

IMPACT REPORT serving Brain Datients Across C A N A D A

Avery, pediatric brain tumour survivor, nd her dad. Bob

# **Every day, 27 Canadians** are diagnosed with a brain tumour.

Thanks to the generosity of donors, Brain Tumour Foundation of Canada continued to bring hope to patients in 2013.

10,317 connections were made with patients, families and health care professionals, empowering them on their journey.

12 research projects were invested in, to bring hope across Canada.

\$3.32 million was raised - Thank you to donors that make it all happen.

# Thank You for Making an Impact

We are delighted to share with you the impact made in 2013 and to let you know where we are going as we continue to fight this disease together. As we move forward, we have a keen focus on the following challenges:

We don't know enough about the disease – with more than 120 different tumour types, the disease is complex and often life-threatening.

- There is no comprehensive Canadian brain tumour data.
- We need to keep the best and brightest researchers.
- There are life-long educational challenges for pediatric brain tumour survivors.
- Reaching Canadians in all regions of the country.

With your support, we can address these critical needs.

Thank you for the generous gift of your time, your stories and your donations. You make all the work to change the future possible.





Sean Taggart, Chair of the Board Carl Cadogan, Chief Executive Officer

Jennifer, brain tumour survivor

The impact of a brain tumour on a patient and their family is immense. It is only because of the generosity of donors that this burden can be lifted. From finding information through resources, relief through support, respite at events, and change through advocacy – it all happens because people like you give.

# **Spreading Awareness and Making Change**

Awareness efforts aim to educate, engage and inspire action from people all across the country. Advocacy works to ensure patients receive equal access to services, no matter where they live.

#### In 2013:

- 271,716 website visits brought people together, provided information, and spread awareness about the disease and the ways that everyone can help, while 652 stories in media across the country helped reach even more Canadians.
- 242 stories were sent to government during October's Brain Tumour Awareness Month. These stories talked about brain tumour diagnoses, the need for better access to drugs, and the importance of increased funding for research.

A key focus in 2013 was the need for equal access to drugs across Canada. Advocacy efforts continue as we aim to make change on this critical issue.

We were originally shocked when the oncologist mentioned the cost of the medication and asked if we had drug coverage. If my special application had been denied, I was debating having to sell our house to pay for the medication or consider refusing treatment for my husband. Finances were tight enough at the time – we were in our mid-30s trying to make ends meet with student loans, mortgage, car payments, etc. and my husband had just lost his job. I feel the patient and family is going through enough trauma during this journey, They shouldn't have to worry about funding for medication on top of everything else. It's hard to put a price on a loved one's life.

A Caregiver

#### A Caregiver

### **Determined and Passionate Volunteers**

More than 700 volunteers gave of their time in 2013 to help patients and families affected by a brain tumour. In recognition of their extraordinary service, four volunteers were awarded the Volunteer of Distinction award: Keith Anderson of Edmonton, AB; Janice Laberge, London, ON; Dr. Arjun Sahgal, Toronto, ON; and Karen Vickers, Halifax, NS.

**Dr. Arjun Sahgal**, radiation oncologist and 2013 Volunteer of Distinction

# **Reaching Patients and Families**

A national network of programs and services reaches the 55,000 Canadians living with a brain tumour. A suite of programs is offered online and ensures that no matter where you live, you can connect with others who understand the brain tumour journey, learn and connect. The impact this support has on patients is that:

Patients, survivors and caregivers connect with others and they don't feel alone.

- Events and information resources empower patients to be their own best health care advocates.
- When that handbook was put in our hands, it really made all the difference to our understanding of and our ability to deal with the shocking diagnosis we had just been given.

Being able to be with other kids who have been affected by a brain tumour is really helpful to me and my parents.

> Sabine, pediatric brain tumour survivor and BrainWAVE Support Program member

Chris, mother of a pediatric brain tumour survivor

### In 2013:

- 696 people learned through education programs offered across Canada and online.
- 1,371 people received information and support through email or phone.
- 238 activities offered support to patients, survivors and families adult and pediatric.
- 478 Health Care Professionals were reached with events all across Canada.
- 7,536 informative resources were distributed to patients and families across Canada.

### New! Youth Education Awards

Going to college and university is a milestone for young adults, but for pediatric brain tumour survivors, sometimes post-secondary school can be out of reach. Today, because of the generosity of donors, there is a special funding program dedicated to this unique group of young adults.

In 2013, four Youth Education Awards were awarded to pediatric brain tumour survivors.



I am thankful – thankful for my health, for the support of my family and friends, for the opportunity to gain an education, and for programs such as this that provide financial assistance to aid survivors in achieving their goals.

**Bailey,** pediatric brain tumour survivor and Youth Education Award recipient

# **Research:** Moving Forward, Together

Research holds the key to unlock the mysteries of brain tumours. Scientific excellence and the ability to test new ideas are vital in the search for better treatments and a cure for the disease.

Research is moving forward our understanding of this complex disease through:

- Searching for better treatments and looking for the cause of brain tumours.
- Improving quality of life for patients so they can live to the fullest, despite the challenges of the disease.
- Building capacity among the next generation of . researchers.
- Contributing on an international scale to the collective understanding of this disease and the global search for a cure.

brings much-needed funds to brain tumour research so that we can learn more about

Dr. Glenn Bauman, radiation oncologist

and Brain Tumour Foundation of Canada

better treatments for this disease.

Thanks to donors, the total investment in research in 2013 was:

- \$341,000 invested in 12 projects at centres of excellence across Canada.
- Ongoing investments through seven funding methods to spur projects at several points in the research pipeline including project grants, fellowships, studentships, the Brain Tumour Tissue Bank, international collaboratives, and the Canadian Brain Tumour Registry project.
- The William Donald Nash Research Fellowship was awarded for the second time, thanks to a generous legacy gift. It was awarded to Dr. Slawomir Kumala at the Jewish General Hospital, Segal Cancer Centre, in Montreal. His project evaluates the effectiveness of combi-molecules on glioblastoma brain tumours.



monthly donor



The Boomer family made a commitment to help new researchers into the field with one of several new Research Studentships, this one in memory of Taite Boomer. Their generosity made it possible for Rajas Tipnis at the University of Manitoba to work on a project focused on malignant brain tumours. Thanks to this generous investment, Rajas says he has now, "decided on a future in neuro-oncological research."

#### Every brain tumour patient matters let's make sure they count

The feasibility study into the Canadian Brain Tumour Registry continued in 2013 and gained both momentum and media coverage. The need for a standardized system to gather brain tumour statistics can wait no longer. When every person with a brain tumour in Canada is counted and accurate Canadian data about brain tumours is available, efforts to ensure equal access to drugs, treatments and services for all brain tumour patients will accelerate.



# **Your Donations Bring Hope** to Patients and Families

#### In 2013, \$3.32 million in generous support was given towards the mission to reach every Canadian affected by a brain tumour with support, information, education and research.

# Where do the funds come from?

Fundraising events:

**Donations:** 

Investment income and other revenue:



## Where are they invested?

71%

Research and **Patient Programs:** 

Fundraising:

Management:

Program investment highlights in 2013 included the launch of the new Youth Education Awards, a new support group in Winnipeg, MB and funding for 12 research opportunities across Canada.

#### 4%

24%

Management expenses ensure the organization is run with transparency and integrity, and include the annual external audit of financials, receipting of donations, legal, facility costs for one office.

Total expenses in 2013: \$2,696,438



Brain Tumour Foundation of Canada is a proud member of the Imagine Canada Ethical Code program. If you are interested in a detailed financial report, please contact Carl Cadogan, CEO, at ccadogan@braintumour.ca or 1-800-265-5106 ext. 222 or visit BrainTumour.ca/Financials.

# **Thank You**

Thank you to each and every donor who makes programs and services for brain tumour patients and families possible. Every gift brings hope to anyone affected by this disease. Thank you to the following individuals, families and businesses for making a special gift in 2013:

#### **SPECIAL AND MAJOR GIFTS**

We gratefully acknowledge those donors who made gifts of \$5,000 or more in 2013.

AD Ventures Alberta Charitable Foundation Anonymous Donors **Diane Cameron** Sheila Duffin Laura Hawthorn John Langford Macquarie Group Foundation

Dr. Joseph Megyesi Jack Nichol Family Fund, a fund within London Community Foundation **Pink Warrior Foundation** David Scragg The Buttrum Family The Taite Boomer Memorial Brain Tumor Foundation **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 Phyllis Randall

Estate of Lois Toll

#### **LEGACY FUNDS**

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

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

The Kelly Northey 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.

Ken Arnott

**Ryan Fraser** 

Jane Arnott Sue Barnes Leendert De Goffau Marion De Goffau **Douglas Flood** Peter Jacobsen Susan Marshall Grace Schenk

Joseph Barnes Peter Chislett Farida Chislett Shelley Fitak Carina Jacobsen Barbara Kennedy Anne-Marie Kinahan Donna McKee Bridget Plumb Michelle Thibodeau Valerie Wicks

#### **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 **Mariorv Buttrum** Rosemary Cashman Dawn & Ron Fulmer Patricia Klein Marvanne MacDonald Alykhan Mamdani Heather Mastromattei Joseph Megyesi Vincent & Moira Nash Jeff Patt Susan Relecom Arjun Sahgal Richard Seewald & Carol Van Evera Norman Sonnenberg Sean & Michelle Taggart Fred Wilder Peter & Susan Yates

Chantalle Butler Carl Cadogan Pamela & Rolando Del Maestro Jeane King Marianne Lee Margaret MacDougall Susan Marshall Jennifer & Kyle McIntosh Dwight Moulin Steve & Melodie Northey Ken Ramsav Phyllis Retty Ben Seewald Sharon Whiteside Megan Winkler & Scott Courtice

#### **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.

Marvann Abele James Anderson Dr. Lewis Balsdon Dr. Glenn Bauman Lori Betik Iona Bolger Jennifer Bruno Bulatao **Cindy Burns** Michael Cattani Ann Clark Michael & Irene Cranstone **Phyllis Derbyshire** Marie Duff-Whichelo **Diane Duplessis** James & Beth Dynes Fran Ferguson Patrick Fraser Muriel Grant Jean Gross **Betty Lou Haldane** Diane Halliwell Joshua Hunt Sheila Jackson Leslie Jager Daiva Jocius Andrew Kaszowski Brenda Kennedy

Theresa Acchione Parkinson Madeh Badaoui Tony & Joan Barton Wendy Bethune Nick Betik **Denis Bouchard** Keith Burling Trice Cameron Judy Chisholm Debbie Collins Adele Crocker Trevor Dodd Scott Duffield Marie Claire Duthie Lawrence Ewanchuk Joan Francis Monika Goodluck Patti Gray Koch Marie Gwilvm Harry & Marian Hall Sarah Hollins Bruce Innes Peter & Carina Jacobsen Emile Jetzer Arlene Jolv Sarah Keels Karin Larson

#### MONTHLY GIVING CLUB CONTINUED

Alice Lawes Angelo Ligori Priscilla Loates Liliane Macko Valerie March Bennett Ron Mazza Theresa McCombs Kathleen McKay Joan Medve Amitabh Mukerii Carolvn Naus **Catheline Nemeth** Susan Purchase Carolvn Reed Carolyn Ross **Elizabeth Schneider** James Seigel Patricia Sharpe Wendy Sidwell Elizabeth Smith **Gwladys** Tanner Albert Toews Thomas Ward Sheree Wilson

Carol Lidbetter Wenli Liu Jennifer MacKinnon Frances Mandell-Arad **Brian Marriott** Jason McCombs Bronwyn McConvey Gerard Meagher Brian Montag Cora Murphy Teresa Negrich **Everett Pope** Diana Ray Nancy Rideout Ruth Russell Shirley Schwengler Andrea Seymour Kelly Sheardown Ralph Simons Erinn Somerville Graham Thompson **Raymond Turmaine** Kara Wilson Mark Witt

#### **CORPORATE SPONSORS**

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

Eisai Limited Elekta Limited **RBC** Foundation Roche Canada

#### **CORPORATE DONORS**

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

3M Employees' Charitable Trust Akbar T. Nathu Professional Corporation Blackberry Hydro One Employees and Pensioners' Trust Fund IBM Employees' Charitable Fund National Steele Car Limited Northbridge Financial Corporation Salesforce.com Foundation **Telus** Corporation

A.M.A. Plastics ATCO Limited Edmonton Public Teachers **Encana Corporation** Marcovecchio Construction Nexen Inc. Par Fore Marketing Sinopec Daylight Energy Limited

#### **COMMUNITY EVENTS AND SPRING SPRINT**

Thank you to the thousands of donors who raised \$1.72 million by supporting the 7,000 participants in 20 Spring Sprint events across Canada in 2013. Heartfelt gratitude is also given to the families, friends and co-workers of brain tumour patients who raised \$486,752 through 128 Community Events held in 2013.

#### A special thank you is extended to those community events that raised \$5,000 or more.

A Night to Remember Birdies for Brain Tumours Concert for the Cure Howard Fink Memorial Golf Tournament Jeff Graham Memorial Golf Tournament Journey of Hope Kathrine Turek Memorial Golf Tournament Mulligans for Michelle Rigatoni for Research SNC Golf

**Banff Jasper Relay** Cindy's Aquathon **Davey Bell Fundraiser** Imagine Gala Jennifer's Hope Gala Kadri Golf Classic Lachance Hockey **Ride Strong Rival Golf** 

# **2013 BOARD OF DIRECTORS**

A volunteer board of directors guides the mission and vision of the organization. We are proud to say that 100 per cent of the Board of Directors supports the mission through their gifts of time and financial support.

In 2013, the Stephen Buttrum Brain Tumour Research Fellowship was generously created in memory of Director Marjory Buttrum's husband.

**We chose to fund a Brain Tumour Research** Fellowship because it was important to us that our gift would make a difference to the wellbeing of others. Steve was a generous man – generous with his money, time and compassion for others, particularly children. He would be happy to know we are funding research to better understand and treat pediatric brain tumours.

Marjory Buttrum, Brain Tumour Foundation of Canada donor and board member

#### Executive Committee

Sean Taggart John Stevenson Sarah Keels Jane Arnott

Chair Acting Vice-Chair Treasurer Secretary

#### Directors

Marjory Buttrum Jeane King Marianne E. Lee Dr. Joseph Megyesi Fred Wilder

**Rosemary Cashman** Patricia Klein Alykhan Mamdani

#### **Honourary Members**

Steve Northey, Co-Founder Pamela Del Maestro, Co-Founder Dr. Rolando Del Maestro, Co-Founder Perry Ferguson, Founding Director David Lucy, Founding Director Jane Hauser, Honourary Member Phyllis Retty, Honourary Member

The determination to overcome brain tumours has been bringing together everyone affected by this disease since 1982. Our vision, mission and values reflect this goal.

#### Vision:

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

#### Mission:

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

#### Values:

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

### Hope, Caring, Integrity, Accountability and Collaboration



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