# 2009 REPORT

TO THE BRAIN TUMOUR COMMUNITY









# REACHING YOU ARE HOPE

# BRAIN TUMOUR PATIENTS IN 2009

- 847 people participated in monthly adult support groups in 22 Canadian cities
- 123 families participated in BrainWAVE support programs in Ontario and British Columbia
- 6,915 patient resource handbooks in both English and French were delivered to people affected by a brain tumour across Canada and internationally
- 2,059 children's storybooks in English, French and Italian were delivered to young people affected by a brain tumour
- 1,465 people were helped through the toll-free information and support line
- 6 new brain tumour research projects were awarded funding
- 67 patients donated brain tumour tissues to the Brain Tumour Tissue Bank at London Health Sciences Center in London, Ontario

# FOR THE FUTURE

During 2009 generous donations of money, time and talent brought hope to even more people affected by brain tumours across Canada.

Our donors continued to be generous and dedicated to supporting the efforts of Brain Tumour Foundation of Canada. As a result of a favourable outcome of revenues over expenditures, we were able to allocate a substantial portion of this excess to our growing focus on funding research grants, as well as to the development of an updated and more user-friendly website in 2010.

In this report back to you, our community, we extend our sincerest 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.

Thank you everyone,



Joe Megyesi Chair of the Board



Susan Marshall
Executive Direct

### 2009-2010 BOARD OF DIRECTORS

Chair Joseph Megyesi, MD, FRCSC

Vice Chair Beth Tyndall

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### **SUPPORT**

**People Helping People** 

In 2009 Brain Tumour Support Groups were implemented in Burlington, ON and initiated in Fredericton, NB. Due to the expansion of the program and increased awareness efforts, the total number of support group members in 2009 increased to 847, a 30 per cent increase from the 650 members in 2008.

"It is vital to keep on growing. The Foundation is an amazing group that does incredible things on a shoestring budget. The kind of support they offer is just remarkable, and it's in the process of getting better."

Jane Arnott, mother of 22-year-old son Ben, a brain tumour survivor



Jane Arnott

# **FAMILY SUPPORT**

**Respite, Education & Sharing** 

Throughout 2009 the BrainWAVE Program – led by dedicated volunteers and parents – continued to grow with ongoing expansion in Lower Mainland British Columbia and increased enrollment in Southwestern Ontario.



Sarah Smith and Sarah Laberge

The program provides fun opportunities for children and teens to connect with others with similar experiences while giving parents the chance to learn, share information and network with other parents. Through the BrainWAVE Program, families are able to inspire each other with hope and support.

"As parents, BrainWAVE provides a great opportunity for Sarah to have a lot of fun with kids who are like her. Sometimes that's important. Where do you find the new normal after brain tumour treatment? At BrainWAVE events it doesn't really matter. The kids have fun and it lets parents deal with the special needs that we have around our children and their brain tumours. The information sharing is invaluable."

Russell Smith, Sarah's Dad



Lower Mainland BC BrainWave Event

# **HANDBOOKS**

**Empowerment through Information** 

During 2009, 6,915 adult and pediatric Patient Resource Handbooks were distributed free of charge across Canada and internationally to meet the needs of survivors, family members, caregivers and health care professionals.

"Many devour it, saying how great it is. Patients and families especially like the diagrams and glossary, because the world of brain tumours presents a whole new language."

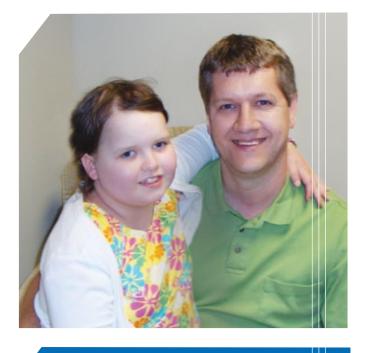
**Marianne Lee, Neurosurgical Social Worker** 

"You are so overwhelmed when your child gets the diagnosis. The handbook gives you security and power. You feel so helpless. You can't fix your child, you don't understand the problem and you don't understand the potential solutions. With the pediatric handbook I could read and then understand when I spoke with Sarah's doctors".

Russell Smith, Sarah's Dad



Storybook MRI



Sarah & Russell Smith

### **HELPING CHILDREN**

Making a Difference in Young Lives

During 2009, 2,059 children storybooks, in English, French and Italian, about a little girl with a brain tumour and her journey through her treatment were delivered free of charge to families, children and schools across Canada and internationally.

"I love to share 'A Friend in Hope' with children. With each word I read, each picture I share, I can feel, see, and hear their joy, sadness, laughter, love. They are eager, open to sharing their feelings, asking questions, wanting to help. And then one child softly shares, 'Miss Pia, my sister has a brain tumour.'

The storybooks make a difference in children's lives."

Pia DiBacco, Volunteer who introduced the children's storybook to the Montreal school system and was the impetus and fundraiser for the translation of "A Friend in Hope" into the French version "Mon Amie Claire."

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### **EDUCATION**

#### **Information Day Conferences**

Leading researchers and brain tumour experts were keynote speakers at the annual Halifax, London and Calgary Brain Tumour Information Days. Dr. Vivek Mehta, Neurosurgeon from the University of Alberta, Dr. Peter Dirks, Pediatric Neurosurgeon at The Hospital for Sick Children in Toronto and Dr. Brian Thiessen, Neuro-Oncologist at the BC Cancer Agency all shared their expertise along with other leading healthcare professionals.

Topics ranged from a look at the role of stem cells in brain tumour growth to advances in brain tumour treatment.

In 2009, 820 people from across Canada attended in a warm, comfortable and supportive atmosphere for survivors and their families. They were able to connect with one another, empower themselves with knowledge from experts in the field and ultimately find hope. "You can't put a price on Information Days. I've learned so much from the excellent speakers. You meet people from all over and sharing experiences gives you a great sense of hope."

Tom Hicks, brain tumour survivor

"There is always something new and more hopeful.

It's especially encouraging when your specific type of treatment is the topic of a presentation. Having a brain tumour and the associated treatments is not easy."

**Annele Robertson, brain tumour survivor** 



Dr. Timothy Walker, Information Day

# **ADVOCACY**

#### **Speaking Out for Better Healthcare**

As a member of the Canadian Alliance of Brain Tumour Organizations (CABTO), Brain Tumour Foundation of Canada participates in CABTO's efforts to advocate for improved patient care, increased government funding for brain tumour research in Canada, and increased public awareness. Two issues were of particular note in 2009:

1. The need for better data collection around the incidence of brain tumours in Canada. In 2009, a report was prepared through the Public Health Agency in cooperation with the Council of Cancer Registries. It outlines opportunities to improve the consistency and completeness of statistics about brain tumours and is being considered by the Council of Cancer Registries for implementation.

2. Equitable access to and coverage for cancer drug therapies in all provinces. During 2009, CABTO members continued to learn about the differences between provincial access and coverage for drug costs with the hope of creating positive change where possible.

In 2009, the traveling Hats Tribute collection grew to 140 hats, raising awareness about people affected by brain tumours while on display at conferences, open houses and various community events. Each hat tells an inspiring story of courage on a personal journey with a brain tumour.



Hats Tribute

### **RESEARCH**

#### **Funding Hope**

One of the highlights of 2009 was the August launching of the William Donald Nash Brain Tumour Research Fellowship, to advance the Brain Tumour Foundation of Canada's vision to find the cause of and cure for brain tumours while improving the quality of life for those we serve. The fellowship will run for two years and will include funds to cover salary and lab expenses of \$50,000 per year.

This Fellowship will encourage and enable young clinicians and scientists to enter the field of brain tumour research and will accelerate studies leading to a cure for brain tumours.

The expectation is that Bill Nash's generous gift will allow us to fund at least five fellowships over the next 10 years.

Six brain tumour research projects with grants totaling \$146,714 were awarded in 2009. There were 34 applicants to the annual program and the six Canadian researchers will be conducting research projects focusing on causation, diagnosis and treatment. One grant was awarded specifically to investigate the role of genetic and environmental factors in the development of pediatric brain tumours.

With high quality brain tumour tissue samples critical to advances in research, the Brain Tumour Tissue Bank funded entirely by Brain Tumour Foundation of Canada, collected and banked samples from 67 patients in 2009. These samples yielded 369 samples which were added to the library of nearly 1,500 samples available for researchers.



The Nash Family with Phyllis Retty, Chair of the Research Committee and Dr. Joseph Megyesi, Chair of the Board

"Bill's generosity has created a legacy of support for young people interested in brain tumour research and will help to move our joint mission forward, to find the cause, better treatments, and one day a cure for brain tumours."

Dr. Joseph Megyesi, Neurosurgeon and Chair of the Board of Brain Tumour Foundation of Canada





William Donald Nash

Annele Robertson

"I am very grateful for research funding, that is what brings hope for people who are suffering."

**Annele Robertson** 

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# **VOLUNTEERS**

The Heart of our Services

Brain Tumour Foundation of Canada was proud to recognize four volunteers who embody the spirit of volunteerism with the presentation of the Volunteer of Distinction Awards. These volunteers represent the more than 700 people who generously donate their time to helping brain tumour patients.

The Volunteers of Distinction honoured in 2009 were: Claudine LePage of Moncton, New Brunswick; Crystal Tellett of Calgary, Alberta; Robin Bateman of London, Ontario and Melissa Martin of Windsor, Ontario.

"Volunteering gets me out of the house and makes me forget about my rheumatoid arthritis. I love the staff and the work that I do, helping get thank you letters and receipts to donors as quickly as possible.

My volunteer role, now that I've learned the donor database system, makes me feel needed and productive."

**Robin Bateman, Administrative Volunteer** 

"Seven years after I began volunteering for the Support Group, some of the same members are still here and it's like a little family. I love seeing the progress people in the group have made and how everyone helps new members cope with a diagnosis. Just knowing that you made a little difference makes a huge difference to me, I just like giving back and it does feel great to know that you may have helped someone."

Claudine Lepage, Moncton Support Group Volunteer Facilitator



Claudine LePage



Crystal Tellett



Melissa Martin



Robin Bateman

DONORS ARE THE **LIFEBLOOD** OF ALL THE SERVICES AND RESEARCH FUNDING PROVIDED BY BRAIN TUMOUR FOUNDATION OF CANADA. **WE SALUTE YOU** ALL FOR YOUR GENEROSITY AND YOUR COMMITMENT TO **MAKING A DIFFERENCE** FOR THOSE MAKING THE JOURNEY WITH A BRAIN TUMOUR.

# Named foundi society its me

### **KELLY SOCIETY**

Named for Kelly Northey, the 8-year-old who inspired the founding of Brain Tumour Foundation of Canada, this special society honours the generosity and multi-year commitment of its members.

Ken Arnott Joseph Megyesi

Chantalle Butler Melodie and Steve Northey

Ted Cooney Susan Relecom
Pam & Rolando Del Maestro Phyllis Retty

Patricia Klein Michelle and Sean Taggart

Ben Seewald

Maryanne MacDonald Beth Tyndall
Heather Mastromattei Fred Wilder
Susan Marshall Peter & Susan Yates

#### Kelly Northey

# **HERITAGE CLUB**

Heritage Club members ensure support, education and research funding for the future through making a legacy gift in their wills or through insurance policies.



Chauna Horner

Susan Marshall
Grace Schenk
Michelle Thibodeau
Shelly Thierman
Lois Toll
Valerie Wicks

Leslie Carter

"I'm sure the money will help with research and the other important work being done by the foundation. I've had a good life, in fact I'm still having a good life and I just want to help."

93-year-old Leslie Carter, who makes annual donations to the Foundation, in addition to a significant bequest in his will.

# MONTHLY GIVING CLUB

Our monthly donors provide important and sustainable support.

Lewis Balsdon Marianne Lee
Tony Barton Carol Lidbetter
Faheem Bokhari Angelo Ligori
Iona Bolger Priscilla Loates
Diane Bradshaw Brian Marriott
Keith Burling Steven McGaffney
Wendy Camp Joan Medve

Courtney Channon Brian and Jo-Anne Montag

**Debbie Collins Carolyn Naus** Claude Cote **Catheline Nemeth** Irene Cranstone Marian Parker George Daniel **Everett Pope** Miriam Deverett Farida Rasulbaksh Isabella Di Cristofaro Nancy Rideout Marie Duff-Whichelo Carolyn Ross **James Dynes Ruth Russell** Justin Erdman Justin Shannahan Larry Ewanchuk Patricia Sharpe Marianne Franklin Wendy Sidwell

Patrick Fraser Fred Siemonsen
Monika Goodluck Ralph Simons
Muriel Grant Erinn Somerville
Bruce Innes Cara Stein
Patti Gray Koch Gwladys Tanner
Terri Jones-Morgan Graham Thomps

THE BRAIN TUMOUR COMMUNITY

2009 PROGRAM EXPENSES

**HOW WE SERVED** 

% OF SPENDING

Terri Jones-Morgan Graham Thompson
Andrew Kaszowski Albert and Rosemary Toews
Patricia Lafreniere Raymond Turmaine
Karin Larson Belinda Wagg
Charlotte Le Melledo Kara Wilson

**SUPPORT** 

SERVICES 29%

# SPECIAL/ MAJOR GIFTS

We salute those donors who have made major gifts to help in 2009.

Estate of Andrea Dalton Baker
The Crone Family
Alison and Darrell Jones
Joseph Megyesi
Estate of Patricia Moore

## **LEGACY FUNDS**

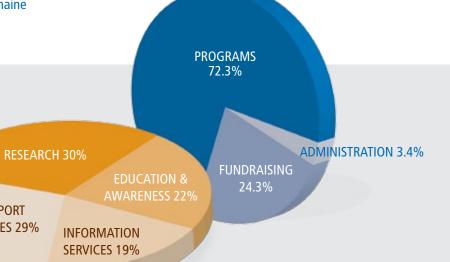
These special Legacy Funds continue to provide funding to chosen services thanks to the ongoing support of our legacy families.

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

HOW WE REACHED

MORE CANADIANS AFFECTED

BY A BRAIN TUMOUR IN 2009



# CORPORATE AND FOUNDATION DONORS

Thanks to those corporations and foundations that help significantly through sponsorships or through special program funding.

Deloitte & Touche Foundation Canada, Platinum Sponsor Schering-Plough Canada Inc., Gold Sponsor AstraZeneca Canada, Inc., Silver Sponsor IMRIS Inc., Silver Sponsor

WestJet, Silver Sponsor

Hoffmann-La Roche Ltd., Bronze Sponsor

In addition to corporate sponsorships, special gifts were received from the following corporations and foundations:

A.M.A. Plastics Ltd.

**Great West Life Assurance Company** 

HB Group Insurance Management Ltd.

Marchand Fairchild Blais Financial

North Waterloo Farmers Mutual

Par Fore Marketing

**Vivid Creative Communications** 

**RBC** Foundation

**Suncor Energy Foundation** 

Sun Life Assurance Company of Canada

The Plunkett Foundation

The Valley Gourmet

# SPECIAL EVENTS

Thank you to the thousands of people who supported the 5,527 participants in the 22 Spring Sprints in cities across Canada in 2009.

Thanks to the families, friends and co-workers of brain tumour patients who raised funds through the 97 Community Events held in their honour or memory.

"Just seeing so many people get together at the Spring Sprint was great. An aunt of ours had a friend in Iowa who contributed and there was our uncle Ted from Australia — it's just amazing to see people from different areas come together to give money and offer their support."

Jennifer Fagan, mother of 11-year-old Max, a brain tumour survivor

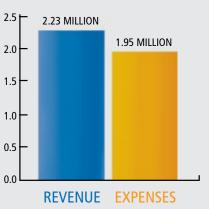


Jennifer Fagan and son Max Van Den Driesschen

# **REACHING CANADIANS**

In 2009, our gross revenue totaled almost \$2.23 million and our expenses totaled \$1.95 million. With this positive position, we have been able to direct more dollars to support programs, and particularly research, thanks to the generosity of our donors.

#### **2009 REVENUE & EXPENSES**



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% OF SPENDING

# istockphoto

# WISION MISSION VALUES

### WWW.BRAINTUMOUR.CA

# **VISION**

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

# **MISSION**

To reach every Canadian affected by a brain tumour through support, education, information and research.

# **VALUES**

These serve as our guidelines for our conduct and behaviour as we work toward achieving our vision:

- Hope
- Caring
- Integrity
- Accountability
- Collaboration
- Connecting the Brain Tumour Community



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