell
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Fran Ferguson	Brian Marriott	Raymond Turmaine
Patrick Fraser	Ron Mazza	Belinda Wagg
Monika Goodluck	R. Gerard Meagher	Thomas Ward
Muriel Grant	Joan Medve	Kara Wilson



“ Within the last few years I have discovered more and more people in my life have been affected by brain tumours. When I learned my career mentor was one of these people, I decided to get involved with Brain Tumour Foundation of Canada as a volunteer and monthly donor to do what I could to help in the fight that so many friends and loved ones are facing. ”
[Andrew Kaszowski](#)

“ Bill has always been a fighter and his fight with brain cancer has been the biggest battle he’s ever had to face. But he’s not alone, this is a family disease. As much as it has affected him, it’s also been challenging for his caregivers, his friends and our family. He’s continuing to fight, and we’re standing with him in this battle. As a family, we’ve decided to support the efforts of Brain Tumour Foundation of Canada because we believe that continued funding of research is the best way to help other families, in the future, as they begin their own battles with this dreadful disease. ”
[MacDougall Family](#)



Thank You

Corporate Gifts

2011 NATIONAL SPONSORS

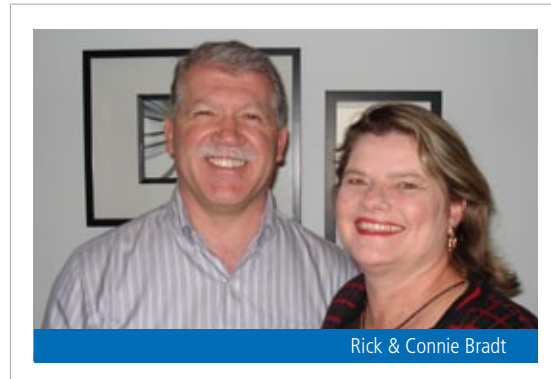
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 The GlaxoSmithKline Foundation
 The Ottawa Hospital Family Health Team
 The Wells Trust Fund
 TransCanada Pipelines Limited
 U Dayal Professional Corporation
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 Union Gas Ltd.
 Vancouver Foundation



When Rick Bradt was diagnosed with a brain tumour in February 2000, he, his wife, Connie, and his father-in-law, Allen Monsma, decided to help make a difference for those affected by the disease. As the managing director of A.M.A. Plastics Ltd., Rick developed a donor relationship with Brain Tumour Foundation of Canada. Since the partnership began, A.M.A. Plastics have given thousands of dollars to support brain tumour research and the organization's patient services through sales of Al's Flower Pouch. When asked why he chooses to partner with Brain Tumour Foundation of Canada, Rick says, **“ Since my own brain tumour diagnosis, I've felt that getting information into patients' hands is important. Knowing our Flower Pouch is seen across Canada, it offers a good opportunity to put Brain Tumour Foundation of Canada's name in front of thousands of people for virtually no cost. Using the pouch to raise funds was a logical next step. I've since learned that there are other brain tumour-related projects that require funding and support. We're proud to be a part of the Brain Tumour Foundation of Canada family. ”**





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