



Planning and Growing: The Next 10 Years

C¹⁷ has had some big new and exciting things happen in the past few months; great timing as we move through the process of planning and dreaming about the next 10 years!

In March 2012, Childhood Cancer Canada sent us a cheque for \$250,000.00 that will be used for childhood cancer research priorities in C¹⁷. The funds were raised in partnership with the St. Baldrick's Foundation through head-shaving events held in Canada and will be used to fund projects in the June 2012 research grants competitions.

The C¹⁷ DVL group is participating in an industry-sponsored trial in a very hard to recruit patient population. The first patient has been enrolled at one of our sites.

The first fully supported C¹⁷ study is about to start. The protocol "Phase 1 Dose Finding Study for Melatonin in Pediatric Oncology Patients with Relapsed Solid Tumors" was written by Donna Johnston, funded through an application to the C¹⁷ Research Network, and will be sponsored and monitored by the C¹⁷ Regulatory Office. Once approved by the Health Canada Natural Health Products Directorate and each local ethics board, sites can start enrolling patients. We also hope to have a web-based database for sites to enter data.

The Sears National Kids Cancer Ride will have a C¹⁷ team again this September. Lesleigh Abbott, a Fellow at Sick Kids will ride the national ride and will be joined by several C¹⁷ relay members. Coast to Coast has donated \$3.2 million into C¹⁷ research programs over 4 years!

In the Canadian Cancer Society's Top CCS-funded research stories of 2011, we had a pediatric oncology researcher: David Malkin (Sick Kids). The research team found that a new cancer surveillance protocol dramatically improves survival for adults and children with Li-Fraumeni syndrome, a hereditary disease that significantly increases a person's susceptibility to cancer. Those under surveillance had a 100% survival after cancer was detected; those not under surveillance had a 21% survival rate. The article was published in The Lancet Oncology.

We now have insurance to sponsor studies in Canada, and several smaller cooperative groups are asking for our assistance. By filing Clinical Trial Applications with Health Canada and monitoring studies for compliance with Canadian regulations, we are enabling more sites to join the cooperative groups and providing increased access to new therapies across Canada. We support COG, DFCI, TACL and C¹⁷, and are exploring the issue with 3 more groups.

CIHR announced The Late Effects of Childhood Cancer Treatments Initiative on April 10, 2012 (photo above). Four pediatric oncology teams led by Shinya Ito (Sick Kids), Paul Nathan (Sick Kids), Kirk Schultz (BC Children's Hospital) and Daniel Sinnett (Ste. Justine) will receive funding of \$12 million over 5 years. CIHR partnered with the Garron Family Cancer Centre at The Hospital for Sick Children, C¹⁷ Council, Canadian Cancer Society, Cancer Research Society, Ontario Institute for Cancer Research and Pediatric Oncology Group of Ontario to fund them.



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Photo above courtesy Creative Services Studio, Sick Kids

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





C¹⁷ Researcher Lesley Mitchell

In 2008 C¹⁷ awarded a grant, **Relationship of Prothrombotic Markers to Thrombosis in Survivors of Childhood Cancer** to Lesley Mitchell (University of Alberta) with funding from Childhood Cancer Canada. In collaboration with C¹⁷ pediatric centres across Canada, Mitchell has identified 4 novel biomarkers that are associated with increased risk for thrombosis in children with cancer (Journal Thrombosis Haemostasis 2011 Vol 9 s2). One biomarker is a single nucleotide polymorphism (SNP) in the MTHFR gene that has never been associated with thrombosis in adults or children. These findings may indicate that this SNP is a unique identifier of thrombotic risk in pediatric cancer. Another biomarker is a protein that can easily be measured in blood samples in a hospital lab. The study showed that younger and older children are at an increased risk for thrombosis, which is another novel observation. Mitchell showed that when these

children are treated with the chemotherapeutic agent asparaginase, it puts them at an increased risk for thrombosis.

Results from this study led to a new successful CIHR team grant Applying **Biomarkers to Long-term Effects in Child and Adolescent Cancer Treatment (ABLE Team)** in June 2011; Mitchell is a Principal Investigator. The total funding is \$4,337,000 over five years. The concept of the grant is to build on the findings from the C¹⁷ funded study to identify additional biomarkers for risk of thrombosis with the aim of prevention of long term adverse outcomes in high risk patients. In the final year of funding, Mitchell will be embarking on a pilot intervention study where the children at increased risk for thrombosis, as determined by measuring biomarkers, will be treated with anticoagulation to attempt to safely prevent thrombosis. The results of the C¹⁷ and CIHR funded study is imminently translational, leading to better care of children with cancer. This highlights the strengths of a Canadian network of clinical pediatric oncology researchers supported by C¹⁷.

The study has recruited the largest cohort of survivors of childhood cancer who have had a thrombotic event in the world. We have plasma and DNA banked at the PI's lab at the University of Alberta. These samples can be shared with other investigators for research into thrombosis in a collaborative manner

C¹⁷ Grant Programs

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

C¹⁷ DVL Preclinical Grants are designed to fund pre-clinical work on drugs that have a high probability of translation into Phase 1 trials.

C¹⁷ Targeted Grant competitions support a target idea when we receive specific funding. Currently, we are supporting research in Ewing Sarcoma. Previously we funded grants in rhabdomyosarcoma and aplastic anemia/MDS.

C¹⁷ Education Grants fund educational research, KT, educational interventions or teaching. Preference is given to projects with the potential to be easily transferred across Canada.

C¹⁷ Senior Medical Officers

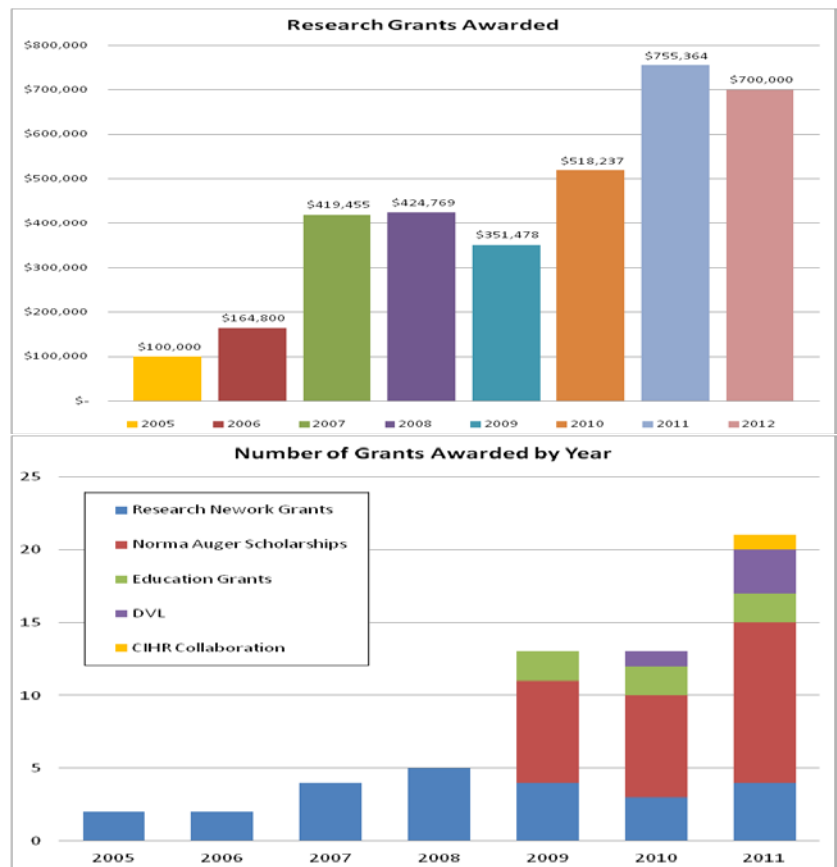
COG and DFCI protocols

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TACL and C¹⁷ DVL protocols

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C¹⁷ Research Funding and Grants 2005 - 2011



Above is a summary of the funding and numbers of grants that have been awarded by C¹⁷ since 2005. Expanding numbers of grant recipients and dollars awarded, and the capacity of our collaborative partnerships have made these programs extremely successful. The C¹⁷ Council, Executive, Co-Chairs and committee members have been discussing and planning goals and directions for the next 10 years.

Teen Connector 2.0 from Childhood Cancer Canada

Childhood Cancer Canada (CCC) has launched Teen Connector 2.0, its new and improved online connectivity site for teens with cancer. Teen Connector is the only connectivity site of its kind, providing a unique mentorship component allowing teens with cancer to interact with young childhood cancer survivors who provide both hope and guidance during this very difficult time. This website provides a safe and confidential platform where teens in treatment can connect with other teens with cancer, and with young mentors. Teens can connect at any time and from even the most remote parts of the country with their peers, allowing them to share their journeys, and provide support to one another. CCC wants to raise awareness nationwide about this Program to encourage as many teens, between the ages of 13 and 19 with cancer to get online and start connecting.



Please refer teens to the Teen Connector website at teenconnector.ca where they can register as a 'Teen.' Registration is quick and easy! If you are interested in distributing Teen Connector cards or if you would like additional information on the Teen Connector Program, please contact Dana Stanescu at dana@childhoodcancer.ca

C¹⁷/CPAC Adolescents and Young Adults: Improving Outcomes

The C¹⁷/CPAC AYA Improving Outcomes Conference was held March 29 -30, 2012 in Toronto with over 100 clinicians, researchers, survivors and policy makers in attendance. Thursday morning included: presentations by the Task Force leadership; a panel discussion about the 6 priority areas identified by the 2010 meeting (Journal of Adolescent and Young Adult Oncology, April 2011, 1(1): 53-59); and case studies provided by international AYA colleagues. The second day of the conference was meant to be very practical with attendees assigned to provincial/regional breakout sessions to start getting provincial plans developed. The final take away from the Friday planning meetings was that all the AYA advocates in each province across Canada should have meetings in September to develop plans for moving forward. We were also reminded by Jessica Hill from CPAC... Don't try to "boil the ocean", let's get some early initiatives started and share best practices as we move forward.

The 6 recommendations highlight the need for age appropriate psychosocial, survivorship, palliative and medical care as well as research to address the care of AYAs in Canada.

The Task Force on AYAs with Cancer, started in 2008, is led by Co-Chairs Ronnie Barr (McMaster), Paul Rogers (BC Children's) and Brent Schacter (CancerCare Manitoba). They are developing a new strategic plan for the next 5 years which will include providing support to the regional action partners (RAP's) as they move the AYA agenda forward, with the continuing support of C¹⁷ and CPAC/Health Canada.



CYP-C electronic data collection is now installed at all centres and the national database is growing rapidly. In addition to retrospective data collection, 5 centres have now received REB approval to start collecting data prospectively.

Another successful CRA training session was held in February 2012 in Ottawa with good feedback and enthusiasm about the project. The first research application to use the data has also been received and is under review. The first on site data quality monitoring has been performed and additional sites are to be scheduled over the coming year.

C¹⁷ in Partnership

C¹⁷ has committed funds to the following:
ANR 2012: Advances in Neuroblastoma Research: \$15,000.00 Gold Sponsorship.

15th International Symposium on Pediatric Neuro-Oncology (ISPNO): \$15,000.00 Silver Sponsorship.

Canadian Association of Psychosocial Oncology Conference: Invited international speaker for a pediatric session at CAPO, up to \$1600.00 for expenses.

Norma Auger Scholarships

The C¹⁷ Norma Auger Education Fund supports health professionals involved in pediatric Oncology/ Hematology and BMT across Canada to advance their knowledge, skills and experience and to promote presentations and knowledge translation.

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

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.

Next Deadline: May 11, 2012

Application is available at www.c17.ca



Children's Cancer
& Blood Disorders

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4th Annual C¹⁷ Pediatric Fellows Conference

The 4th Annual C¹⁷ Pediatric Hematology/Oncology Career, Educational and Scientific Development (PHOCESD) Symposium was held in Niagara-on-the-Lake April 12-14, 2012. Thirty fellows and eight program directors from across the country, plus seven guest faculty, spent an intensive two days together learning and teaching each other everything from transfusion cards and osteosarcoma risk with water fluorination to publication tips and career planning. We were able to enjoy the sunny weather in an outdoor classroom, while colleagues in Alberta were under snow, and to brainstorm the future of Ped Hem/Onc education for the country. While some of us were better than others with linguine and penne, we all enjoyed the opportunity to meet and share ideas and experience. Thank you to C¹⁷ for this invaluable time together!



Inside Rides by Coast to Coast

Coast to Coast Against Cancer Foundation will once again be holding Inside Rides across Canada with the Sears National Kids Cancer Ride. Funds raised stay with your local foundation; so encourage them to hold an event and put a Peds Hem/Onc team together!

Implementing a Pediatric Oncology program in Botswana

Currently children with a malignancy in Botswana (population 2 million) are treated at the Princess Marina Hospital in Gaborone (capital). Due to the lack of resources – for parts of the year coverage is provided by a pediatric oncologist from Texas Children's Hospital, otherwise care is provided by pediatricians – quite a number of children are treated in South Africa. The purpose of this project is to implement pediatric oncology in Botswana with a training and education program for nurses/ pharmacists/ physicians and other health care professionals.

Goals are optimization of diagnostic tools, implementation of standardized evidence-based and



feasible treatment protocols which would allow for earlier diagnoses, reduced toxicity and improved outcomes. A cancer registry and a self sustaining twinning program with 2 academic pediatric oncology centers in Johannesburg (Johannesburg General Hospital and the Chris Hani-Barawanath Hospital) will be established.

Health Canada Inspection Report: What did they find?

C.05.010 (c) – quality systems and procedures in place for all aspects of the trial

C.05.012 (1) – record, handle and storage of all information

C.05.010 (b) – clinical trial conducted in accordance with protocol and regulations

C.05.010 (g) – qualification, education and training of staff

Conclusions from the 2011 Health Canada report released in March 2012 are:

2004-2011 – 3148 observations noted – 54% minor; 39% major; 1% critical (remaining 6% were findings against REBs)

1. Highest numbers of observations pertain to inadequate documentation/ implementation of systems (26.7%)
2. Second highest numbers of observations pertain to inadequate record retention (25.4%)
3. Other significant deviations relate to informed consent and inadequate personnel qualifications, education and/or training