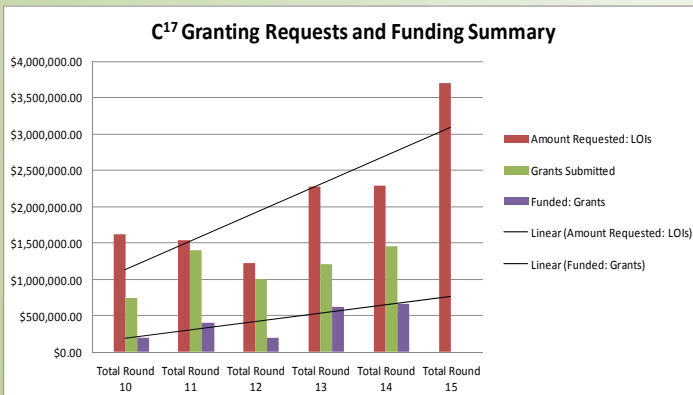


## Energy and spring!

Bring them both to the C<sup>17</sup> Annual General Meeting in Canmore, Alberta on June 4-7, 2013. The C<sup>17</sup> Council, Research Grants panel, the Developmental Therapeutics Network, Education, Guidelines, Regulatory and Human Resources committees will meet. As well, the Canadian Pediatric Brain Tumour Consortium will hold a meeting in conjunction with the C<sup>17</sup> AGM. As we organize and plan for the next 10 years of the C<sup>17</sup> Council, we hope that you will join us with plenty of ideas.

One agenda item for discussion for the future will be matching dollars to the research need and capacity in Canada. For several years we have seen an increase in the number of grants, the quality of grants and the opportunities for partnering with other organizations such as CIHR, smaller foundations, and the Canadian Partnership Against Cancer. We have had a long-standing productive partnership with Childhood Cancer Canada, who have supported



the mission of C<sup>17</sup> since it's inception.

Taking a look at the graph, there has been an increase in both Letters of Intent and grants, as well as funding, but as

you can see, the gap is widening. Our goal, over the next few years, is to work together to fund all scientifically sound research projects that will provide us with better outcomes for the children with cancer and serious blood disorders in Canada.



## Inside This Issue

C <sup>17</sup> AGM	Page 1
Dr. Paul Steinbok Grant	Page 2
SPIRIT Initiative	Page 2
C <sup>17</sup> Research Grant Panel	Page 2
TACL Studies in Canada	Page 3
DVL Relapse Registry	Page 3
Ewings Grant Update	Page 3
Norma Auger Scholarships	Page 3
CYP-C	Page 4
International Development	Page 4
C <sup>17</sup> Guidelines	Page 4
C <sup>17</sup> Communities of Practice	Page 4

*C<sup>17</sup> 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.*



## C<sup>17</sup> Researcher Dr. Paul Steinbok

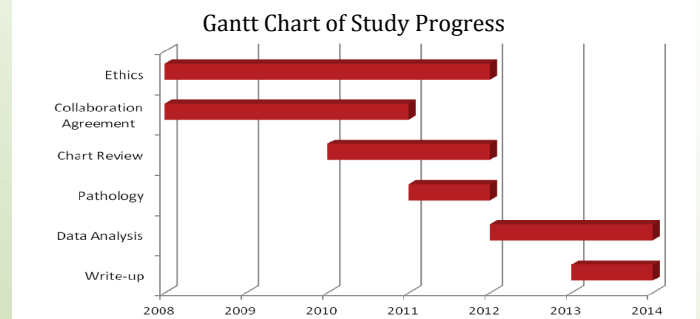


Dr. Paul Steinbok (BC Children's Hospital) was awarded a C<sup>17</sup> grant in 2009 with matched funding from the Brain Tumour Foundation of Canada for **Thalamic Tumours in the MRI Era**. The goal of the study was to conduct a comprehensive retrospective clinical analysis of patients with thalamic tumours treated at pediatric neurosurgical centres in Canada over the

last 20 years - a time period during which Magnetic Resonance Imaging (MRI) scans were available. His study included 11 C<sup>17</sup> sites.

All sites have now submitted their study data and samples for central pathology review. Analysis has been completed for 75 completed case reports and radiology samples, and a total of 65 pathology samples have had central pathology review. It was found that more than half had one form of astrocytoma.

Astrocytoma is a malignant tumor of nervous tissue composed of well-differentiated astrocytes (star-shaped brain or spinal cord cells). A tissue microarray is under construction which will include the astrocytoma cases with sufficient material. Astrocytomas will be characterized for genetic BRAF fusion status and H3.3 mutation status. This will allow for better patient and physician education, which may improve patient's quality of care and quality of life.



### Life Cycle of a Grant

*Ever wonder how long it takes to conduct a research study and get the results published so that practices can change? Here is a record of the time it is taking for this research study.*

***Hopefully this information will help us better understand how these tumours behave and grow. Researchers may be able to find out positive or negative factors related to patient's prognosis and help improve patient care and quality of life.***

### C<sup>17</sup> Research Network Committee

- Dr. David Malkin**, Chair
- Dr. Stephen Robbins**, Vice-Chair,  
Translational Research
- Dr. Donna Wall**, Stem Cell Transplantation
- Dr. Josee Brossard**, Small Centre  
Representative
- Dr. Mary McBride**, Epidemiology
- Dr. David Dix**, Clinical Research, Oncology
- Dr. Anthony Chan**, Clinical Research,  
Hematology
- Dr. Isabelle Montour-Proulx**, Outcomes/  
Quality of Life—Psychology
- Dr. Anne Klassen**, Qualitative Research/  
Health Services Research
- Dr. Jason Berman**, Basic Laboratory  
Research
- Dr. Nada Jabado**, Basic Laboratory  
Research
- Ms. Lynn Russell**, Data Management—  
Clinical Research Coordinator

### SPIRIT 2013 Statement: Defining Standard Protocol Items for Clinical Trials

An-Wen Chan, MD, et al.  
*Ann Intern Med.* 5 February 2013;158(3):200-207

#### ABSTRACT

The protocol of a clinical trial plays a key role in study planning, conduct, interpretation, oversight, and external review by detailing the plans from ethics approval to dissemination of results. A well-written protocol facilitates an appropriate assessment of scientific, ethical, and safety issues before a trial begins; consistency and rigor of trial conduct; and full appraisal of the conduct and results after trial completion.

In response to gaps in protocol content and guidance, the SPIRIT (Standard Protocol Items: Recommendations for Interventional Trials) initiative was launched in 2007. This aim is to improve the completeness of trial protocols by producing evidence-based recommendations for a minimum set of items to be addressed in protocols. The SPIRIT 2013 Statement includes a 33-item checklist that applies to clinical trial protocols and focuses on content rather than format. An associated explanatory paper (SPIRIT 2013 Explanation and Elaboration) details the rationale and supporting evidence for each checklist item, along with guidance and model examples from actual protocols.

The C<sup>17</sup> Regulatory Office acts as the sponsor of the TACL clinical trials in Canada. There are currently 3 TACL sites in Canada; Sick Kids, BC Children's Hospital and Hôpital Sainte Justine. Over the past 2 years the following studies have opened or are in process of opening in Canada:

**T2008-002** A Phase I Trial of NECTAR (Nelarabine, Etoposide and Cyclophosphamide in T-ALL Relapse): A Joint Study of TACL and POETIC.

**T2008-004** A Phase I Trial of Temsirolimus in Combination with Etoposide and Cyclophosphamide in Children with Relapsed Acute Lymphoblastic Leukemia and Non-Hodgkins Lymphoma (On hold)

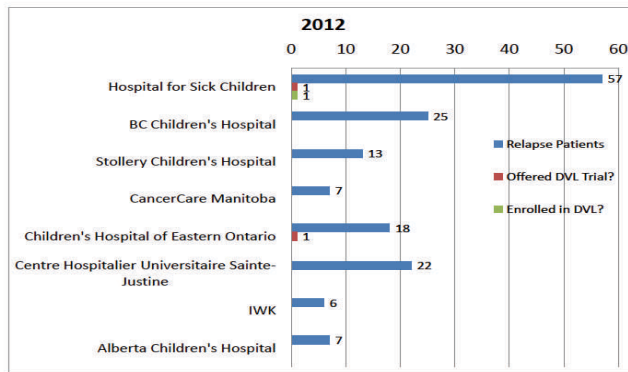
**T2009-008:** A Phase I Study of GNKG168 in Pediatric Patients with Acute Lymphoblastic Leukemia or Acute Myeloid Leukemia (Pending)

**T2009-012** A Phase I Study Dose Finding Study of Panobinostat in Children with Refractory Hematologic Malignancies (Pending)

**T2011-002** A Study of 5-Azacytidine in Combination with Chemotherapy for Children with Relapsed or Refractory ALL or AML (Pending)

### Relapse Registry Summary

The DVL committee started collecting information on numbers and types of relapse patients in Canada just over 1 year ago. The goals are to identify the needs and types of DVL trials that this patient population requires, and to identify how many studies we can support and should be actively searching for, or developing in Canada. As the summary of the first year shows, we need to develop more capacity to provide access to investigational trials all across Canada.



### Norma Auger Scholarships

#### 2012 Recipients

- **Naomi Evans, BCCH**  
International Symposium of Pediatric Neuro-Oncology, Toronto ON
- **Andrea McKinnon, BCCH**  
World Hemophilia Congress, Paris, France
- **Cindy Stutzer, BCCH**  
APHON 36<sup>th</sup> Annual Conference, Pittsburgh PA
- **Lyn Limoges, CHEO**  
SIOP London, UK
- **Patricia McCarthy, CHEO**  
Grounded Theory Jamboree, Calgary AB
- **Kristina Chapman, IWK**  
SIOP, London, UK
- **Cheryl Covey, IWK**  
APHON 36<sup>th</sup> Annual Conference, Pittsburgh PA
- **Amy Long, IWK**  
APHON 36<sup>th</sup> Annual Conference, Pittsburgh PA
- **Cecily Bos, McMaster**  
World Hemophilia Congress, Paris, France

### Education Grants

#### 2012 Recipients

**Patricia McCarthy, CHEO**  
Inuit Children's Book about Cancer

**Isabelle Sjoberg, CHEO**  
Impact of School Visits on Siblings of Children with Cancer

#### 2011 Recipients

**Janine Piscione, Sick Kids**  
Implementation and Evaluation of the Beanstalk Program on the Haematology/Oncology/BMT Program at SickKids

**Marta Wilejto, Sick Kids**  
Professional Skills Development: A Program to Develop Non-Medical Expert CanMEDS Roles for Pediatric Hematology-Oncology Fellows

*Watch the C<sup>17</sup> website for applications for educational grants in Spring 2013!*

### C<sup>17</sup> Videoconferences

**Parental Stress with Caregiving**  
Dr. Anne Klassen, McMaster University  
Wednesday, March 20, 2013, 2:00-3:00 EST

• **Physiotherapy in Oncology**  
Ms. Anne Rankin, UBC  
Wednesday, April 17, 2013, 2:00-3:00 EST



submitting their first manuscript showing the role of the Y Box-1 binding protein (YB-1) in Ewing sarcoma metastasis. They have seen that these cancer cells spread to the tail and the lungs in both fish and mouse models when YB-1 is expressed, and that there is an absence of this spread when YB-1 is suppressed. They are optimizing the doses of standard chemotherapy agents used in Ewing sarcoma and will test



**Dr. Jason Berman, IWK**

whether YB-1 expression affects the response to these drugs. They are studying bevacizumab in zebrafish xenografts to look at the effect of blocking blood vessel growth on tumour formation. In addition, they are studying a new compound that blocks the focal adhesion kinase protein (FAK), which can stop Ewing sarcoma cell proliferation. Their studies promise to provide new insights into the mechanisms underlying the aggressive behaviour of Ewing sarcoma and potential novel targets to interfere with this process.

### Ewings Grant Update

Since August of 2012, Drs. Jason Berman and Poul Sorensen have made excellent progress on the Ewings Cancer Foundation funded project in zebrafish



**Dr. Poul Sorensen, BC Cancer Research Centre**



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Website: [www.c17.ca](http://www.c17.ca)

## CYP-C

Across Canada, C<sup>17</sup> centres began retrospective data collection starting with year 2001 and are currently entering data in the national database from 2004 right up to 2011 at some sites. New cases are continuously being added. Currently, data quality checks and on-site monitoring are ensuring that data is collected consistently and accurately. Next steps are to develop reporting functions so that the data is accessible and useable. IWK is developing several standard reports with the goal of sharing the templates with other institutions. Reports will include:

1. Survival analysis curves
2. Contact delays
3. Late effects pamphlet
4. General query builder

## Success: A new Ped Onc Nursing Curriculum for Developing Countries

A pediatric oncology nursing curriculum has been developed by the South African/Vancouver Initiative. Nurses at Johannesburg General Hospital (JGH) in South Africa put on a local, very well-received workshop for medical professionals in the peripheral and rural areas of Johannesburg. As a result, the Childhood Cancer Foundation of South Africa has decided to fund a full time nursing position to provide pediatric oncology nursing education at hospitals outside of Johannesburg.



Busi, the clinical resource nurse taking on this position, will continue to work with the nurses at JGH on the curriculum and will use it in communities that do not have access to this education. It is expected that this initiative will raise awareness of pediatric oncology in these communities so that signs and symptoms are recognized sooner by all medical professionals

## New C<sup>17</sup> Guidelines

C<sup>17</sup> has recently endorsed two guidelines following a formal evaluation by the C<sup>17</sup> Guidelines Committee and stakeholder feedback from the tertiary centres:

**International Guideline for the Management of Fever and Neutropenia in Children with Cancer and/or Undergoing Hematopoietic Stem Cell Transplantation (2012)** The complete guideline, a short version (published in the *Journal of Clinical Oncology*) and supporting materials are available at: <http://www.sickkids.ca/HaematologyOncology/IPFNG/index.html>

**The Pediatric Oncology Group of Ontario Guideline for the Prevention of Acute Nausea and Vomiting Due to Antineoplastic Medication in Pediatric Cancer Patients (2012)** A condensed version of this guideline has been accepted for publication in *Pediatric Blood and Cancer*. The complete guideline and a summary version are available at: <http://www.pogo.ca/healthcare/practiceguidelines/acuteainvguideline/>

The C<sup>17</sup> Antifungal Guideline Panel has completed a **Guideline for Primary Antifungal Prophylaxis for Pediatric Patients with Cancer and Hematopoietic Stem Cell Transplant Recipients**. Its release is pending journal publication.

## C<sup>17</sup> Communities of Practice

Communities of Practice, or CoPs, are collaborative groups that rely on bottom-up rather than top-down social structures for integrating knowledge across regions and agencies. Members of a CoP have a shared practice to talk about, which can both improve practice and decrease frustration levels.

**C<sup>17</sup> Pharmacy CoP:** Started in Feb'11, and meets monthly

**C<sup>17</sup> CRA CoP:** Started Nov'12, still in startup phase, next meeting Mar'13

There is interest in two new C<sup>17</sup> CoPs that could get started if there is interest: pediatric psychologists/ neuropsychologists and Physiotherapy / Rehabilitation. If you are interested, send us an email.

## Resources

The Public Health Agency of Canada is offering hard copies of the publication title "*This Battle Which I Must Fight: Cancer in Canada's Children and Teenagers*". English and French copies can be directly ordered through the PHAC website or these links: [English](#) [French](#)

## Best Practices for Health Research Involving Children and Adolescents

The guide for health researchers and Research Ethics Boards in the context of pediatric research has been finalized and released by the Centre of Genomics and Policy and MICYRN (2012).

