Children's Cancer & Blood Disorders

June 2013

Welcome to the Next 10 Years!

In June 2013 we will hold our Annual General Meeting and committee meetings. This is the opportunity to bring together our standing committees and to introduce new groups and individuals to the work that C^{17} does. For the first time, the C^{17} DVL committee will be holding a meeting at the AGM. The DVL group is focused on conducting and funding preclinical and early phase I/II clinical trials in Canada. With only 1 COG Phase 1 centre in Canada (Sick Kids), and the regulatory requirements for clinical trials in Canada, this committee is developing Phase I/II studies in 8 centres. This involves working with NCIC Clinical Trials group (IND 203, 206, 212 trials), conducting pharmaceutical trials (BMS), supporting other cooperative groups (TACL, PBMTC), writing protocols for funding in the C^{17} research grant competition (Melatonin, TOPAZ—pending review) and joint protocol development (ITCC).

The key to successfully supporting COG and the C^{17} DVL trials in Canada is monitoring. Clinical trials supported or sponsored by C^{17} must be monitored according to Division 5 Health Canada regulations and GCP ICH guidelines. We achieve this through a combined central and peer-to-peer monitoring system. COG sites are monitored by the regulatory office in the 2 years between their COG audits. This year, 12 of 16 sites are being monitored. We are working with DFCI to review the French informed consents and will monitor all three sites. Plans for monitoring other affiliated cooperative groups (TACL, PBMTC, Histiocyte Society, ITCC, Headstart) and the C^{17} melatonin study are under development.

At the June 2013 AGM we will also appoint our new Executive Board. This board has expanded the number of officers and opened up executive positions to non-MDs. This is in keeping with our broad mission for all health care professionals working in pediatric hematology, oncology and BMT.

Thank you to the sponsors of our AGM, Childhood Cancer Canada, Hospital for Sick Kids Foundation and Kids Cancer Care Foundation in Calgary.

Inside This Issue

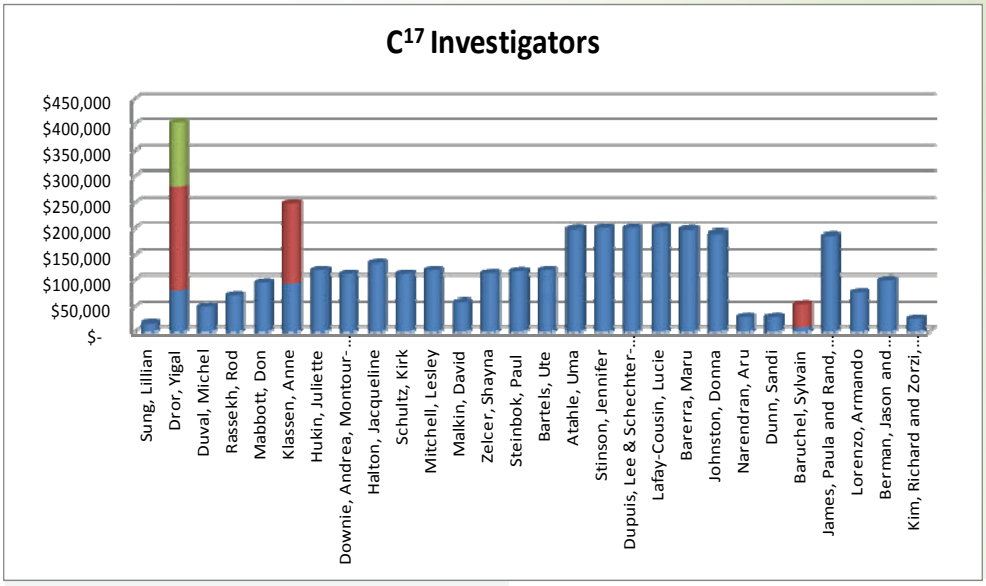
C^{17} strives to improve health outcomes and quality of life for children and adolescents in Canada with cancer and blood disorders, and to eliminate disparities in care and outcomes wherever they occur

C17 Researcher Profile

Dr Yigal Dror
The Hospital for Sick Children

Dr. Yigal Dror leads The Canadian Inherited Marrow Failure Registry (CIMFR) a multicentre longitudinal study involving 17 centres and he has held more C17 grants than any other researcher. The aim is to shed light on the clinical characteristics and biological mechanisms of blood diseases that affect blood cell formation and carry a very high risk of cancer. He received his first C17 grant in 2005 in Round 1, the first year we gave awards. The first one "**Defining the Clinical Phenotype of Inherited Marrow Failure Syndromes and the Risk Factors for Severe Hematological Complications and Cancer by the Canadian Inherited Marrow Failure Registry"** set the base for future studies. Its successes included the establishment of a blood and marrow sample bank for future fundamental and translational research. His second C17 grant, "**Characterization of myelodysplastic syndrome secondary to inherited marrow failure syndromes and the spectrum of inherited marrow failure syndromes through the Canadian Inherited Marrow Failure Registry (CIMFR)"** was funded in 2009. This study was successful in achieving it's two aims: to characterize the spectrum of novel and previously categorized syndromes with inherited bone marrow failure and to determine the outcome and unique features of IBMFS-related MDS. The 3rd C17 grant was funded in November 2012. This study, "**Bone Marrow failure-causing alleles in Canada and genotype phenotype correlation"** will continue to answer research questions related to the genetics of bone marrow failure, and develop a new diagnostic tool that will improve clinical care in the future.

They have published 5 academic papers and presented 9 abstracts.



C17 Education Grants

In 2011, C17 education grants were awarded by our Education Committee to Dr Marta Wilejto and Janine Piscione, both from Sick Kids in Toronto.

- **Janine Piscione** developed and created components for their Beanstalk program. They secured materials, including books, toys, music and equipment such as mats, feeding chairs and benches. They created novel and multi-disciplinary family educational materials addressing developmental issues for children hospitalized over the long-term. The program is currently ongoing at the Hospital for Sick Children.
- **Marta Wilejto** developed non-medical expert CanMEDS roles for Ped Hem-Onc fellows. They ran their official curriculum in 2011-12, some sessions in 2012-13 and plan to run it again in 2013-14. They concluded that developing a learner-centered curriculum in a sub-specialty fellowship program is feasible and well received by trainees.

CCRA ACRC
Canadian Cancer Research Alliance • Alliance canadienne pour la recherche sur le cancer

The Canadian Cancer Research Alliance (CCRA) has committed to posting all funding opportunities from their member organizations on their website. The funding opportunities information is now available on the CCRA web site:

English – http://www.ccra-acrc.ca/index.php/funding-opportunities

French – http://www.ccra-acrc.ca/index.php/fr/possibilites-de-financement

ISCT Initiative

The Canadian Cancer Research Alliance (CCRA) report on the State of Cancer Clinical Trials In Canada (October 2011) outlined the current threat to the conduct of oncology clinical trials. "Without clinical trials, the outcomes of cancer patients will not continue to improve." The report concluded that cancer clinical trials performance metrics are falling, institutional clinical trials units are under stress, regulatory environment has changed and is more onerous. The Initiative to Streamline Clinical Trials, established in 2013 to encompass all academic clinical trials, is developing a draft Guidance Document to present to Health Canada at a meeting on June 17, 2013. This guidance document hopes to help address the second recommendation in the CCRA report to streamline the clinical regulatory environment for academic and cooperative group researchers. Members of C^{17} involved with drafting the guidance are Kathy Brodeur-Robb and Jackie Halton.

POGO 30 PEDIATRIC ONCOLOGY GROUP OF ONTARIO

COLLABORATING FOR KIDS WITH CANCER SINCE 1983

POGO Quality Indicators

Researchers at POGO have identified, defined and adopted a set of 20 quality indicators, for use across Ontario, which span the trajectory of care from diagnosis and treatment to survivorship. These indicators reflect seven quality dimensions - safety, effectiveness, accessibility. responsiveness, equitability, integration, and efficiency. In developing pediatric oncology quality indicators, they first carried out a systematic review of the literature. This step confirmed that, while isolated indicators exist, there was no (published) pediatric oncology-specific set of quality indicators according to which systems could be evaluated. They then undertook an iterative, methodologically rigorous and labour intensive process which led to the identification and endorsement of 20 quality indicators specific to childhood cancer care delivery and selection of a balanced framework of quality dimensions.

l. Bradley NME, Robinson PD, Greenberg ML, Barr RD, Klassen AF, Chan YL, Greenberg CM. *Measuring the quality of a childhood cancer care delivery system: Quality indicator development.* Value in Health, 2013 [In Press].

2. Bradley NME, Robinson PD, Greenberg ML, Barr RD, Klassen AF, Chan YL, Greenberg CM. *Measuring the quality of a childhood cancer care delivery system: Assessing stakeholder agreement.* Value in Health, 2013 [In Press].

CYP-C: Publication and Data Use

CANCER IN YOUNG PEOPLE IN CANADA PROGRAM
PROGRAMME CANCER CHEZ LES JEUNES AU CANADA

Did you know that all participating CYP-C pediatric oncology centres are custodians of their own data and, within the constraints of their Research Ethics Board and institutional policies, have unlimited access and use of their own data? Talk to your local CYP-C CRA to discover the reporting functions already built into the program. Notification of any publication using the institutional CYP-C data should be provided to the CYP-C Data Access, Use & Publications Committee.

CYP-C Data Access, Use & Publication Guidelines have also been developed to outline the guidelines and procedures for accessing information contained in the national CYP-C database. Contact Randy Barber for a copy at randy.barber@albertahealthservices.ca or by phone at 780-492-7084.

C^{17} Videoconferences

Some C^{17} Education Videoconference presenters have agreed to share their slides.

Visit the C^{17} Education Committee page for these presentations. Powerpoints that are available on the website are:

Late Effects: After Therapy for Childhood Cancer
Dr. Karen Goddard, BCCH
Wednesday, March 20, 2013

The physical therapy treatment of children with rotationplasty: BCCH's experience
Ms. Anne Rankin, UBC
Wednesday, April 17, 2013

Health Canada Clinical Trials

On May 29, 2013, Health Canada announced a new Clinical Trials Database. The Clinical Trials Database will provide to the public a listing of specific information relating to phase I, II and III clinical trials. The database is managed by Health Canada and provides a source of information about Canadian clinical trials involving human pharmaceutical and biological drugs. Here is a link to information about the new Health Canada database:

http://www.hc-sc.gc.ca/dhp-mps/prodpharma/databasdonclin/index-eng.php

Here is the link to the database:
http://ctdb-bdec.hc-sc.gc.ca/ctdb-bdec/start-debuter.do?lang=eng

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EMMY DUFF SCHOLARSHIP FOUNDATION

Recognizing the perseverance of students with Cancer

Emmy Duff was a three time leukemia survivor who lost her battle at 23 in September 2012. She was diagnosed at the age of 7 completing 3 years of chemotherapy at Sick Kids. At 14, the cancer returned and she successfully completed a further treatment protocol. Part way through her second year at Laurier, the disease returned for a third time requiring further aggressive chemotherapy. A fourth relapse occurred during the fall term exams in December 2011. A scholarship in her name is open to Canadian students who have had treatment (or are currently being treated) for cancer currently residing in Canada. Eligible students will have demonstrated an ongoing volunteer commitment to causes that are important to them. Applications for $1500 scholarships for 2013-14 are available at www.emmyduffscholarship.org . Deadline is July 31, 2013.

C17 –CPAC Task Force on Adolescents and Young Adults with Cancer (AYA)

Following up on a very successful stakeholder's workshop in March of 2012, the Task Force released the AYA Framework for Action in August. The Framework includes a plan for new Regional Action Partnerships in all Canada's provinces and territories to take action on implementation of the Task Force recommendations for care of AYA. All RAPs have met at least once as they begin their work, each one crafting a plan about how to make things better for AYA in their jurisdiction. A final report on the Task Force's activities and accomplishments between 2008 and 2012 was released in the early Fall along with a new strategic plan for 2012-2017. The Canadian Partnership Against Cancer has now agreed to provide funding for some work to be done in the next two years, and further funding will be sought with a view to sustaining longer-term efforts to improve care for AYA with cancer and survivors of cancer in childhood, adolescence or young adulthood.

TACL Update

TACL
Therapeutic Advances in Childhood Leukemia & Lymphoma

Currently in Canada we have one TACL study open and recruiting patients:
T2008-002: A Phase I Trial of NECTAR (Nelarabine, Etoposide and Cyclophosphamide on T-ALL Relapse): A joint study of TACL and POETIC.

The Investigators Meeting was held in May for the **T2011-002:** A Study of 5-Azacytidine in Combination with Chemotherapy for Children with Relapsed or Refractory ALL or AML. The NOL has been received from Health Canada

Two studies are pending collaboration from the pharmaceutical companies:
T2009-008: A Phase I Study of GNKG168 in Pediatric Patients with Acute Lymphoblastic Leukemia or Acute Myeloid Leukemia

T2009-012: A Phase I Study Dose Finding Study of Panobinostat in Children with Refractory Hematologic Malignancies.

T2008-004 study was closed in March due to the lack of a sponsor.