rothe Brain Lumour Community

braintumour foundation OF CANADA



At just three years of age, Sara was diagnosed with an aggressive brain tumour – a pineoblastoma. The day after her diagnosis, Sara's family received a copy of the Pediatric Brain Tumour Handbook and since then has taken part in Brain Tumour Information Days, Spring Sprint and BrainWAVE events.

Now, five years since the Stapletons first heard that startling diagnosis, Sara is an active eight-year-old who loves art and recess, and the entire family is grateful for the support they received from Brain Tumour Foundation of Canada. As mom Gillian says, "It's been good to know we're not alone."

You support specialized programs to help families cope with a brain tumour. braintumour foundation

Dear Friends,

Last year was a very special year for Brain Tumour Foundation of Canada. In 2012, because of you, the organization celebrated its 30th year – three decades of progress as together we work towards finding a cure for brain tumours while improving the quality of life for those affected.

As the only organization in Canada that provides dedicated services to the brain tumour community, we take our responsibility to meet this need seriously. By trusting in us and giving of your time and generosity, resources needed for today and tomorrow are coming into place.

In addition, it's vital that the reach of Brain Tumour Foundation of Canada is continuously extended. This ensures everyone has access to important support and information, helping people to find hope in the face of this terrifying disease.

As always, the words of those we serve best illustrate the impact of your support:

We have found it challenging to access brain tumour information and support as we live in a remote area and don't have access to the support that one can find in bigger cities. We have been using technology and resources via BrainTumour.ca and the Information Day webinars have been very helpful. It helps to talk and hear about other people going through the same things as us and realizing that we are not alone.

It is with the deepest gratitude that we reflect on 2012 and its successes. Thank you for everything you do to lift the burden of a brain tumour.



R

Joseph Megyesi Chair, Board of Directors

Susan Marshall Executive Director

Natasha Foy



Carl Cadogan CEO

As the new CEO of Brain Tumour Foundation of Canada, it is with great enthusiasm that I look toward the future and working with everyone who contributes to making the journey with a brain tumour one of hope. I want to give thanks to outgoing Executive Director Susan Marshall for her tireless dedication to the community and cause. Under her leadership, the national network of programs and services has grown exponentially and the increased capacity for brain tumour research has accelerated the work into the causes of and cure for the disease.

Thank you as well to the incredible donors, volunteers and supporters whose efforts make all of this work possible.

Together, we will overcome this disease.

How Your Donations Help the Brain Tumour Community

During the past year, donors continued to be generous and support the brain tumour community through all areas of Brain Tumour Foundation of Canada's fundraising endeavours. Our gross revenue in 2012 was \$2.83 million.

At Brain Tumour Foundation of Canada, 75 cents of every dollar spent goes toward the brain tumour community through research, support, information and education. Fundraising (21%) and Administrative (4%) expenses are well-managed, accounting for 25% of total expenditures. Last year, the organization continued to meet its goal of investing 30% of overall program expenditures in research. A greater investment was also made in 2012 into providing impactful support services, which resulted in 34% of overall program expenditures towards this area of the organization.

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 Carl Cadogan, CEO, at 1.800.265.5106 ext.222 or ccadogan@braintumour.ca.

2012 Financial Highlights



to Research Grants committed and expensed in 2012. The funds for these grants are payable in 2013.

In 2012, a special projects campaign was launched by the board of directors and leadership volunteers.

These projects include:

- A brain tumour registry that by 2017 will be Canada's first and only complete source of brain tumour data.
- **Research Studentships** that accelerate brain tumour research and encourage young scientists to pursue careers in the neuroscience field.
- Education Awards for pediatric brain tumour survivors pursuing post-secondary studies, ensuring a brighter future for young adults who have endured the challenges of a brain tumour.



Gilles Cayouette is a glioblastoma multiforme brain tumour survivor and has chosen to support the Research Studentships.

I discovered Brain Tumour Foundation of Canada in 2006 and have been involved ever since. When I learned that the organization was planning different ways to draw students and researchers to the field of neuroscience, I was happy to fund this promising endeavour directly through a studentship. I mentioned the project to our oldest son who immediately said, "Dad, how about joining forces to fund a studentship?" My face beamed my delight: Imagine a father (and eight-year GBM survivor) and son team. One of these research students could find a cure, and we must do anything we can to make it happen.

Bill and Carol Deys are long-time supporters of the brain tumour community and have chosen to support the Education Awards.



We became involved with Brain Tumour Foundation Canada 16 years ago when a close friend's daughter was diagnosed with a brain tumour. Throughout the years, we've been involved in various fundraising activities and enjoyed each one! Last year, when we were presented with a few different scenarios of ways to help families and brain tumour patients, the Education Awards struck us as a unique opportunity. It really tugged at our heart strings to hear about the incredible challenges pediatric brain tumour survivors can face and how this could impact their futures. Knowing we could help others accomplish goals we feel all young adults should have was important to us. In our eyes, the real heroes are the individuals and families affected by brain tumours and they deserve our support.



Bev and Arbelle are neuroscience nurses at one of the country's leading health care facilities. Their project on speaking to adolescents about their brain tumour diagnosis won a Brain Tumour Foundation of Canada & Canadian Association of Neuroscience Nursing award for excellence in their field.

Now their research findings have influenced how neuroscience nurses at their hospital work with patients on a daily basis. Bev and Arbelle's research increased awareness on the importance of identifying and addressing any potential ethical conflict that may arise at patient admission. This helps patients because the nurses are now more effective advocates, better anticipate needs and access appropriate resources on patients' behalf.

Research

Funding leading Canadian brain tumour research, and working collaboratively across North America and the globe, is a priority for Brain Tumour Foundation of Canada. When you give, you support researchers looking into the causes of and cure for the disease, as well as quality of life challenges for those affected by a brain tumour.

In 2012, over half a million dollars was awarded in research funding. This includes eight grants, funding for the brain tumour registry, a \$100,000 research fellowship, and critical funds for the London, Ontario-based Brain Tumour Tissue Bank that provides tissue samples to researchers all around the world.

" Medulloblastoma brain tumours are the leading cause of pediatric cancer deaths in Canada. Those children who do manage to survive usually have a severely impaired quality of life due to the aggressive treatment for the disease. Strategies are needed to improve the quality of life for families of children with brain tumours, to increase survival rates, and to minimize the impact on health care systems. We try to improve treatment success by performing molecular analysis to define prognostic and biological subgroups. Large sizes of high quality tumour samples are needed to evaluate molecular mechanisms that lead to tumour formation, and this is where the Brain Tumour Tissue Bank fits in. We have obtained 16 tumour samples from the bank, which were an important contribution to our brain tumour research.

Dr. Michael Taylor, Toronto, ON

You give to change brain tumour patient care.

Community Events

Community events play an important role in the support available for the brain tumour community across Canada. Each year, these events are organized by individuals and groups whose efforts pay tribute to those affected by a brain tumour and raise funds for patient programs and services plus brain tumour research.

In 2012, 120 community events raised over

\$368,000. New for the year was the 'Making Cents of Brain Tumours' awareness and fundraising campaign that had 180 displays set up coast-to-coast throughout October, as part of Brain Tumour Awareness Month.

I knew that starting a fundraiser of my own would be a huge challenge, especially after just being diagnosed with a brain tumour. As a person battling the disease, I wanted to raise as much money as possible for research, in hopes that one day a cure will be found. I decided to start the Birdies for Brain Tumours Golf Tournament. Our tournament managed to raise almost \$30,000 in its first year. I was overwhelmed with the success in what not only I had achieved, but what an entire community of family and friends can achieve when people come together for a great cause. We are continuing our efforts in 2013 with the 2nd Annual Birdies for Brain Tumours Golf Tournament.

> My hope is that anyone who has been affected by a brain tumour would consider creating a community event, as I believe that one day a cure will be found if we all continue to strive towards it.

Connor Thomson, Winnipeg, MB



2012 Winnipeg Spring Sprint

Spring Sprint

The Canada-wide Spring Sprint is the country's largest fundraiser dedicated to the brain tumour community. With 20 events taking place annually between April and June, along with the Virtual Run, Spring Sprint supporters fund important brain tumour research and the unique programs that help patients and their loved ones better understand the journey with the disease.

In 2012, Spring Sprint raised \$1.49 million through individual and team donations and corporate partners.



When my husband Charlie passed away because of a brain tumour in 2011, our family was devastated. There were good days and bad days as we learned how to cope with Charlie's death. Planning our own event as part of the 2012 Virtual Run was surprisingly helpful in the healing process, more than I could have ever realized at the time. Charlie wanted to see more done in our community for those with brain tumours, and this way we could do something in his name.

Wendy Dickieson, North Rustico, PEI

For small business owner and pilot Tom, his brain tumour journey began with periodic seizures that caused blackouts, resulting in a frightening car accident. Though the experience was terrifying, the accident led Tom and his loved ones to the answers they were desperately looking for: Tom was diagnosed with a non-malignant meningioma. Surgery removed the kiwi-sized brain tumour and with no lasting effects from the disease, Tom says he is one of the lucky ones.

What helped the Hartais stay positive throughout Tom's diagnosis and surgery were the Brain Tumour Handbooks, there to walk them through, step-by-step, what can happen from diagnosis to treatment and recovery.

Today, Tom and his family make it a priority to give back, supporting the Spring Sprint with their South Huron Heading for Hope team. Friends and family rally to take part, and for Tom it's been surprising to learn just how many people, even those close to him, have been affected by a brain tumour. "To me Spring Sprint is not only about fundraising, which is so important, but it's also about getting together and helping people know they're not alone."

You give to transform the future for brain tumour patients and survivors.

Public Awareness

The mission to reach every Canadian affected by a brain tumour drives our work as a community and public awareness plays a significant role in accomplishing this goal.

For the first time ever, in early 2012, three professional television commercials were produced for Brain Tumour Foundation of

Canada. These public service announcements are helping the organization reach more individuals coastto-coast. This increased public awareness was the wish of 46-year-old brain tumour activist Rob Blair who lost his 13-year battle with a brain tumour in August 2011. Near the end of his life, he expressed to his brother, filmmaker David Ray, a desire that he carry on his awareness-raising efforts. Rob's request was that David uses his talent and expertise to create commercials for the organization that supported Rob while he braved this devastating disease.

Brain Tumour Foundation of Canada is extremely grateful for the support of Rob, David and the filmmaking community that produced these remarkable pieces.

Advocacy

In 2012, the organization's advocacy efforts focused on two key issues: Data Collection and Equal Access to

Treatments. Volunteer advocates took part in discussions with government officials and partners in the cancer community around data collection and the importance of The Ontario Cancer Registry (OCR) counting every brain tumour, regardless of stage or grade.

In addition, Brain Tumour Foundation of Canada is now registered with the pan-Canadian Oncology Drug Review (pCODR) committee. By registering with pCODR, the organization can act as a patient voice to the review group when new drugs are put forward for approval.





The production crew on set for the PSA filming

Education

Information Day Conferences and Webinars offer the opportunity to learn from leading health care professionals in neuroscience and related fields. At the conferences, attendees are also encouraged to connect with one another, empower themselves with knowledge and, ultimately, find hope.

In 2012, 1650 individuals took part in

Education events. More than 590 people attended Information Day Conferences in seven locations across Canada: Moncton, Ottawa, Hamilton, London, Calgary, Edmonton and Vancouver. In addition, the web-based component to Information Days grew as a new webinar series launched. More than 1050 online users took part in two online sessions and viewed Information Day event and webinar videos.

My challenge is to learn what new treatments and technologies are available for brain tumours in Canada. Attending Information Days also gives me the opportunity to meet and talk with brain tumour patients, survivors and their families, and to know that we are not alone in this battle. The London event is one of the best sources for information on research and it's delivered in an understandable language. I don't think there is any other way for me to find such detailed information, directly from the medical professionals who are on the leading edge.

Coming away from these events, I find hope by learning about subjects such as DNA sequencing and brain tumour surgery simulators. It also gives me hope to see so many dedicated health care professionals working to help cure and treat brain tumour patients.

Rosemary Hayes, London, ON





2012 London Information Day



2012 Calgary Information Day

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Riley was six years old when he was diagnosed with a fast-growing medulloblastoma – the leading cause of pediatric cancer deaths in Canada. It was a shocking diagnosis for his entire family. Several surgeries, chemotherapy and radiation treated the brain tumour but left Riley unable to feed himself, or walk or talk.

Riley was fed for two years through a tube and relearned how to walk and talk. Despite all the challenges that came with Riley's diagnosis and recovery, his family never lost hope. It's through the Pediatric Brain Tumour Handbook and by meeting other families at BrainWAVE events and Brain Tumour Information Days that they are able to understand the impact of the disease on Riley and his future.

Today Riley is 18 years old and recently celebrated a milestone for any teenager – graduating from high school.

You give to help lift the emotional burden of a brain tumour.

Support

Managing the journey with a brain tumour can be emotionally challenging.

Whether through the cross-Canada adult support groups; BrainWAVE, the pediatric support program; or by phoning the toll-free information and support line, connecting with others who have similar experiences or with a professional who can provide one-on-one support helps thousands of Canadians affected by a brain tumour find comfort each year.

Having been recently diagnosed with a brain tumour I was feeling unsure of what to do next and how to advocate for myself. I called Brain Tumour Foundation of Canada and the support I received was really useful and reassuring. I was also told about the Ottawa support group and have now become a regular member and the group's convenor! It's been extremely helpful to connect with other patients and families. Learning about how they navigated the health care system prepared me for my own journey and has helped me understand how to better communicate with my medical team about my needs.

Lianne Brodeur (nee O'Kane), Gatineau, QC



BrainWAVE, summer 2012

In 2012, hundreds of individuals found comfort through Support Services. One-hundred and three families connected through BrainWAVE – a 72% increase in participation from 2011.



Jacqueline Huff and her twins Quinlan and Conner, Chilliwack, BC

Five years ago, Quinlan was still recovering from his initial brain tumour procedures when we got involved with Brain Tumour Foundation of Canada to launch the Lower Mainland BC BrainWAVE group. Our family was looking for a way to meet and connect with others facing the journey with a brain tumour.

Jacqueline

I really wanted the chance to talk to other siblings of brain tumour patients and survivors, and share our experiences. We could be with people we'd met during hospital visits but in a happier environment. We could have quality time with our friends in places focused on having fun rather than being sick.

Conner, 16

BrainWAVE has given me the chance to feel like a regular kid, to have fun and build friendships that have lasted for years.

Quinlan, 16

Information

Information through the Brain Tumour Handbooks, children's storybook and information kits empower patients and their loved ones to learn more about the brain tumour journey and to be the strongest advocates for their best care.

Programming dedicated to health care professionals provides learning opportunities and workshops across the country. As a result, relationships are built with the health care community and specialized information increasingly reaches those affected. And, health care teams are better prepared to care for and support those diagnosed with a brain tumour.

In 2012, over 500 participants from the medical community joined workshops and in-service presentations – a 47% increase compared to 2011.



As an oncology nurse and patient navigator, I have ordered the Adult and Pediatric Brain Tumour Handbooks and other resources for my patients. The materials have provided me with an easy and concise resource of information to help support patients and their families through the brain tumour journey. I was very pleased to hear about the medical team and the research that guides Brain Tumour Foundation of Canada's materials. I can feel confident that the information included is current and best practice.

As a health care professional I now feel more confident in providing guidance and brain tumour information to patients and their families. I can also direct the health care professionals at our busy cancer centre to appropriate information about brain tumours.

Debbie McNairnay, Brandon, MB

Volunteers

More than 700 volunteers helped run programs and services for the brain tumour community across Canada in 2012. Volunteers give of their time and expertise through Spring Sprint, as convenors or facilitators for support groups, as BrainWAVE event organizers and more. For many, it's a personal connection to the cause that drives their commitment. Without this support, dedicated brain tumour services and programs would not be available.

As a recent brain tumour survivor, volunteering with Spring Sprint and Brain Tumour Foundation of Canada has given me a sense of place and community, and allowed me the chance to give back to individuals and families who are facing tough challenges in their lives. I cannot imagine not being involved in this organization.

Christina Hagberg, Vancouver, BC

Two years ago my daughter Vicki lost her battle with a brainstem glioma. As a family, we treasured the times that we escaped her reality and did something fun together. BrainWAVE is devoted to providing just such times for children and their families whose "normal" is facing difficult challenges every day due to a brain tumour. Volunteering with BrainWAVE has given me the opportunity to help organize and participate in these special events. The best part is we get to watch these kids just be kids, which is the way life should be.

Elizabeth Ozard, London, ON



Volunteers at the 2012 Montreal Spring Sprint

Thank You

Brain Tumour Foundation of Canada extends its deepest gratitude to every donor who makes programs and services for the brain tumour community possible. Each donation, no matter the size, helps change the future of brain tumour research and patient care, and brings hope to anyone affected by this disease. Thank you to the following individuals, families and businesses for making a special gift in 2012.

Special and Major Gifts

We gratefully acknowledge those donors who made gifts of \$5,000 or more in 2012.

AD Ventures Alberta Charitable Foundation Canadian Society for Life Science Research Mr. and Mrs. O. Iacobelli Dr. Joseph Megyesi Jack Nichol Family Fund, a fund within London Community Foundation Mr. and Mrs. D. Scragg Ultragiving Foundation

Our sincere thanks to the generous donors who made a gift through their wills to support brain tumour patients and research across Canada.

Estate of Andrea Dalton Baker Estate of Mary Katherine Bruce Estate of Leslie Carter Estate of John George Coppard Estate of Donald J.T.A. de Jong Estate of Lillian Janet Hodgert Estate of Ilonka Seder Szabolcsi



Ted and Irene Megyesi (middle and right), friends of the late Leslie Carter, accepting a recognition plaque for Leslie's generous legacy gift to brain tumour patients

Ryan Fraser and Bridget Plumb, Heritage Club members

Legacy Funds

These special Legacy Funds continue to provide endowed funding to chosen services thanks to the ongoing support of our legacy donors.

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

Heritage Club

Heritage Club members ensure support, education and research funding for the future by including Brain Tumour Foundation of Canada in their estate planning.

Jane Arnott Ken Arnott Joseph Barnes Sue Barnes Peter Chislett Farida Chislett Leendert De Goffau Marion De Goffau Shelley Fitak Douglas Flood Ryan Fraser Carina Jacobsen Peter Jacobsen Barbara Kennedy Susan Marshall Donna McKee Bridget Plumb Grace Schenk Michelle Thibodeau Lois Toll Valerie Wicks





It is empowering to give back and help others who have been diagnosed with a brain tumour. Our family has been a part of the Brain Tumour Foundation of Canada family for the past 17 years. Our oldest daughter was 11 when she was diagnosed with a non-malignant brain tumour requiring two surgeries. In spite of having permanent endocrine deficiencies because of the tumour, she thrives in all aspects of her life. At the time, though, there were months of uncertainty and a gap in available information that was easily understood. The Brain Tumour Handbook became a well-thumbed resource in our household. With three young children we also found support through BrainWAVE activities. The diagnosis of a brain tumour impacts the entire family in so many different ways and I have watched the variety of ways the organization works to respond to these needs.

Over the years we have continued to support the organization in different ways. I was part of the Board of Directors for several years and we've given financially as a family through personal contributions, golf tournaments, dinners and the Spring Sprint. When I heard last year that Brain Tumour Foundation of Canada was embarking on three new projects, I wanted to help by getting information out to others. By offering different types of opportunities to support families affected by the disease, donors are enabled to choose the one that best suits them. Our family hosted a dinner bringing together friends that have supported us and the organization over the years. It was at the dinner that we learned about the special projects campaign and had the opportunity to ask questions. In a small way I hope that by spreading information about the unique ways people can personally and financially support the organization, we will help others who have had their life impacted by a brain tumour.

Heather Mastromattei, Ilderton, ON

Kelly Society

Named for Kelly Northey, who inspired the founding of Brain Tumour Foundation of Canada, these leadership donors generously made a multi-year commitment to support brain tumour patients.

Jane Arnott Chantalle Butler **Marjory Buttrum** Scott Courtice & Megan Winkler Rolando & Pam Del Maestro Ron & Dawn Fulmer Terry Kincaid Jeane King Patricia Klein Marianne Lee Maryanne MacDonald William & Margaret MacDougall Alvkhan Mamdani Susan Marshall Heather Mastromattei Joseph Megyesi **Dwight Moulin**

Kelly Society continued

Vincent & Moira Nash Steve & Melodie Northey Jeff Patt Susan Relecom Phyllis Retty Ben Seewald Richard Seewald & Carol Van Evera Norman Sonnenberg Sean & Michelle Taggart Beth Tyndall Fred Wilder Peter & Susan Yates

Monthly Giving Club

Monthly donors make gifts that provide a stable groundwork for programs and services for brain tumour patients as well as crucial funding for research.

Maryann Abele Dave Allen James Anderson Madeh Badaoui Lewis Balsdon Tony & Joan Barton Glenn Bauman Wendy Bethune Lori Betik Nick Betik Iona Bolger **Denis Bouchard** Jennifer Bulatao Keith Burling Trice Cameron Michael Cattani Judy Chisholm Ann Clark **Debbie Collins** Irene Cranstone Marie Duff-Whichelo **Diane Duplessis** Marie Claire Duthie

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Corporate Sponsors

Special thanks to the corporations that help significantly through sponsorships and special program funding.

Deloitte, Platinum Sponsor Roche, Platinum Sponsor Merck Canada Inc., Silver Sponsor CriticalControl Solutions Corp., Silver Sponsor Eisai Limited, Bronze Sponsor



Deloitte team members at the 2012 Windsor Spring Sprint

Corporate Donors

In addition to corporate sponsorships, special gifts of \$1,000 or more were received from the following corporations and foundations:

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Community Events

Thank you to everyone who planned and hosted a Community Event in 2012. Your unwavering support means patients and survivors across the country can find hope through important research and by connecting with others on the journey with a brain tumour. A special thank you is extended to the organizers and planning committees of the following events that each raised \$5,000 or more.

27th Sultan Marathon Des Sables A Night to Remember in memory of André Medeiros Banff Jasper Relay **Bill Manners Memorial Golf Tournament** Birdies for Brains Golf Tournament Concert for a Cure Dan Cote Memorial Golf Tournament **Direct Line Golf Tournament** Jeff Graham Memorial Golf Tournament Journey of Hope Through Music Kathy Turek Memorial Golf Tournament Pasta Night, Hamilton Spring Sprint Precision Hair Gallery Cut-A-Thon Racing for Dad (Ironman Triathlon) **Ride Strong Poker Rally** SNC Law Golf Tournament Team Strong - Bottle Drive



Ehlana James presents her Team Strong - Bottle Drive proceeds at the 2012 BrainWAVE holiday party

Brain Tumour Foundation of Canada Board and Staff

(as at December 31, 2012)

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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 Vision

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

Our Values

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 rigor 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.

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