



The James Fund Neuroblastoma Family Retreat – So Much More

September 28-30, 2007

Some people think of a retreat in a military fashion, movement away from a foe. Some think of it in a religious manner, a time for quiet contemplation and thought. What The James Fund organizers did for us at Camp Ooch this September was so much more.

We had a weekend-long opportunity for private, phone-free time with our families and new and old friends. There were activities: a scavenger hunt, hiking in the woods, cartoon drawing and wrestling with our faith and our fears.

There is a deep, unspoken bond of fellowship among those who have faced the same terrible disease and decided to commit their time and energy to helping others in the same circumstance. You know when you see it, in their eyes. This community of like-minded people, stepping beyond their own pain, was inspiring and strength-giving in a way that can't be described. And it was so much more.

The volunteers, many with a personal connection to The James Fund or neuroblastoma, were all real people with their own lives and their own worries. They took time to care about our troubles, to make sure our bacon was soft or crispy, to develop friendships with our children at the flagpole and the foosball table and to sit with their arms around us at the campfire. Thank you, and so much more.

I think, what happened at that idyllic lakeside lodge, on a refreshing, sunny weekend in September 2007, was not so much a retreat as an advance. We all knew, before we got there, that we would be fighting neuroblastoma together. But the sum of the commitment, the focus of the energy and the determination to find a cure was more than I expected, so much more.

Faye Whyte, neuroblastoma Mom
<http://writegal.blogspot.com>

The Second Annual James Fund Neuroblastoma Family Retreat is booked for September 26-28, 2008.



From James' Dad

"In this newsletter you will read about just a few of the activities of the James Fund over the past year. Behind each fundraising event is a child fighting neuroblastoma, and encircling that child with their deepest love are their parents, their extended family, their friends, their doctors, nurses and researchers, all desperate to help find a cure for this terrible disease. James Fund research is making very significant contributions to the global fight against this disease, but perhaps a greater achievement is the building of an incredible community that provides its members with the strength, courage and hope to face the unbelievable challenges of children fighting neuroblastoma. Nothing provides more meaning in my life than my work on behalf of neuroblastoma families. Thank you."

Syd Birrell



Announcing the James Birrell Laboratories at SickKids See page 3

On November 13, 2007 SickKids announced the naming of the James Birrell Laboratories, in memory of our own little James Birrell, who said, "I will always be fighting cancer". Whoever would have thought that his words would come to have such poignant meaning?

Neuroblastoma Families . . . Working together

Neuroblastoma is a horrific childhood cancer affecting the central nervous system that claims one child every 14 hours in Canada and the USA. It is an "orphan disease" and no pharmaceutical company has adopted it to find a cure. There are not enough children fighting neuroblastoma to attract the attention of profit-driven pharmaceutical companies. As a consequence, the mortality rate has remained at 85% for 30 years. It has been left to the neuroblastoma families and their supporters to take matters into their own hands and raise awareness and funds to save their children.

Through The James Fund, neuroblastoma families are pooling resources to fund world-class research in the areas of diagnosis, genetics, and treatment, including discovering how neuroblastoma arises and progresses, and finding new drugs and therapies. Partnerships with researchers in Canada, the USA, Europe, and Japan have taken our efforts to the global level. Our research findings have been published in prestigious medical journals and featured at premiere international cancer conferences. We are making a difference!



Neuroblastoma Children . . . our inspiration, our hope, our cause

Sam's Day

www.samsday.org

Sam's Day is the pinnacle of family fun in the Burlington community with a circus-themed afternoon of carnival games, magic, dancing, drumming, reptiles, birds of prey, puppetry, crafts, woodworking and face painting. Sam's Day has contributed \$72,000 to James Fund research.

In Memory of Elgin Fraser

www.embraceofhopefund.com

Peterborough supporters held the second annual Walk/Run for The James Fund with neuroblastoma families from Ottawa, Toronto, Burlington and New York. Honorary Chair of this event was Ottawa Senators Centre, Mike Fisher. The event was in memory of Elgin Fraser of Ottawa, who lost his battle to neuroblastoma earlier this year. Proceeds will help fund a joint neuroblastoma research project between The James Fund and The Children's Hospital of Eastern Ontario, where Elgin was treated.

Matthew's Fundraising

Matthew and his family have hosted ladies' nights, a Halloween party and many good ol' fashioned prairie socials. Special thanks to Matthew's friends at St. Ignatius School who keep surprising us with fundraising events.

Horseshoes Anyone?

Congratulations to the Mutton family on the success of their first annual Horseshoe Tournament. You Grandmas *really* rock!

Mitchell Fraser Slo-Pitch Tournament

A classic down-home softball tournament in memory of little Mitchell. This year saw the total proceeds from this event reach \$100,000 in support of the families still fighting this disease.

Lilah's Fund

www.lilahsfund.com

Congratulations to Lilah's Fund at the milestone achievement of \$250,000 raised through Sunday in the Park with Lilah, supporting research initiatives which have received global recognition.

Aquila Thunder Ride for Mac

www.thunderride.ca

12 members of the Aquila Cycling Club rode 1,200 kms. to raise money for The James Fund. This incredibly fit group battled gruesome weather, exhausting hills and 18 wheelers to raise \$29,000 for The James Fund. The ride was dedicated to Mac. The skuttlebug is that Aquila has really big plans for a James Fund fundraiser next year... you guys are awesome!

Solving Kids Cancer - "Every Kid Deserves to Grow Up"

www.kidcancer.org

James Fund research successes have attracted the attention of discerning donors in New York City, resulting in their generous support of ongoing James Fund projects. We are delighted to be working with our friends at Solving Kids Cancer, created in memory of Penelope and Hazen, two extraordinary children who will not be forgotten.

Working together...



THE JAMES FUND

For Neuroblastoma Research at SickKids

Award-winning kids - they truly are Stars!

Krystianna

At SickKids, children receive a bravery bead for every medical procedure. Krystianna has earned over 700 beads and this fall she made a TV commercial for SickKids. Krystianna runs a lemonade stand every Canada Day and sells home made keychains and pens as fundraisers.

Sydney and Georgia HOPE Fund www.writegal.blogspot.com

Sydney met Michael Burgess at an Oldtimers hockey game and he graciously sold her bracelets in the locker room. The Kingston Gymnastics Club sold bracelets; we had a multi-family yard sale in the spring; and we met Mike Fisher at CHEO. Sydney also recorded 2 radio ads for SickKids, and the Georgia & Sydney bracelets are now available on-line, with all proceeds to The James Fund.

Shania's Sunflower of Hope www.shaniasunflower.blogspot.com

April 28th was a very special day, as Shania's Sunflower of Hope Fun Fair was held at the Markham Fairgrounds, raising \$45,000 for The James Fund. The excitement included visits from celebrities such as Michael Burgess, and Bridget from the TVO Kid's show SPELLZ, but the most anticipated visit was from Shania herself. Although hospitalized, she somehow convinced her doctors to let her attend her fun fair and the crowd was deeply touched as she presided over the event.

Although Shania lost her battle to neuroblastoma, this truly remarkable little girl will live on in our hearts forever, and has been recognized in her community with:

- The Citizen of Character Award (age 6-9), to an individual whose actions demonstrate and model a continuous commitment to the York Region Character Attributes
- Celebrating Student Success, to a student who personifies student excellence and exemplifies student success
- Kids Believe in SickKids Award for 2007, for Top Fundraising Individual.



James Fund Research

This past year marked another period of successful research projects sponsored by The James Fund. The scientists of the James Birrell Neuroblastoma Laboratories made several important discoveries, including the identification by my lab together with Drs. Meredith Irwin, Paul Thomer, and Herman Yeger's groups of the rare cells in neuroblastoma (cancer stem cells) that we think are responsible for why this cancer relapses and returns following chemotherapy, and the identification of these cells in the bone marrow of neuroblastoma patients in remission, which may aid us in determining whether chemotherapy is effective. Drs. Sylvain Baruchel and Yeger's groups discovered that neuroblastoma cells have an "address" on their surfaces that that enables them to metastasize and travel to different parts of the body. Dr. Baruchel will be testing drugs that mask this "address" to determine whether it will prevent neuroblastoma from metastasizing. Dr. Irwin's lab found two drugs, COX inhibitors and nutlin, that killed neuroblastoma cells, and discovered how they do this. We are most excited at the creation using this past year's donations of a James Fund Drug Discovery Group. We are convinced that we, at SickKids, will need to produce a new generation of effective anti-cancer drugs for children, and we are setting up a major drug discovery effort to discover drugs that will be effective against patient's cancer stem cells. The group has already discovered novel drugs in the past year, one of which has been administered to patients. We are very fortunate that Dr. Baruchel has been invited to be the first Canadian member of NANT, a consortium of American universities and hospitals that conducts clinical trials to test new drugs and new combinations of drugs against neuroblastoma, and that will greatly enhance our ability to bring new drugs to children with cancer in Canada. We are grateful for your generous support that will enable us to fulfill Syd and Pam Birrell's dream of truly making a difference and providing hope for all with children's cancer.

David Kaplan, Ph.D.
Senior Scientist, Cell Biology Program,
Hospital for Sick Children

Canada Research Chair in Cancer and Neuroscience
Professor, Department of Molecular Genetics,
University of Toronto

Full details of individuals, projects and institutions involved are available at www.JamesFund.ca

**Syd Birrell, Dr. David Kaplan,
Dr. Sylvain Baruchel**



"The Stem Cell Network is a non-profit corporation, established in 2001, that brings together more than 80 leading scientists, clinicians, engineers and ethicists from universities and hospitals across Canada. The Stem Cell Network is one of Canada's Networks of Centres of Excellence (NCE), Canada's flagship science and technology program. The mission of our organization is to be a catalyst for enabling translation of stem cell research into clinical applications, commercial products and public policy.

The James Fund exemplifies the quality of innovative research that The Stem Cell Network aspires to fund. We are proud to support its work, which has made considerable impact to the growing wealth of stem cell knowledge, and is opening doors to finding new approaches to neuroblastoma treatment."

Drew Lyall – Executive Director, Stem Cell Network
www.stemcellnetwork.ca



Announcing the James Birrell Laboratories at SickKids

James used to say, "I will always be fighting cancer," and never have his words been so true. In memory of our little James, who inspired so many, and in recognition of the contribution of the Birrell family to the fight against neuroblastoma, on November 13, 2007, SickKids announced the naming of The James Birrell Laboratories. James Fund supporters and neuroblastoma families joined us for the celebration. The James Birrell Laboratories are located within the Kaplan/Miller labs and will house future projects, personnel and equipment for all neuroblastoma research at SickKids. We couldn't be more proud of this honour!

To ensure the long term stability of neuroblastoma research at SickKids within The James Birrell Laboratories, the Birrells and The James Fund have committed to raising \$10M in endowed funds in order to:

- ensure the longevity of the James Birrell Laboratories as a global leader in neuroblastoma research;
- enable SickKids to better plan the future of neuroblastoma research;
- encourage significant support for neuroblastoma from individuals and families;
- provide resources for The James Fund to partner with larger granting agencies;
- better enable SickKids to attract and maintain top scientists.

"James has effectively left his tiny footprint in the vast world of research in this country, and that is an immensely powerful legacy to leave," said Dr. David Kaplan.

Canadian Star, Michael Burgess, has agreed to help raise the \$10M.



"Neuroblastoma is one of the most terrible diseases any small child can suffer, and one of the most devastating to the family members. So when you meet a family who has made immense efforts to save their child, fundraise for research, and almost single-handedly commit to conquering the disease – well, your heart and mind shout out to become involved. That's why I am so pleased to be able to help."

Michael Burgess – Chair, James Birrell Endowment Fund Committee

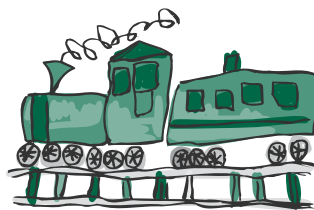
Dr. Sylvain Baruchel and Canadian Neuroblastoma Research at the Forefront

James Fund Researcher/SickKids Oncologist, Dr. Sylvain Baruchel, has recently been appointed as a board member to the Advances in Neuroblastoma Research group. This elite group is an international think tank of scientists who are dedicated to raising the bar on neuroblastoma research globally. Sylvain represents Canada on this group, is one of the few representatives for all of North America, and brings to the international table the important work of The James Fund.

Sylvain has also been invited to join NANT, New Approaches to Neuroblastoma Therapy. This consortium is a group of 13 universities and children's hospitals in the USA with strong research and treatment programs for neuroblastoma. Working closely together, they test promising new therapies for high-risk and relapsed neuroblastoma. Sylvain is the first person outside of the USA to ever be invited to join the group, and was invited based on his work with The James Fund.



James Birrell



*"With all this experimenting
they'll get it figured out and then
all the kids with neuroblastoma
will be able to survive."*

James Birrell

Yes, I want to help The James Fund!

Name: _____

Address: _____

City: _____

Country: _____ Postal Code: _____

Phone: _____

Email: _____

- I would like to make a *One-Time Donation to The James Fund.*
- \$40 \$50 \$75 \$100 other \$ _____
- Enclosed please find my cheque/money order payable to The James Fund, OR.
- Please process my donation on my credit card as below

- I would like to make *Monthly Donations to The James Fund.*
- \$10 \$25 \$50 other \$ _____
(minimum of \$10 for monthly gifts)
- Please withdraw my monthly donation from my chequing account. I have enclosed a blank "Void" cheque, OR
- Please process my donation on my credit card as below

Please read and sign for Monthly Donations:

A single tax receipt for each year's total contributions will be sent at the beginning of the next calendar year. Monthly deductions will be process on the 15th of each month.

I hereby authorize SickKids Foundation to make automatic withdrawals from my bank account or credit card as indicated. I understand that I may cancel this authorization at any time by notifying the Foundation.

Signature: _____

- For Credit Card Donations*
- VISA MC AMEX
- Credit Card Number: _____
- Expiry date: _____ / _____
- Signature: _____



Please mail donations to:

The James Fund

625 Whitaker Street #4, Peterborough
Ontario, CANADA K9H 7L5
diana.birrell@jamesfund.ca

Heatwave Events — Rallying for a Cure

“Our goal is to win the fight against childhood cancer,” says Rosanne O’Neill of Heatwave and Icewave Beach Volleyball Events. It takes real team work to achieve this goal. Together, the players, volunteers and corporate sponsors continue to be leaders in helping to make a difference in the lives of these children with neuroblastoma. In the last three years alone, over \$500,000 has been raised for The James Fund at SickKids from these incredible beach volleyball events. This represents one giant spike towards finding a cure.

www.heatwaveevents.com



Songs for Hope

May 29, 2008

Join Michael Burgess for an unforgettable evening of gourmet food at Romagna Mia Ristorante in Toronto, and perhaps a song or two, along with a glass of wine or two, and learn about the legacy of research inspired by James Birrell, a little boy whose dream was to cure cancer. Wine by FABiano.

Visit www.jamesfund.ca for details.



The Green Train March

As well as James, whose favourite colour is green? None other than Canada’s Armed Forces! Many thanks to our guys (and gal) in green for spending your day off fundraising for The James Fund by marching through Peterborough.

Cathedrals Express

Members of the Peterborough Singers, conducted by Syd Birrell, made several performances at Winchester Cathedral in England. Wowed by the acoustics, scenery, and British hospitality, the group sang to an impromptu audience on the historic Cathedrals Express steam train, raising \$1,000 for The James Fund.

Viper Day

Professional drivers from The Viper Club of Ontario, along with ILR Car Control School, gave both little kids and big kids rides in a sleek, exotic Viper sports car and raised money for The James Fund. Thanks to everyone who came out, including a big fan from Montreal, and our very special neuroblastoma guests from Winnipeg!

James Fund Research Featured to International Scientists

The American Association of Cancer Research hosts the premier international meeting featuring novel cancer therapeutics. Featured in their October, 2007 press release was a drug discovery project funded jointly between The James Fund and Lilah’s Fund.

About Neuroblastoma Research at SickKids

In September of 2007 SickKids distributed a document outlining the status of neuroblastoma research at The Hospital for Sick Children. We are pleased to report that your donor dollars can be found hard at work. This document shows that The James Fund has made a significant contribution to the bank of leading edge research being done globally. The document is available at www.JamesFund.ca



“Ya Can’t Let Cancer Ruin Your Day”

Ronald McDonald House Charities Canada has distributed Syd’s book to all 12 of the RMH’s across Canada, where families staying there will be able to seek comfort and strength when facing a similar challenge that the Birrells faced.

From a neuroblastoma parent: “Syd’s book is incredible. I started handing out copies of the book to everyone I knew and all of a sudden they stopped asking dumb questions. They understood what my family was going through!”

Syd’s book is available at Chapters/Indigo/Smith Coles stores across Canada and online at www.indigo.ca. For bulk book orders contact info@GreenTrainBooks.com

A portion of the proceeds of Syd’s book supports The James Fund.

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The James Fund Advisory Council includes Casey Watson, Ray Hendriks, James Mewett, Diane Wolf, Peter Pula, Jane Ulrich, Pete Lawless, Judy Keith, Greg Anderson, Jennifer Logan, and Syd and Pam Birrell.
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THE JAMES FUND

For Neuroblastoma Research at SickKids

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