2010 REPORT
TO THE BRAIN TUMOUR COMMUNITY

Ryan N., survivor, and his parents Yvonne and Rick
REACHING CANADIANS AFFECTED BY BRAIN TUMOURS IN 2010

7  Brain Tumour Research Grants awarded by Brain Tumour Foundation of Canada

11 Brain Tumour Research Grants awarded through the Brain Tumor Funders’ Collaborative

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

152 Hats telling the stories of courage and hope in the travelling Hats Tribute

812 People participated in monthly Adult Brain Tumour Support Groups across Canada

1,236 Requests for information and one-on-one emotional support

525 Health care professionals attended 22 in-service educational presentations

90 Health care professionals attended three Health Care Professionals’ workshops

574 People participated in Brain Tumour Information Day Conferences and Education Seminars

4,500+ Participants in the Spring Sprint program in 22 cities across eight provinces

24,000 BrainStorm newsletters (print only) distributed across Canada

97,004 Unique visitors to Brain Tumour Foundation of Canada’s website
Two thousand and ten was a year of growth for Brain Tumour Foundation of Canada. Our impact in the brain tumour community continued to evolve and extend to new research initiatives, increased program and service opportunities, and additional educational events. This was achieved through the generous contributions and gifts from our committed donors, partners and volunteers.

During the past year our donors continued to support our efforts through all areas of our fundraising endeavours. This dedication, and with a favourable outcome of revenues over expenditures, allowed us to allocate additional funds to further build our research program and the organization’s sustainability fund.

In this report to you, our community, we extend our heartfelt appreciation for the positive impact of your support. Together we will find the cause of and cure for brain tumours, while improving the quality of life for those affected.

In 2010, Brain Tumour Foundation of Canada took on a variety of new projects in an effort to continue to reach the over 55,000 people across Canada affected by brain tumours.

We introduced our Facebook and Twitter profiles and focused on the re-launch of www.braintumour.ca. These three initiatives bring you different ways to connect with others in the community, and seek out information and support essential to those facing the journey with a brain tumour.

Search for Brain Tumour Foundation of Canada on Facebook or Twitter.

Joseph Megyesi
Chair, Board of Directors

Susan Marshall
Executive Director
A LOOK BACK:
DR. TOMMY ALAIN

In spring 2010, Dr. Tommy Alain was awarded the inaugural William Donald Nash Memorial Brain Tumour Research Fellowship. Created in 2009, the Fellowship recognizes the critical need for increased focus on brain tumour research by encouraging and enabling young clinicians and scientists to enter the field of brain tumour research and accelerate studies leading to a cure for brain tumours.

Dr. Alain’s study titled, “Active-site mTOR Inhibitors and Oncolytic Viruses Against Malignant Gliomas,” aims to establish and characterize the potential of using certain drugs in combination with viruses, to eliminate brain cancer.

“During my studies, my aunt died of a glioblastoma which put my research even more so into perspective,” Dr. Alain explains. “I hope my research will provide a better understanding of brain cancers and lead to more effective treatments of this disease.”

Through the generosity of William Donald Nash, this first Brain Tumour Foundation of Canada fellowship was created.

RESEARCH

Funding and supporting research into the cause of and cure for brain tumours is a priority for Brain Tumour Foundation of Canada.

• Between January and December 2010, the Brain Tumour Tissue Bank, an initiative funded entirely by Brain Tumour Foundation of Canada, collected samples from 80 patients, yielding 440 specimen vials for study. These samples were provided to 16 different research investigators across Canada, the United States and internationally.

• The organization awarded seven brain tumour research grants totalling $156,000 in 2010. In addition, the Brain Tumor Funders’ Collaborative, a North American partnership in which Brain Tumour Foundation of Canada is a founding member, launched its second joint initiative for brain tumour research. Eleven projects were each awarded $100,000 with results to be released in 2011.

BRAIN TUMOUR FOUNDATION OF CANADA RESEARCH GRANTS

Dr. Caroline Chung
Princess Margaret Hospital, Toronto, ON
Project: Evaluating biomarkers to guide individualized therapy for patients with brain metastasis

Dr. Kim Edelstein
Princess Margaret Hospital, Toronto, ON
Project: The developmental impact of both brain tumours and radiation therapy on adolescent and young adult brain tumour survivors

Dr. Barbara Fisher
The University of Western Ontario, London, ON
Project: How to precisely identify the point in time when brain tumours start to recur in order to offer additional treatment at the optimal time
Dr. Marshall W. Pitz
Cancer Care Manitoba, Winnipeg, MB
Project: Molecular markers of Glioblastoma Multiforme (GBM) brain tumours which will enable the identification of key therapeutic targets and assist in personalized care for those diagnosed with GBMs

Dr. Arjun Sahgal
Sunnybrook Health Sciences Centre, Toronto, ON
Project: Optimal timing and type of treatment for low grade Astrocytoma brain tumours and the impact of treatment on health care resources and quality of life

Dr. Nahum Sonenberg
McGill University, Montreal, ON
Project: The role of proteins in both the development of brain tumours and possible treatments

Dr. Slav Yartsev
London Health Sciences Centre, London, ON
Project: Monitoring brain tumours’ response to radiation treatment through a new type of CT test

BRAIN TUMOR FUNDERS’ COLLABORATIVE GRANTS

Kenneth D. Aldape
University of Texas MD Anderson Cancer Center, Houston, TX
Project: A combined molecular and clinical predictor of progression vs. pseudoprogression in newly diagnosed GBM

Jaishri O. Blakeley
Johns Hopkins University, Baltimore, MD
Project: Amide Proton Transfer MR Imaging to Assess Tumour Response in Patients with Gliomas

Bob S. Carter
Massachusetts General Hospital, Boston, MA
Project: Exosome Analysis: A Non-Invasive Approach to Monitor Treatment Responses in Glioma Patients

Luis A. Diaz
Johns Hopkins University, Baltimore, MD
Project: Circulating Tumour DNA as a Dynamic Biomarker in Malignant Gliomas

Alena Hoska
Johns Hopkins University, Baltimore, MD
Project: Non-invasive Assessment of Glutamate in Glioblastoma Multiforme: Effect of Treatment

Andrew B. Lassman
Memorial Sloan-Kettering Cancer Center, New York, NY
Project: Molecular Determinants of [18F] FACBC-PET Imaging in Brain Tumours

Whitney B. Pope
University of California (David Geffen School of Medicine at UCLA), Los Angeles, CA
Project: Combining Genomics with Physiologic Imaging Biomarkers to Predict and Follow Treatment Response in Glioma

Edward R. Smith
Children’s Hospital Boston, Boston, MA
Project: Urinary Biomarkers for Non-invasive Assessment of Therapeutic Efficacy in Glioma

Kristin R. Swanson
University of Washington, Seattle, WA
Project: Patient-specific Metrics of Treatment Response

Erwin G. Van Meir
Emory University School of Medicine, Atlanta, GA
Project: Development of Protein Arrays for the Detection of Biomarkers in the CSF of Brain Tumour Patients

Kyle D. Weaver
Vanderbilt University Medical Center, Nashville, TN
Project: Monitoring Response to Therapy in Malignant Glioma Patients Using Blood-Based Epigenomic and Proteomic Biomarkers
ADVOCACY

The brain tumour community is a vast connection of organizations, health care institutions, patients, families and initiatives. Through the Canadian Alliance of Brain Tumour Organizations (CABTO), of which Brain Tumour Foundation of Canada is a founding member, leaders advocate for improved patient care and increased government funding for brain tumour research in Canada.

Two key items were identified as priorities for CABTO in 2010:

- Better data collection about the incidence of brain tumours in Canada.
  
  CABTO continued to monitor the implementation of Bill M235 which was passed in February 2007. There was no reportable advancement in the implementation of this bill, which mandates better reporting guidelines for brain tumours, both malignant and non-malignant. In 2011, CABTO will contact the Public Health Agency of Canada and Provincial Cancer Registries to further advocate for the bill.

- Equitable access to and funding for approved drug therapies.
  
  During 2010, CABTO members continued to learn about provincial access to and funding for approved drugs for brain tumour patients. The group will continue to monitor this issue with the goal of creating positive impact where possible.

NATIONAL AWARENESS

In 2010, CABTO members continued to raise awareness about brain tumour issues during the month of October, which serves as the official Brain Tumour Awareness Month. These efforts included the public display of the Hats Tribute which shares the stories of hope and courage from brain tumour survivors and families who have lost a loved one to the disease.

A LOOK BACK:
THE NOBBS FAMILY

Ryan Nobbs was just three-and-a-half when his parents were shocked to learn he had a brain tumour. Following his diagnosis, Ryan underwent emergency surgery to remove the golf ball-sized pilocytic astrocytoma. During this time, a hospital social worker shared information about Brain Tumour Foundation of Canada with Ryan’s parents Rick and Yvonne. “We felt like we had no idea what was happening,” Rick adds.

The family signed up for the BrainWAVE pediatric support program. “We really enjoy attending BrainWAVE events,” Yvonne explains. “They’re a wonderful opportunity to reconnect with families we met while in hospital and to create new relationships with families similar to ours. The program means a lot to us because it’s helped Ryan realize he is not alone and there are many other kids going through the same things he has or may still have to go through.”

After two surgeries and Ryan’s recovery, the Nobbs now look optimistically to the future. “We are really blessed,” says Yvonne. “Ryan continues to be monitored with regular MRIs and hasn’t needed radiation or chemotherapy. He’s doing really well. We look forward to being a part of the BrainWAVE family for years to come.”

In November, a private members motion was tabled, calling on the government to designate March of every year as “National Brain Health, Education and Awareness Month.” This would encourage Canadians to learn how to nurture a healthy brain and help recognize individuals and families that have been adversely affected by brain disorders, including brain tumours. CABTO is monitoring the motion and will leverage this national opportunity to focus on raising awareness and educating the public about brain tumours during the month of March.
SUPPORT

In 2010, Brain Tumour Foundation of Canada continued to build on its commitment to provide support for those affected by a brain tumour.

ADULT BRAIN TUMOUR SUPPORT GROUPS

In total, more than 800 people participated in twenty-three Adult Brain Tumour Support Groups across Canada. New for 2010 were the introduction of the Fredericton adult support group, and the initiation of a Barrie group with the goal of a 2011 launch.

BrainWAVE PEDIATRIC SUPPORT GROUP

Last year, 97 families took part in BrainWAVE events in British Columbia and Southern Ontario. Almost 200 people took part in Southern Ontario BrainWAVE’s annual holiday party which marked a milestone in the program’s history as its largest-ever event.

INFORMATION

Brain Tumour Foundation of Canada provides information to patients and survivors, families and caregivers through a variety of initiatives and programs.

In 2010:

- 5,211 Patient Resource Handbooks, a guide to brain tumours, current treatments, medications, imaging, clinical trials and community resources, were distributed free-of-charge.

- 1,306 storybooks, about a child with a brain tumour and her journey through treatment, were delivered to families, children and schools across Canada and internationally.

- 1,236 requests for support and information were received.

Another role of the organization’s Information Services is to provide learning opportunities for health care professionals across Canada. This includes in-service presentations that bring a facilitator into a health care setting to outline Brain Tumour Foundation of Canada programs and resources available to patients. In 2010, more than 500 health care professionals attended in-service presentations.

A LOOK BACK: CATRIONA LECKIE

The first Calgary Health Care Professionals’ Workshop was held in October 2010, designed to connect health care providers and provide a learning opportunity about the latest complementary and alternative medicine options for brain tumour patients.

Catriona, a nurse practitioner in neuro-oncology, says it was the chance to hear speaker Dr. Lynda Balneaves that brought her to the event. “It was fantastic to learn about the Complementary Medicine Education and Outcomes Program (CAMEO) program in BC and the resources available to health care providers and patients. The presentation has allowed me to approach this subject with my patients confidently.”

Catriona Leckie

Additionally, three Health Care Professionals’ workshops were held in Edmonton, Calgary and Halifax, to provide opportunities to share knowledge and expertise in the field of brain tumours (neuroscience and neuro-oncology) with a focus on cross-disciplinary learning and networking. Brain tumour survivors also took part in the workshops offering an important patient perspective.
A LOOK BACK: PAM AND ROLANDO DEL MAESTRO

Pam and Rolando Del Maestro, co-founders of Brain Tumour Foundation of Canada, alongside Steve Northey, have spent over 30 years working to provide critical information and support to patients.

“I remember planning the first Info Day all those years ago. We worried that no one would come and that it would be difficult to get professionals to come and speak. How wrong we were,” remembers Pam. “The conferences offer support to so many now. Watching Info Days grow and start to move across the country makes me proud of how far we have come from the days when a few of us met in our living room with some ideas and lots of energy to plan our first event.”

In 2010, the London Brain Tumour Information Day Conference celebrated its 25th anniversary. “We are both so proud to see how far the organization has come. Our dream so many years ago to reach out and support Canadians who have a brain tumour has become a reality. But, there is still much to be done.”

EDUCATION

New to education programming was the addition of Education Seminars, half-day events designed to provide attendees with a smaller-scale learning environment to address topics such as quality of life and treatment. Five seminars were held across Canada and featured presentations from patients and local speakers. Locations included Barrie, Edmonton, Vancouver, Fredericton and Ottawa. In total, 171 people took part in the inaugural Education Seminars including survivors, caregivers and health care professionals.
SPRING SPRINT AND
COMMUNITY EVENTS

Brain Tumour Foundation of Canada’s Spring Sprint walk-a-thon program generated over $1.5 million in 2010. With more than 4,500 participants, the Spring Sprint is the organization’s largest fundraiser. Events took place in:

- Belleville, ON
- Brampton, ON
- Calgary, AB
- Chatham, ON
- Edmonton, AB
- Fredericton, NB
- Guelph, ON
- Halifax, NS
- Hamilton, ON
- Kitchener-Waterloo, ON
- Lloydminster, AB
- London, ON
- Montreal, QC
- Ottawa, ON
- Saskatoon, SK
- Sudbury, ON
- Toronto, ON
- Vancouver, BC
- Victoria, BC
- Windsor, ON
- Winnipeg, MB
- Virtual Run -- Online

A total of $1,513,815 was raised in 2010, exceeding the original goal of $1.35 million. This includes donations from those who pledged participants, contributions from local and national sponsors, and funds raised by supporting Community Events, silent auctions and other event fundraising activities. Pledges alone accounted for $1,376,588 of the total raised.

Additionally, 111 Community Events were held across Canada -- an increase from the 97 events held in 2009. More than $160,000 was raised through these events, organized in honour of or to support those affected by a brain tumour.

A LOOK BACK:
THE BLOOM FAMILY

David Bloom was 17 and undergoing treatment for an inoperable brain tumour when he came across a flyer for the annual Toronto Spring Sprint to raise money for Brain Tumour Foundation of Canada. Despite the health challenges he was enduring, he decided to participate.

On the day of the event, David asked organizers why there was not a Sprint in his hometown of Brampton. He was told there was no one local to coordinate it. “He turned to me and said, ‘what do you think, Dad?’” recalls Lawrie Bloom.

David was 19 when he passed away on April 24, 2001, just ten days before the inaugural Brampton run. The Sprint is a labour of love for the Bloom family, who still coordinate the annual event, driven by their hope to help others affected by a brain tumour and to find a cure.

“It’s a little bit of good that has come from something so devastating,” says Charron, David’s mother, of the Sprint, the money it raises, and the awareness it creates. “It doesn’t make it easier; it’s just a little bit of good.”

Now surpassed its $1.2 million mark, the Brampton Spring Sprint held in honour of David Bloom celebrated its 10th anniversary in 2010 and continues to grow.
VOLUNTEERS

Each year, Brain Tumour Foundation of Canada is privileged to have the support and dedication of tireless volunteers. In 2010, more than 700 people gave of their time to help organize and run special events, host support groups, assist with fundraising and more.

VOLUNTEER OF DISTINCTION AWARDS

The Volunteer of Distinction Award is given to individuals who embody the spirit of volunteerism, acting as leaders and ambassadors of Brain Tumour Foundation of Canada. In 2010, five volunteers were honoured with this award of distinction.

- Lori and Stephen Wilson of Calgary, Alberta, were recognized on October 1st at the Calgary Information Day reception.
- Michael Kennedy of Halifax, Nova Scotia, was recognized on October 29th at the Halifax Information Day reception.
- Danielle Griffiths of London, Ontario and Ingrid Exner of Burlington, Ontario, along with Lori, Stephen and Michael, were honoured at a national recognition ceremony at the London Brain Tumour Information Day conference reception on October 15th.

A LOOK BACK: LORI AND STEPHEN WILSON

Some experiences steer people’s lives into unexpected directions. For Lori Wilson and her husband, Stephen, their life-altering moment came when Lori was diagnosed with two brain tumours in June 2001. Since that time, they have learned more about the disease and have become determined advocates, volunteering their time to support other patients and help raise brain tumour awareness in their community and across Canada.

Lori’s brain tumour journey began early in life when her father became ill from a brain tumour and passed away when she was 10 years old. Later, Lori’s step-father would also be diagnosed six months after her own diagnosis; he told her she inspired him to fight his own battle with the disease.

The Wilsons have been involved with Brain Tumour Foundation of Canada for many years. They regularly attend support groups and take part in educational events—Lori was a guest speaker for a past Information Day Conference and spoke at health care professionals’ in-service presentations. The couple has also been involved with the Spring Sprint program; Lori helps manage merchandise at Calgary events and has even designed a vanity license plate as a fundraiser for the organization.

In 2010, Lori and Stephen were recognized as Volunteers of Distinction at the Calgary Brain Tumour Information Day Conference.
A LOOK BACK: CARINA AND PETER JACOBSEN

When Peter and Carina Jacobsen’s daughter was diagnosed with an Oligodendroglioma brain tumour in 2001, their lives were changed forever. Sadly, a year and a half after her diagnosis and at only 38 years of age, Christina passed away. “It was such a difficult time for us all,” recalls Carina.

When Christina was first diagnosed, the Jacobsen family began a tradition of giving support to brain tumour research as well as programs and services for patients and families. Now, the Jacobsens are updating their wills to include a legacy gift to Brain Tumour Foundation of Canada. “A brain tumour diagnosis is very tough on the patient and their family; we want to support that now and in the future,” explains Carina. “We want to know that the work will continue long after we are gone.”

FUND DEVELOPMENT

Brain Tumour Foundation of Canada salutes you, our donors, for all of your generosity and your commitment to helping those making a journey with a brain tumour.

SPECIAL AND MAJOR GIFTS

In 2010, philanthropic donors made Special and Major Gifts to support programs, research and services for brain tumour patients.

- The Crone Family
- Alison Jones
- Joseph Megyesi
- Judith Meloche-Burwash

LEGACY FUNDS

These special Legacy Funds continue to provide funding to selected services thanks to the ongoing support of our legacy families.

- The David Bloom Legacy Fund
- The Kelly Northey Legacy Fund
- The Hannah Patterson Legacy Fund

LEGACY GIVING

Heritage Society members include bequests in their wills or have made gifts of life insurance.

- Joseph Barnes
- Sue Barnes
- Leslie Carter
- Peter Chislett
- Farida Chislett
- Shelley Fitak
- Douglas Flood
- Ryan Fraser
- Bridget Plumb

- Carina Jacobsen
- Peter Jacobsen
- Barbara Kennedy
- Susan Marshall
- Donna McKee
- Grace Schenk
- Michelle Thibodeau
- Lois Toll
- Valerie Wicks

Carina and Peter Jacobsen
**KELLY SOCIETY**

Named for Kelly Northey, who inspired the founding of Brain Tumour Foundation of Canada, these leadership donors have made a multi-year commitment in 2010 to support brain tumour patients.

- Chantalle Butler
- Pam & Rolando Del Maestro
- Chauna Horner
- Terry Kincaid
- Jeane King
- Patricia Klein
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- Margaret & William MacDougall
- Susan Marshall
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- Joseph Megyesi
- Vincent & Moira Nash
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- 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 Giving Club donors provide sustainable support for programs and services, as well as critical research funds to find the cause of and cure for brain tumours.

- Anonymous
- Lewis Balsdon
- Ioan & Tony Barton
- Glenn Bauman
- Wendy Bethune
- Faheem Bokhari
- Iona Bolger
- Diane Bradshaw
- Keith Burling
- Judy Chisholm
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- Graham Thompson
- Albert Toews
- Raymond Turmaine
- James Vreugdenhil
- Belinda Wagg
- Kara Wilson

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Corporate giving provides essential support to Brain Tumour Foundation of Canada programs and services.

**2010 National Sponsors**

- Deloitte & Touche Foundation Canada, Platinum Sponsor
- Hoffmann-Laroche Ltd., Gold Sponsor
- Merck Canada Inc., Gold Sponsor
Corporate Partners and Foundations contribute in various ways: through gifts to specific programs and services, cause-related marketing programs or matching gifts in support of their employees’ volunteer or financial contributions. Organizations that participate in these partnerships include:

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(as at December 31, 2010)

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HOW YOUR DONATIONS HELP THE BRAIN TUMOUR COMMUNITY

In 2010, Brain Tumour Foundation of Canada’s gross revenue totalled $2.5 million and expenses totalled $2.18 million. As a result of this positive financial position, we directed more dollars towards the organization’s research program and its sustainability fund, which helps ensure support and information is available to the brain tumour community for years to come.

If you are interested in receiving a detailed financial report, please contact Susan Marshall at 519.642.7755 / 1.800.265.5106 ext. 222 or smarshall@braintumour.ca.

REACHING CANADIANS

Overall Organizational Expenditures

Allocation of Program Expenditures

Administration

3.5%

Fundraising

24.5%

Programs

72%

Support Services

21%

Research Program

30%

Information Services

23%

Education Services

26%
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 MISSION

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

OUR VALUES

These values serve as guidelines for our conduct and behavior as we work toward achieving our vision.

Hope
Caring
Integrity
Accountability
Collaboration
Connecting the Brain Tumour Community