



braintumour  
foundation  
OF CANADA

# IMPACT REPORT

# 2014



*The grey ribbon is a symbol of awareness for the brain tumour cause*



**27 Canadians are diagnosed with a brain tumour every day.**

- 11,032 connections were made with patients, families and health care professionals, empowering them as they fight this disease
- 17 research projects were invested in, bringing hope across Canada
- A formal presence was established in Quebec
- \$2.72 million was raised

SERVING BRAIN TUMOUR  
PATIENTS ACROSS CANADA

# THANK YOU FROM LEADERSHIP

*Your support changes lives*

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.

## In 2014:

- A formal presence was established in Montreal, including support groups.
- Advocacy efforts took action on issues like equal access to drugs.
- The feasibility study for the Canadian Brain Tumour Registry is now complete.
- More pediatric brain tumour survivors were able to achieve their dreams through post-secondary education.

## AND TOGETHER WE CONTINUE TO FIGHT THIS DISEASE.

- The survival rate for brain cancer patients hasn't increased since the 1950s – we must accelerate this.
- We know a Canadian Brain Tumour Registry is possible – we need to make it happen.
- Together we can keep the best and brightest researchers focused on brain tumours.
- Through specialized programs, we can bring all patients and families hope.

Thank you for your generous gifts. Let's put an end to brain tumours.



SEAN TAGGART,  
*Chair – Board of Directors*



CARL CADOGAN,  
*Chief Executive Officer*

# ADVOCACY AND AWARENESS

*Increasing Awareness and Advocating for Change*

Awareness efforts aim to educate, engage and inspire action while advocacy works to ensure important change is made for all brain tumour patients and families.

“It makes absolutely no sense that the standard-of-care for brain cancer is not covered equally for all patients. People should not have to struggle to pay for medication they need – it's such an unnecessary stressor, especially when you should be focused on getting well.”

LYNSEY FRANGAKIS,  
*brain tumour survivor*

## In 2014:

- 466,389 website visits connected the community, provided important information, and drove awareness about the disease, while advertising and media stories across the country helped reach even more Canadians.
- 198 stories were sent to government during October's Brain Tumour Awareness Month. Families shared their experience and asked for government help in making change. Better access to drugs, counting every brain tumour, and the importance of increased funding for research were key issues.



## Unwavering Volunteers

Great effort was put into the need for equal access to drugs across Canada by joining the CanCertainty Coalition. This partnership is helping to make change on this critical issue.

More than 700 volunteers gave of their time in 2014 to help patients and families affected by a brain tumour. In recognition of their extraordinary service, three volunteers were awarded the Volunteer of Distinction award: **David Kelly** of Fredericton, NB; **Diane McAuley** of London, ON; and **Siobhan Taylor** of Edmonton, AB.

And for the first time, the Chair's Award for Community Service was presented. **Ross MacDougall** received the inaugural award for his leadership with the annual Concert for the Cure in Halifax. This community event has raised \$120,000 for brain tumour research since 2010.

In 2015, the award will be renamed in honour of brain tumour advocate and fundraising leader **David Kelly**, from Fredericton, NB, who passed away in October 2014.



Lynsey Frangakis



Ross MacDougall



David Kelly

# INFORMATION, EDUCATION AND SUPPORT

*You Are Not Alone*

## Today, no matter where you live, you can connect with others on the brain tumour journey.

In 2014, new support groups were launched in Montreal, QC, in both English and French; a group began in St. John's, NFLD; and Virtual Support Groups were also launched. And, Alberta pediatric patients and their families now have their own BrainWAVE program thanks to the support of the Edmonton Oilers Community Foundation, Edmonton Teachers Association and RBC Foundation.

### In 2014:

- 589 people learned through education programs offered across Canada and online.
- 1,250 patients and families received information and support by email and phone.
- 272 activities offered support to patients, survivors and families – adults and pediatric, including new support groups and the BrainWAVE expansion to Alberta.
- 1,262 Health Care Professionals were reached with events across Canada.
- 7,675 informative resources were distributed to patients and families nationwide.

## New! Supportive Care Advisory Group

Supporting patients and families facing a terminal brain tumour diagnosis is something we are committed to. In 2014, patients, caregivers and health care professionals came together to form the Supportive Care Advisory Group (SCAG). This group is identifying gaps in services for those living with a terminal diagnosis and developing programs to meet these needs. This new program has been supported entirely through a partnership with Hoffman-LaRoche Ltd.

“The workshops give me new things to take back to work and to my team. They also help us understand patients better.”

CONSTANCE LAM, RN at Foothills Medical Centre Department of Neurosurgery

“Virtual group attendance is definitely a good thing. Just talking to people who are going through the same thing I am made me feel like I was not alone. I do have support here but they have no idea how I feel. This was just something I always looked forward to doing... I live in an area which is not close to any type of in-person support.”

L.L., brain tumour survivor and Brain Tumour Virtual Support Group Member

“Participating in the Supportive Care Advisory Group hits home for me, as I am a patient who may require supportive care in the future. I am a Grade IV GBM survivor, and have been for nearly 2 years. Being a part of the SCAG allows me to bring in my own experiences, in hopes that future patients will benefit.”

DENIS RAYMOND, brain tumour survivor and Supportive Care Advisory Group member

# RESEARCH

*Investing in Hope*

Investing in research means ensuring there is scientific excellence and the ability to test new ideas in Canada. This is vital in the fight against brain tumours.

*Research advances our understanding of this complex disease by:*

- Building capacity among the next generation of researchers.
- Contributing on an international scale to the global search for a cause and cure.
- Searching for better treatments with fewer impacts on the brain tumour patient.
- Improving quality of life for patients so they can live well today.

*Thanks to donors, the total investment in research in 2014 was:*

- \$1.09 million invested in 17 projects at centres of excellence across the country.
- Ongoing investments through seven funding methods spur projects at several points in the research pipeline; these include project grants, fellowships, studentships, professional awards, the Brain Tumour Tissue Bank, international collaboratives, the Canadian Brain Tumour Registry project and the Impact Grant with the Canadian Cancer Society and Brain Canada. Advancing research is truly funding hope: Hope for better treatments and hope for discovering the cause and cure for brain tumours.

“I want everyone to know how far we've come. It's understandable to think research is too slow, that looking for a cure is taking so long; but from a science perspective, it's been a whirlwind of change. Even the past decade, with its advances in technology and information sharing, has transformed everything.”



DR. LISA PORTER, Scientific Director, Windsor Cancer Research Group

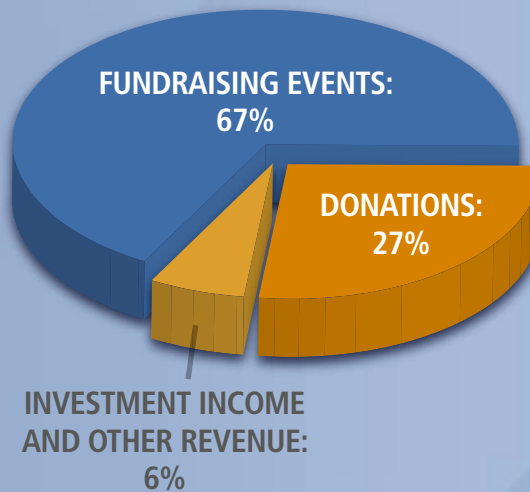
*The Canadian Brain Tumour Registry is close...*

The feasibility study into a Canadian Brain Tumour Registry is now complete. We are confident that a standardized system to gather brain tumour statistics is possible and a three-year plan for its development is now in progress. When established, this registry will help accelerate efforts to ensure equal access to drugs, treatments and services for all brain tumour patients. A report on the next steps for this exciting project is expected in 2015.

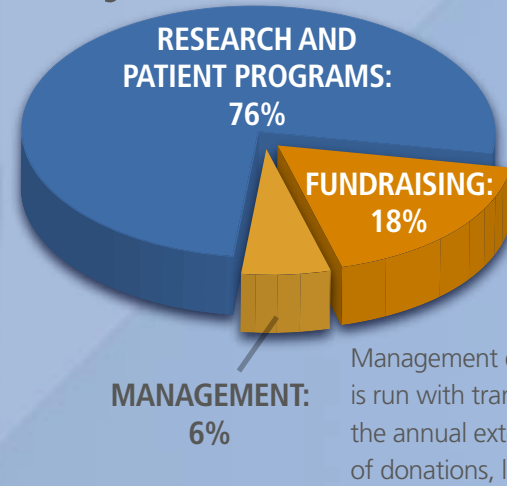
# YOUR GIFTS GIVE HOPE

In 2014, \$2.72 million in generous donations was given to reach every Canadian affected by a brain tumour with support, information, education and research.

## Where do the funds come from?



## Where are they invested?



Program investment highlights in 2014 included the launch of a formal presence in Quebec including two support groups, support group growth in Newfoundland, the launch of Virtual Groups, expansion of BrainWAVE into Alberta, and funding for 17 research opportunities across Canada.

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

## TOTAL EXPENSES IN 2014: \$3.61 MILLION

**NOTE:** The difference in expenses versus revenue is accounted for largely by the five-year commitment to the matching Impact Grant program with the Canadian Cancer Society and Brain Canada.



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](mailto:ccadogan@braintumour.ca) or **1-800-265-5106 ext. 222** or visit [BrainTumour.ca/Financials](http://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 2014:

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

**Estate of Joanne Sue Dunn**      **Estate of Conrad James Morgan**

### ENDOWMENT FUNDS

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

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

### LEADERSHIP GIFTS

We gratefully acknowledge those donors who made gifts of \$5,000 or more in 2014.

|  |
|--|
| A.M.A. Plastics Ltd.   |
| Diane Cameron  |
| Rene Cayouette   |
| Edmonton Oilers Community Foundation                               |
| Laura Hawthorn   |
| Steve Harrison   |
| Hey! Wire Electric   |
| Ian Hobbs & Kim Staikos  |
| Nexen Energy ULC   |
| Jack Nichol Family Fund, a fund within London Community Foundation |
| Olympia Charitable Foundation                                      |
| RBC Foundation   |
| David Scragg   |
| Selectpath Benefits and Financial                                  |
| SickKids Hospital Foundation                                       |
| The Jeff Davie Foundation  |
| The Nazira Mamdani Brain Tumour Research Fellowship                |
| The Taite Boomer Memorial Brain Tumor Foundation                   |

### HERITAGE CLUB

Heritage Club members ensure support, education and research funding for the future by including Brain Tumour Foundation of Canada in their will or through a gift of life insurance.

|                            |                    |                    |
|----------------------------|--------------------|--------------------|
| Theresa Acchione Parkinson | Leendert De Goffau | Anne-Marie Kinahan |
| Jane Arnott                | Marion De Goffau   | Susan Marshall     |
| Ken Arnott                 | Ann Estill         | Donna McKee        |
| Joseph A. Baldanza         | Shelley Fitak      | Norman McLeod      |
| Rosaria Baldanza           | Douglas Flood      | Bridget Plumb      |
| Joseph Barnes              | Ryan Fraser        | Grace Schenk       |
| Sue Barnes                 | Jane Hawkins       | Diana Stott        |
| Wendy Bethune              | Carina Jacobsen    | Joan Sutherland    |
| Farida Chislett            | Peter Jacobsen     | Michelle Thibodeau |
| Peter Chislett             | Barbara Kennedy    | Valerie Wicks      |

### CORPORATE AND FOUNDATION DONORS

Special gifts of \$1,000 or more were received from the following corporations and foundations:

|                                     |   |
|-------------------------------------|---|
| 3M Employees' Charitable Trust      | JL Stayners Consulting Ltd.             |
| ATCO Limited                        | London Community Foundation             |
| BHP Billiton                        | National Steele Car Limited             |
| Crich Holdings and Buildings Ltd.   | North Waterloo Farmers Mutual Insurance |
| Edmonton Public Teachers            | Par Fore Marketing                      |
| Encana Corporation                  | Shell Canada                            |
| Fondation de la Famille J. Rodolphe | Sound Extractor Studio Inc.             |
| Rousseau                            | Spyglass Resources Corp                 |
| Gamma-Dynacare Medical Laboratories |   |

### FUNDRAISING EVENTS: SPRING SPRINT, BRAIN TUMOUR WALKS & COMMUNITY EVENTS

Events bring together the community and raise critical funds. In 2014, special events raised a total of \$1.82 million. For the 20 Spring Sprint events, three new Brain Tumour Walks, and community events all across Canada, heartfelt gratitude is expressed to the families, friends and co-workers of brain tumour patients who support these special events, every day.

|   |  |
|---|--|
| 10 <sup>th</sup> Annual Strikezone Mixed Slow Pitch | Kinsmen Golf Classic Oshawa                |
| 4 <sup>th</sup> Annual Rumsey/Givon Halloween Event | Kumar Classic 3v3 Basketball               |
| ASCIS Walkathon                                     | Markville Fitness Challenge                |
| Awareness Events                                    | Mission Fun Day-St Elizabeth Public School |
| Banff Jasper Relay                                  | MPI Dress Down Days                        |
| Battle on the Beech Golf Tournament                 | Mulligans for Michelle                     |
| Bearduary   | NPT LLP Golf Tournament                    |
| Birdies for Brain Tumours                           | Olive Walker Zinkham & Waller Casual Days  |
| Black Knight Badminton                              | Pick Your Brains                           |
| Bloom Sprint Mayfield Secondary School              | Pursuit of Wisdom                          |
| BMO Vancouver Marathon 2014                         | RBC Royal Bank - Pakenham BBQ              |
| Brawl on Bay St                                     | Rene's Battle                              |
| Calithumpian Weekend Festival                       | Rival Office Solutions Golf Tournament     |
| Cardinal Leger Secondary School Activites           | Server Auction/Ladies night                |
| CDL Beach Dodgeball                                 | Showing Up Cancer                          |
| Celebration of Significant People                   | Social Committee, Ottawa Hospital,         |
| Colour Paradise Greenhouse Ltd. BBQ                 | Civic Campus - Casual Days                 |
| Concert for the Cure                                | Spirit Wear                                |
| Coquitlam Celebration Choir                         | St Timothys School fundraiser              |
| Curl for a Cure                                     | Swing for a Cure Golf Tournament           |
| Dan Cote Foundation Charity Golf Tournament         | This Ain't Hollywood - Tribute to Imants   |
| Everything Financial Group Golf Tournament          | Krumins                                    |
| Gains for Brains                                    | UK Marathon                                |
| Game-A-Thon   | Victoria Marathon                          |
| Hak-Elliott Golf Tournament                         | West Coast Walk                            |
| Hike for Hope                                       | Wish Upon on a Song                        |
| Ironman Norway                                      |  |
| Jonasaurus Nickname Challenge                       |  |
| Kathy Turek Memorial Golf                           |  |

### KELLY SOCIETY

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

|                           |                          |                         |
|---------------------------|--------------------------|-------------------------|
| Jane Arnott               | Maryanne MacDonald       | Susan Relecom           |
| Chantalle Butler          | Margaret MacDougall      | Phyllis Retty           |
| Marjory Buttrum           | Alykhan Mamdani          | Arjun Sahgal            |
| Carl Cadogan              | Susan Marshall           | Ben Seewald             |
| Rosemary Cashman          | Heather Mastromattei     | Richard Seewald & Carol |
| Pam & Rolando Del Maestro | Jennifer & Kyle McIntosh | Van Evera               |
| Dawn & Ron Fulmer         | Joseph Megyesi           | Norman Sonnenberg       |
| Tracey Jones              | Dwight Moulin            | Sean & Michelle Taggart |
| Sarah Keels               | Vincent & Moira Nash     | Fred Wilder             |
| Jeane King                | Steve & Melodie Northey  | Megan Winkler & Scott   |
| Patricia Klein            | Jeff Patt                | Courtice                |
| Suzanne Lanthier          | Adrianna Ranger          |                         |
| Marianne Lee              | Ken Ramsay               |                         |

### 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              | Monika Goodluck         | Cora Murphy             |
| Theresa Acchione           | Muriel Grant            | Luh Murtadi             |
| Parkinson                  | Patti Gray Koch         | Carolyn Naus            |
| James Anderson             | Jean Gross              | Teresa Negrich          |
| Madeh Badaoui              | Betty Lou Haldane       | Catheline Nemeth        |
| Dr. Lewis Balsdon          | Harry & Marian Hall     | Danika Painter          |
| Tony & Joan Barton         | Diane Halliwell         | Gilda Planamente        |
| Dr. Glenn Bauman           | Joshua Hunt             | Everett Pope            |
| Denna Benn                 | Bruce Innes             | Ken Purchase            |
| Wendy Bethune              | Sheila Jackson          | Sen Raymond             |
| Lori Betik                 | Peter & Carina Jacobsen | Carolyn Reed            |
| Nick Betik                 | Leslie Jager            | Lew Roberts             |
| Iona Bolger                | Emile Jetzer            | Ruth Russell            |
| Denis Bouchard             | Daiva Jocius            | Stephanie Schappert     |
| Shirley Boyle              | Arlene Joly             | Elizabeth Schneider     |
| Jennifer Bruno Bulatao     | Anne-Marie Kinahan      | James Seigel            |
| Keith Burling              | Negar Koochakzadeh      | Andrea Seymour          |
| Cindy Burns                | Karin Larson            | Patricia Sharpe         |
| Trice Cameron              | Alice Lawes             | Kelly Sheardown         |
| Michael Cattani            | Carol Lidbetter         | Kathleen Sherwood       |
| Sandra Celikors            | Angelo Ligori           | Wendy Sidwell           |
| Judy Chisholm              | Wenli Liu               | Ralph Simons            |
| Ann Clark                  | Priscilla Loates        | Elizabeth Smith         |
| Debbie Collins             | Jennifer MacKinnon      | Erinn Somerville        |
| Adele Crocker              | Liliane Macko           | Debbie Swords           |
| Phyllis Derbyshire         | Frances Mandell-Arad    | The late Gwladys Tanner |
| Trevor Dodd                | Brian Marriott          | Graham Thompson         |
| Marie Duff-Whichelo        | Ron and Pam Mazza       | Albert Toews            |
| Scott and Marilyn Duffield | Theresa McCombs         | Raymond Turmaine        |
| Diane Duplessis            | Bronwyn McConvey        | Roberto Valente         |
| Scott Dyke                 | Kathleen McKay          | Thomas Ward             |
| James & Beth Dynes         | Gerard Meagher          | Kara Wilson             |
| Lawrence Ewanchuk          | Joan Medve              | Sheree Wilson           |
| Fran Ferguson              | Brian Montag            | Mark Witt               |
| Joan Francis               | Leo Richard Moreau      | Gary Yorke              |
| Patrick Fraser             | Amitabh Mukerji         |                         |

# 2014 BOARD OF DIRECTORS

A volunteer Board of Directors guides the mission and vision of the organization and 100 per cent of this group supports the organization through their gifts of time and financial support.

## EXECUTIVE COMMITTEE

|                   |                 |
|-------------------|-----------------|
| Chair             | Sean Taggart    |
| Acting Vice-Chair | Marjory Buttrum |
| Treasurer         | Sarah Keels     |
| Secretary         | Jane Arnott     |

## DIRECTORS

|                  |                     |
|------------------|---------------------|
| Rosemary Cashman | Kristin Danniels    |
| Jeane King       | Patricia Klein      |
| Alykhan Mamdani  | Dr. Adrianna Ranger |
| Dr. Arjun Sahgal | Chris Sullivan      |
| Fred Wilder      |                     |

In 2014 the governance model of the organization was expanded to include a new membership structure. This was implemented to ensure the vision of the organization remains connected to the needs of the Canadian brain tumour community. Starting in 2014, the Board of Directors chose 20 to 25 people to become Members of Brain Tumour Foundation of Canada ("Members"). Each Member will serve a five-year term (with a two-term maximum). Members at the end of 2014 were:

|                                     |                               |                    |
|-------------------------------------|-------------------------------|--------------------|
| Barbara Armstrong                   | Dr. Sharon Guger              | Kathy Pronga       |
| Jane Arnott                         | Jane Hauser                   | Phyllis Retty      |
| Denise Bilodeau                     | Marianne E. Lee               | Dr. Brenda Sabo    |
| Marjoree Brazina                    | David Lucy, Founding Director | Dr. Arjun Sahgal   |
| Catherine Bravo                     | Susan Marshall                | Sara Shearkhani    |
| Yaron Butterfield                   | Heather Mastromatti           | Chris Sullivan     |
| Gilles Cayouette                    | Diane McAuley                 | Hany Soliman       |
| Ron Craig                           | Dr. Joseph Megyesi            | John Stevenson     |
| Chris Curry                         | Dan Motyka                    | Dr. Brian Thiessen |
| Dr. Faith Davis                     | Adam Nicholson                | Jennifer Verhelle  |
| Pamela Del Maestro, Co-Founder      | Melodie Northey               | Karen Vickers      |
| Dr. Rolando Del Maestro, Co-Founder | Steve Northey, Co-Founder     | Christopher Wynder |
| Perry Ferguson, Founding Director   | Dr. Kevin Petrecca            |                    |

Since our founding in 1982, the determination to overcome brain tumours has brought together thousands of Canadians affected by this disease.

## 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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