Message from the Executive Director: Investing in Research

Investing in research is C17’s top priority. Whether the goal is improving outcomes with new drugs, better use of old drugs, quality of life during or after treatment, making cutting-edge treatments from around the world available to Canadian children, managing late effects of treatment, or teaching doctors, nurses, pharmacists and others about the latest research—C17 puts resources and effort into making it happen.

In collaboration with the Canadian Partnership Against Cancer (CPAC) and Canadian Cancer Research Alliance (CCRA), we track and review a lot of information. The graph below shows all grant funding for childhood cancer in Canada 2005—2010, the incidence of cancers, and mortality. For the most part, Canadian researchers conduct research where there is need—leukemia, brain tumours and neuroblastoma. Delving further, retinoblastoma is a unique hereditary cancer with a significant impact if treated early and has been a focus of research excellence in Canada. But, there is a need for more research in bone and soft tissue sarcomas—a goal of our current research grants with the Ewings Cancer Foundation of Canada. C17 is about priorities and partnerships, and working with the organizations—large and small who fund the work of C17. From the large—Childhood Cancer Canada, to the small—Aplastic Anemia and Myelodysplasia Association of Canada, we are all working together to ensure that research makes a difference.

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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.
In 2009, Drs. Shayna Zelcer and Danielle Cataudella initiated the “Development of the P-SCS: The Pediatric Supportive Care Scale”, a multi-centre, pan-Canadian C17 project. The P-SCS is being developed as an outcome measure to be incorporated in future Children’s Oncology Group (COG) and Canadian Pediatric Brain Tumor Consortium (CPBTC) early phase trials in patients with advanced or incurable disease.

The rationale for this study was that despite advances in the ability to cure childhood cancer, many children continue to die as a result of this disease. There is very little information about how to improve quality of life (QOL) of these children, particularly towards the latter stages of their illness when suffering increases and relief tends to be suboptimal. Interviews with bereaved parents suggested that current measures of QOL used for children with cancer did not adequately capture important concerns at the end of life. Zelcer and Cataudella felt existing validated Health-Related QOL (HRQL) scales did not fully address pertinent issues, including maintaining a sense of hope and a sense of normalcy in everyday life, and feelings about death. The aim of their study was to create a new measure to assess the quality of life of children whose cancer is less likely to be curable.

As of the fall of 2013, they have successfully completed Phase I of their study, which provided information on the understandability of the P-SCS questions and response options. Review and analysis of this data ensured that all the included questions were either (a) well understood initially or (b) modified to increase understandability. Updated versions of the questionnaire are now being administered to the target population to provide some preliminary psychometrics and to further reduce the questions.

Dr. Zelcer and Dr. Danielle Cataudella’s research is funded by Childhood Cancer Canada.

C17 Round 15 and DVL Round 2 Grant Awards (2013)

1. **Initiative to Maximize Progress in Adolescent Cancer Therapy (IMPACT).**
   Drs. Nancy Baxter and Paul Nathan, St. Michael’s and The Hospital for Sick Children
   Goal: To describe disease characteristics of adolescents treated at pediatric versus adult centres and determine whether adolescents treated at pediatric hospitals have a different probability of survival than adolescents treated at adult hospitals.

2. **A Phase I study of Oral Metronomic Topotecan and Pazopanib in Pediatric patients with recurrent or refractory solid tumours (TOPAZ).**
   Drs. Sylvain Baruchel and Arif Manji, The Hospital for Sick Children
   Goal: To test the safety of two drugs, Pazopanib and Topotecan, when used together in children with solid tumours that have continued to grow or spread despite standard therapies, and to determine the doses that should be used in children with cancer. Another goal of this study is to see if tumour growth is affected by the combination of these two drugs.

3. **Determination of molecular signatures that allow differentiation between unilateral, bilateral synchronous and bilateral metachronous Wilms’ tumors (WT) using genome-wide arrays and whole-exome sequencing.**
   Drs. Rosanna Weksberg and Armando Lorenzo, The Hospital for Sick Children
   Goal: To use new genome-wide testing technologies to compare genetic and epigenetic changes in unilateral versus bilateral WT and their associated non-tumour renal tissues.

   **DVL. Pre-clinical models of natural killer cell-based immunotherapy to cure refractory childhood acute lymphoblastic leukemia.**
   Dr. Michel Duval, Hôpital Ste. Justine
   Goal: To stimulate immune cells that recognize cancer cells following hematopoietic transplantation in a mouse model in order to eradicate residual cancer cells responsible for relapse.

These grants are supported with funds from Childhood Cancer Canada Foundation, Coast to Coast Against Cancer Foundation and the Kids With Cancer Society (Edmonton)

New Member on the C17 Research Network Committee

Dr. Robert Klaassen of Children’s Hospital of Eastern Ontario, has been selected as a member of the C17 Research Network grant committee. He represents hematology clinical research.

He replaces Dr. Anthony Chan of Hamilton Health Sciences/McMaster who served on the committee for 6 years. Dr. Chan’s dedication and insight was highly appreciated.

Welcome Dr. Klaassen

Members are selected to the C17 grant panel for a 3 year term that can be renewed once.
The CYP-C Surveillance program is compiling the first subset of data collected by the pediatric oncology centers across Canada. Children <15 years of age, diagnosed between 2001 and 2006 and included and data comprises a full 5 years of follow-up from the date of diagnosis. Following reconciliation, data quality and integrity checks, the data will be available for research applications in early-mid 2014.

Descriptive tables on epidemiological outcomes (such as prevalence, incidence, mortality and survival rates, by diagnosis, stage, risk category and extent of disease), outcomes (relapse, toxicities, and survival) and patterns in care (health care utilization, timeline between key health events, the location of care, clinical trial enrolment, initial treatment plan) are being produced.

CYP-C is one of nine known population-based surveillance systems in the world to include data from the entire country focusing exclusively on pediatric cancer. We are excited to examine diagnostic patterns, treatment patterns and outcomes across the country. In addition, the CYP-C surveillance system will provide a study base for examining long-term health and functioning and etiologic investigations by the strong research community within C17 and beyond.

Contact Randy Barber at randy.barber@albertahealthservices.ca or 780-492-7084.

**New Adolescent and Young Adults (AYA) Report**

The AYA Cancer Impact Report 2008-2012 from the Canadian Partnership Against Cancer /C17 Task Force on Adolescents and Young Adults (AYA) with Cancer, Responding to the Needs of a “Lost Tribe” was recently released.

The report outlines the 2008-2012 strategic objectives, and their 6 Cancer Care Recommendations. It includes a review of their impact from 2008-2012; how they broke new ground and created a roadmap; how they drove change; and future directions, including a strategic plan for 2012-2017.

This and many other resources regarding AYA are at www.ayacancercanada.ca

**Investment in Research Childhood and Adolescent Cancers, 2005-2010**

In September 2013, the CCRA released the survey of government and voluntary sector investment in pediatric cancer research. This report updates the analysis released in 2009, and shows that growth in research funding from 2005 to 2010 on childhood and adolescent cancers surpassed that found for cancer research overall.

The number of PIs funded for research in childhood and adolescent cancers has risen from 70 in 2005-06 to 80 in 2007-08 to 98 in 2009-10, with 44 of these PIs funded in all three periods. This suggests an increased capacity for research in Canada.

The full report is available on the CCRA website under publications/special topics.
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**C17 Sponsorship of Clinical Trials in Canada**

C17 is currently acting as the sponsor, or as the Canadian representative of the sponsor, for the following academic cooperative groups:

- Children’s Oncology Group (COG): Over 200 clinical trials opened at Health Canada since 2002. Senior Medical Officer: Jackie Halton, MD
- Dana Farber Cancer Institute ALL Consortium: 3 clinical trials opened. Senior Medical Officer: Jackie Halton, MD
- Therapeutic Advances In Childhood Leukemia (TACL): 5 studies opened, 1 is pending, and one was not allowed to be opened in Canada. Senior Medical Officer: Sylvain Baruchel, MD
- Histiocyte Society LCH-IV Protocol: Senior Medical Officer: Jackie Halton, MD
- Pediatric Bone Marrow Transplant Consortium: 2 studies recently opened. Senior Medical Officer: Kirk Schultz, MD
- C17 DVL- Melatonin developed by Dr. Donna Johnston, funded through the C17 Research Network and sponsored by C17. The study has recruited the first patient at CHEO
- C17 DVL—TOPAZ developed by Dr. Sylvain Baruchel, partially funded through the C17 Research Network and sponsored by C17

When C17 sponsors studies from a cooperative group, the C17 office is responsible for filing the Clinical Trial Application with Health Canada, assessing Serious Adverse Events for reporting Serious and Unexpected Adverse Drug Reactions to Health Canada, implementing a Monitoring Plan that ensures compliance with the annual monitoring expected by Health Canada.

Support from Childhood Cancer Canada for these activities has expanded access to clinical trials to many more centres and patients than would be possible if there was not the capacity to centralize the regulatory requirements.

**C17 Partnerships: Funding Grants**

The Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) and the Ewings Cancer Foundation of Canada (ECFC) have both committed to fund research grants for a second time in 2013-2014. By matching these smaller foundations with funding from Childhood Cancer Canada (CCC) we are able to fund more ambitious, larger, multicentre grants. Both partners have funded grants before and we welcome them back to our C17 Research Network.

On November 14, 2013, they held their 2nd Annual Purple Party Fundraiser at the Drake Hotel in Toronto, with over 350 people attending.

AAMAC has a 20 year history of patient and caregiver advocacy. They provide educational materials, produce newsletters and have regional support groups. In 2008, AAMAC funded their first C17 grant, awarded to Dr. Shereck and continued by Dr. Schultz at BC Children’s Hospital.

AAMAC is partnering with C17 to fund research in aplastic anemia, myelodysplasia or paroxysmal nocturnal hemoglobinuria (PNH) in children.

Their largest fundraising event is the Car & Airplane Rally at the Buttonville Airport, in Markham Ontario.

The Ewings Cancer Foundation of Canada 2013 raised $59,000.

The Hewson Family were First Prize winners of the 2013 Car Rally held in August. Front center is 23 year old Sierra who is an Ewings survivor.