



November 2011



A New Partner for C¹⁷ Council

The Ewing's Cancer Foundation of Canada is a charitable foundation that raises funds for research in Ewing Sarcoma to find new and better treatments, and ultimately the cure. On Sunday, August 28, 2011 The Ewing's Cancer Foundation of Canada hosted its 2nd annual Rally for the Cure in Ontario, encompassing a car and airplane rally, launched in memory of Reid Pernica, an aspiring young pilot who lost his battle with Ewing sarcoma in 2007.

As part of their research mandate, the Ewing's Cancer Foundation of Canada (ECFC) has partnered with C¹⁷ Council and the C¹⁷ Research Network to fund a research grant with the goal of improving the survival rate and quality of life of children impacted by Ewing cancer in Canada. The area of research may include clinical trials, disease registries, biological sample banks, quality of life, health outcomes, psychosocial research, or basic and translational research with a direct application into the causes, treatment, cure or quality of life for young people with Ewing Sarcoma.

Under this partnership, ECFC and the C¹⁷ Council will each provide \$25,000.00 per year in funding for a dedicated C¹⁷ Research Network Grant Competition. Funding will be awarded in January 2012 for a total of \$100,000.00 dedicated to Ewing research over 2 years.

Bringing partners such as ECFC and C¹⁷ together on a grant competition is particularly exciting. Small foundations that may not have the capacity to fund larger national projects can rely on C¹⁷ to work across the country, and to match smaller donations. The goal of C¹⁷ is to build capacity in research across Canada; a dedicated competition that is fully integrated with the rigour and standards of the research network and the high standards for scientific review and accountability should produce excellent results. Whether funds such as this go to well established researchers who are already doing Ewing sarcoma research, or whether this funding stimulates new research or partnerships in Canada, this is a win-win for both C¹⁷ and ECFC.

With the partnerships of several foundations, the C¹⁷ Research Network has now partially funded, completely funded or committed to fund 23 research projects for a total of \$2,925,265.00 in grant funds. The foundations now funding our research include:

- Childhood Cancer Canada Foundation
- Coast to Coast Against Cancer Foundation
- Kids with Cancer Society (Edmonton)
- Sandra Sharpe Rhabdomyosarcoma Fund in partnership with CCCF
- Aplastic Anemia & Myelodysplasia Association of Canada
- Optimist International
- Ewing's Cancer Foundation of Canada

Thank you to all our partners who support our national research program!

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C¹⁷ strives to improve health outcomes and quality of life for children and adolescents in Canada with cancer and blood disorders, and to eliminate disparities in care and outcomes wherever they occur



CHILDHOOD
CANCER CANADA
FOUNDATION



kids
with cancer
society

SickKids®
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Public Health
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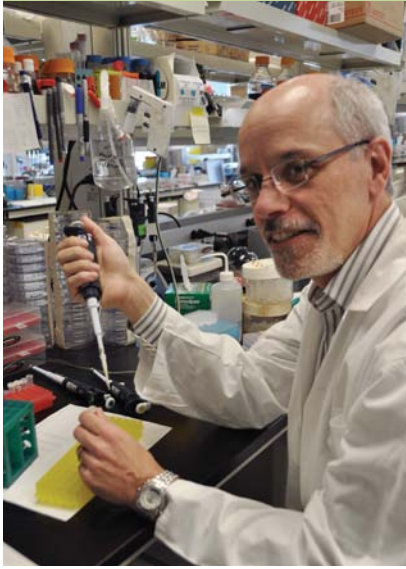
Agence de la santé
publique du Canada

CANADIAN PARTNERSHIP
AGAINST CANCER



PARTENARIAT CANADIEN
CONTRE LE CANCER

THE
EWING'S CANCER
FOUNDATION OF CANADA



C¹⁷ Researcher Dr. David Malkin

In 2009, C¹⁷ awarded a grant, **The Estrogen Receptor Pathway as a Therapeutic Target in Rhabdomyosarcoma** to Dr. David Malkin (Hospital for Sick Children) with funds received from the Sandra Sharpe Rhabdomyosarcoma Fund (SSRF). Rhabdomyosarcoma (RMS) is a relatively rare form of cancer that most commonly affects young children. This cancer forms in the soft tissues of striated muscle, and can occur anywhere in the body, with event-free survival of approximately 50%. In 2008, Sandra Sharpe lost her struggle with this form of cancer. Her friends and family decided to create a fund to support research in her honour. Thanks to their donations, a research competition focused directly on RMS was created. Research into new treatments is important because RMS is a highly malignant tumour which often fails to respond to conventional aggressive multimodal radiation,

surgery, and chemotherapy treatment protocols. Dr. Malkin and his team previously observed two intriguing features of rhabdomyosarcoma (RMS) cells. First, they discovered that RMS cells express a receptor (like a lock) that is recognized by the female sex hormone estrogen (the key to that receptor 'lock'); and second, they showed that exposure of these cells to tamoxifen, a drug commonly used in the treatment of breast cancer, could kill these RMS cells (by preventing the 'key' from opening the 'lock'). With the SSRF grant, Dr. Malkin's team has now worked out the biochemical mechanism by which this tamoxifen-estrogen receptor interaction works. This information is critical to determining how tamoxifen might best be used, together with more conventional forms of therapy for RMS, in the treatment of this disease. Current work in the lab focuses on optimizing the most effective doses and combinations of these agents.

This work represents an example of how an unexpected initial observation leads to the development of a new avenue of possible therapy with a drug that is not considered traditional to the pediatric world.

C¹⁷ Research Network Grants

C¹⁷ Research Network priorities are to fund collaborative research involving multiple centres across Canada; multi-disciplinary research; and to encourage new collaborations and researchers.

The research competition is a two stage process. LOIs are submitted for review by the Committee. Accepted LOIs are invited to submit a grant application or re-submit a LOI for the next review meeting. Grants are reviewed by the Committee and external scientific reviewers. The number of grants funded is determined by funding from the C¹⁷ Council and their partners, and the quality of the grants submitted.

Important Dates for Round 14

- November 1 - LOI submission deadline 4:00 pm (MST)
- End of January - Notification of decision
- April 16 - Grant submission deadline for accepted LOIs
- July - Notification of decision

The Ewings Sarcoma grants will be reviewed in January 2012, with notification of decision in January 2012.

Round 12 - June 2010

Identification of prognostic factors and therapeutic targets in childhood CNS atypical teratoid rhabdoid tumours (ATRT)

Principal Investigator: Dr. Lucie Lafay-Cousin - Alberta Children's Hospital

A study to establish and use a national tumour bank to investigate the ATRT tumour genome with new genetic tools to uncover novel therapeutic targets. In September 12-18, 2011 as part of Childhood Cancer Awareness month, Days Inn donated \$1 to CCC from each guest room sold to support this researcher and her study.

Round 13 - January 2011

Assessing the efficacy of a psychosocial intervention program for siblings of children with cancer.

Principal Investigator: Dr. Maru Barrera – The Hospital for Sick Children

A study to test the benefits of a therapeutic group intervention program for siblings of children with cancer.

What factors do children with cancer and childhood cancer survivors say are important to understanding their quality of life [QOL]? A qualitative study

Principal Investigator: Dr. Anne Klassen and Dr. Samantha Anthony - McMaster

A study to explore quality of life (QOL) from the perspective of cancer patients and survivors in order to gain a full understanding of determinants of QOL as well as QOL outcomes.

Phase I Dose Finding Study for Melatonin in Pediatric Oncology Patients with Relapsed Solid Tumours

Principal Investigator: Dr. Donna Johnston - Children's Hospital of Eastern Ontario

A study to find a pediatric dose of melatonin as an effective treatment for decreased appetite and weight loss, with few side effects, in pediatric patients who have suffered a relapse of their tumour. This study will be conducted by the C¹⁷ DVL Phase I/2 sites across Canada.

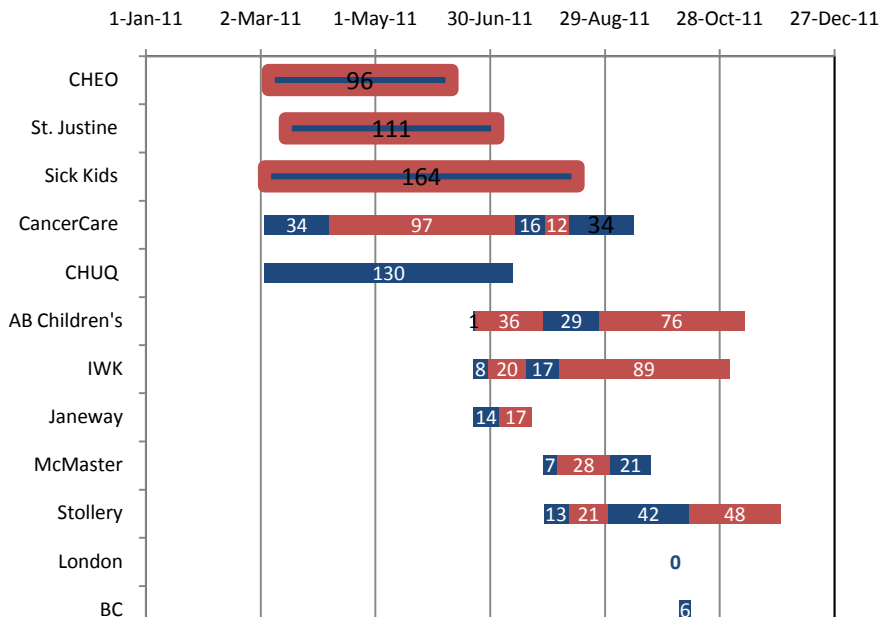
C¹⁷ in Partnership

In partnership with CIHR, C¹⁷ has committed funds to the following grant competitions:

Canadian Pediatric Cancer Genome Consortium - Translating next-generation sequencing technologies into improved therapies for high-risk childhood cancer: \$169,575.00

CIHR Team Grant: Childhood Cancer – Late Effects of Treatment: \$300,000.00

C¹⁷ Clinical Trials Monitoring Program



1. Time to provide cases and monitor names to C¹⁷ office.
2. Time for C¹⁷ to provide protocol worksheet to site.
3. Time to return protocol worksheets to C¹⁷ office.
4. Time for C¹⁷ to provide monitoring worksheets.

After Health Canada Inspections at several sites in 2008-09, C¹⁷ was required to implement a clinical trials monitoring program for research sites to be in compliance with the Health Canada, Food and Drug Regulations, Division 5 "Drugs for Clinical Trials Involving Human Subjects." All centres will be monitored in the 2 years that COG will not be conducting on-site audits. The Monitoring Plan involves a combination of central review of documents in the C¹⁷ office and onsite monitoring by arm's length CRAs at the sites, who have received training through C¹⁷ workshops, COG or other recognized monitor training. The program started as a pilot program in 4 centres (Kingston, Stollery, BCCH and Regina) and has now been initiated in most COG centres.

In January 2012, Dr. Jacqueline Halton, the Senior Medical Officer, Susan Devine from Sick Kids and the C¹⁷ regulatory staff will work together to identify gaps, errors or issues with the program, with a goal of developing Version 2 of the monitoring program. Any feedback from your experience is welcome; please email comments to Tracy Mudri in the C¹⁷ office.

C¹⁷ has also signed an agreement with Therapeutic Advances in Childhood Leukemia & Lymphoma (TACL) to start sponsoring and monitoring the TACL protocols in Canada. Currently Sick Kids, Alberta Children's Hospital and BC Children's Hospital belong to TACL. Other cooperative groups will be added to the monitoring program over the next year.

Multidisciplinary Workshop on Care of the Adolescent with Cancer

Presented by the Division of Oncology/Hematology/BMT, Department of Pediatrics, UBC.

Date: May 10-11, 2012

Location: British Columbia Children's Hospital, Vancouver, B.C.

The workshop will focus on understanding the special needs of the adolescent with cancer with discussion on ethical considerations, strategies and interventions to improve the care for this population. Topics will include clinical/scientific knowledge of adolescent growth and development, sexuality and fertility, post traumatic stress disorder, and implications for care through the trajectory of illness and survivorship.

Norma Auger Education Scholarships

The goal of the C¹⁷ Norma Auger Education Fund is to support health professionals involved in pediatric Oncology/ Hematology and BMT across Canada advance their knowledge, skills and experience and to promote presentations and knowledge translation by these health professionals.

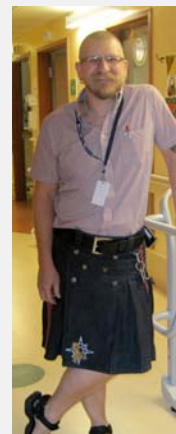
This annual scholarship is offered by the C¹⁷ Education Committee with funding from the Childhood Cancer Canada Foundation and the Coast to Coast Against Cancer Foundation. It is named in honour of Norma Auger, a Leader in nursing children with cancer in Canada.

The 2011 recipients are:

Emily Murray, Susara Joubert, Stephanie Cox, Mary Lou Hurley, Mary Jean Howitt, Jennifer Keis, Janie Lappan, Cindy Stutzer, Brent Hartemink, Billie Dawn Murray and Agnes Piotrowski.

All Norma Auger Scholarship awardees who have presented to their professional peers at a conference, are also asked to present on a national C¹⁷ videoconference.

Kilted for Kids Cancer



Bruce Crooks is a huge hit with the adolescent cancer patients at IWK when he wears his Alt-Kilt. Teenagers never knew doctors could be so cool!

Order your own Alt Kilt at www.altkilt.com

Alt-Kilt.com is a big supporter of kids' cancer, and in September, they gave away kilts for free. Each had a Kilted for Kids' Cancer screen printed on the front apron. They also collect donations for Give Kids The World (GKTW) <http://gktw.org/> with the choice to write in a donation amount with your order of a kid's kilt.

For adult kilt fans, they offer a selection of T-shirts, accessories and the addition of the Kilted for Kids' Cancer logo screen print to an Alt.Kilt order.



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Sears National Kids Cancer Ride Relay Team

The Sears National Kids Cancer Ride is one of the biggest and most ambitious charity cycling events on behalf of childhood cancer in the world. The event began in Vancouver on September 7 and finished in Halifax 16 days later on September 22, 2011.

C¹⁷ is proud to be a part of this fundraiser and especially the relay riders: Mason Bond and Kathy Brodeur-Robb (Vancouver-Calgary); Melissa Johnson (Calgary-Winnipeg); Katrin Scheinemann (Thunder Bay-Toronto); Yves Pastor (Toronto-Quebec); Nicole Mikhael (Quebec-Halifax).

Our goal is to try and have 100% of C¹⁷ members donate!

www.searsnationalkidscancerride.com/en/donate/index.php



Peds OPAL – Assessing Workload Complexity

The Peds OPAL concordance study is now completed. The aim of the study was to confirm the reproducibility of a pediatric oncology clinical study workload complexity measure. The data are currently under review and the study results will be submitted for publication. Two additional studies are in the planning stages. One will look at optimal score ranges in oncology and another to determine if the instrument could be used in other pediatric sub-specialty clinical research.

C¹⁷ Guidelines Committee

Formerly known as the C¹⁷ Standards and Guidelines Committee, they are now known as the C¹⁷ Guidelines Committee. You will now find the results of all of their hard work (developed and endorsed guidelines) under a separate tab on the public side of the C¹⁷ website. To facilitate access and working with other national organizations, this area of the website will be our official depository of C¹⁷ guidelines. Many more guidelines are in development through the formal, rigorous and evidence-based process that committee members have been trained in.



CYP-C continues retrospective data collection for children under the age of 15, who were diagnosed between 2001 and 2008. The electronic data collection system has been installed at all 11 centres, and data is being collected on paper forms as well. With over 700 cases entered nationally, and another 1000 cases collected on forms, it is well on the way to becoming a national, population-based, cancer surveillance system for children and youth. In addition to REB approval for prospective data collection, there is a need to develop methodologies for analyzing CYP-C data. Proposals from Canadian Investigators or ideas on how they will use the data and what type of reports they would like to see generated is encouraged.