



Childhood cancer is unique. It is not just a smaller part of the adult world of cancer.

The biology, treatment and effects of treatment are often unique to children. For this reason, childhood cancer needs to be studied, researched and treated as its own discipline.

The C¹⁷ Council is a non-profit organization composed of the institutionally appointed heads of the 16 pediatric hematology, oncology, and stem cell transplantation programs in 17 institutions across Canada. C¹⁷ acts as a voice representing the interests of Canadian children and adolescents with cancer and serious blood disorders. Our goal is to improve health outcomes and quality of life for children and adolescents with cancer and blood disorders, and we have developed a strategy for achieving this goal.

Research: We encourage, foster and fund multi-centre research. Most centres have too few patients with each cancer to conduct large research studies; collaboration among the sites provides capacity to conduct research in children's cancer.

International partnerships: Much of the increase in survivor outcomes over the past decades is due to the strong international collaboration in clinical trials, particularly through Children's Oncology Group. Getting clinical trials approved by Health Canada, organizing the importation of investigational drugs and making sure that Canadian sites have access to cutting edge research is a part of our mandate. We currently have 175 clinical trials approved by Health Canada, and we make every effort to make sure that new drugs that show promise in treating childhood cancer will be available in Canada.

Education: Keeping our healthcare workers up-to-date is accomplished by developing, organizing and promoting online web-based training, videoconferences, educational research and training opportunities to support health professionals in delivering services across Canada. National evidence-based clinical guidelines are being developed and disseminated by the Standards and Guidelines group.

Advocacy, Communication and Engagement: We communicate and engage with government agencies and other major stakeholders in pediatrics and oncology throughout Canada, especially those on the national stage. We advocate for policies and programs that support our mission of improving health outcomes and quality of life for children and adolescents with cancer and serious blood disorders in Canada.



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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.

Our Major Funding Partners



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CONTRE LE CANCER



C¹⁷ Researcher Dr. Anne Klassen

Anne Klassen and her team received grants from C¹⁷ and the Canadian Cancer Society and recently completed a 3 year program of research focused on parents from the two largest groups of immigrants in Canada -- Chinese and South Asian families. The team recruited 50 first generation immigrant parents from McMaster Children's Hospital, The Hospital for Sick Children, BC Children's Hospital, Children's Hospital of Eastern Ontario, Stollery Children's Hospital, and McGill University Health Centre. Interviews were conducted in Mandarin, Cantonese, Punjabi, Urdu, Hindi and

English. With immigrants making up 19.8% of Canada's population, the team decided they needed to understand the caregiving experiences of immigrant parents of children with cancer. Little research had been done to understand how factors such as being in a new country, not being able to communicate well, and religious or cultural differences influenced how such parents cope with childhood cancer. All interviews were translated, transcribed and have been analyzed to identify important themes related to caring for a child with cancer. The team has now started publishing the results of their work.

Once this study is completed, they plan to apply for CIHR funding to bring together healthcare professionals to discuss the findings from three interrelated studies and the implications they have for the development of pediatric oncology services, programs and policies

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.

- Research areas include all phases of clinical trials, disease or population-based registries, biological sample banks, quality of life, health outcomes/ psychosocial research, basic and translational research
- Since 2004: 12 Grant Competitions, 19 studies funded and \$2,178,904.67 committed in research funding
- \$100,000.00 per year for 2 years
- Funders include Childhood Cancer Canada Foundation, Coast to Coast Against Cancer Foundation, Kids With Cancer Society (Edmonton), Sandra Sharpe Rhabdomyosarcoma Fund, Aplastic Anemia and Myelodysplasia Association of Canada, and Optimists International

Canadian Cancer Research Alliance

In October 2009, the "Investment in Research on Childhood and Adolescent Cancers, 2005-2007", a special section of Cancer Research Investment in Canada, 2007, was released. The annual survey is produced by the Canadian Cancer Research Alliance (CCRA) and in 2009 they focused on pediatric oncology research. This first-ever detailed examination of a country's investment in research in childhood and adolescent cancers focused on 7,203 peer-reviewed cancer research projects funded between 2005 and 2007 by governmental and voluntary sector (non-profit, non-government) organizations, and categorized the investment by research areas and types of cancer.

For the period studied, research investment focused on understanding the causes of childhood and adolescent cancer, and was proportionately double that observed for cancer overall. Research investment in childhood and adolescent cancer was also proportionately higher in areas focused on patient care and survivorship, and the biology of cancer, particularly how genes help turn normal cells into cancer cells. There was no research investment in cancer prevention interventions directed at children and adolescents, which may reflect that relatively little is known about the causes of cancer in this age group.

From 2005 to 2007, a total of \$38.1M was invested in research on childhood and adolescent cancers. This translated into \$1 of every \$30 invested in peer-reviewed cancer research funded by governmental and voluntary sector organizations during the period. The annual investment rose from \$12.4M in 2005 to \$13.2M in 2007, representing a 6.5% increase. For the same period, the annual research investment for all cancers increased by 10.5% from \$364.3M in 2005 to \$402.4M in 2007.

The 23 member organizations of CCRA are the foundations that provided over \$1 million in research funding per year. C¹⁷ is currently an associate member and is participating in ongoing CCRA data collection on annual investment in pediatric cancer research in Canada. C¹⁷ investment and commitment to research grew from \$114,800 in 2006 to \$419,455 in 2007, \$425,005 in 2008 and \$471,475 in 2009. 2010 and 2011 will see approximately \$600,000 each year in grants awarded.



C¹⁷ Education Committee

The aim of the Education Committee is to advocate for, develop, support, and promote, educational research and training opportunities, tools and materials that are required to deliver a high quality national pediatric hematology/oncology/blood and marrow transplantation service to the children and adolescents of Canada, as represented by C¹⁷. This is accomplished through:

- National educational videoconferences
- Norma Auger Education Scholarships
- Educational Grants
- Educational Website www.pedsoncologyeducation.com

Jan 2010 Videoconference with 2009 Norma Auger Recipient Presentations

Jane Hilliard	<i>Environmental Contamination and Occupational Exposure to Cytotoxic Drugs in an Oncology Pharmacy Satellite</i>
Andrea Johnson	<i>Bringing Forth Mutual Respect, Healing and Wellness, Two week Externship in Systemic Family Therapy, Calgary Family Therapy Centre</i>
Angela Pretula	<i>European Symposium on Late Complications after Childhood Cancer</i>
Cindy Stutzer	<i>Transition from Curative to Palliative Care</i>
Emily Hopkins	<i>Building the Bridge between Camp and Hospital: The Role of the Camp Oochigeas Nurse Coordinator</i>

2009 Educational Grant Recipients

Sumit Gupta, Sick Kids	\$2,400.00
"Identification of Educational and Infrastructural Barriers to Prompt Antibiotic Delivery for Children with cancer with Febrile Neutropenia: A Quality Control Project. "	
Poster presentation at SIOP, presenting at a C ¹⁷ educational videoconference	
Ashley Kattlus, Sick Kids	\$1,910.00
Development of a Team Orientation Video for Pediatric Hematology/Oncology.	

C¹⁷ Canadian Fellows Conference

The 3rd Canadian Conference for Fellows and Program Directors was held in June 2010 in Whistler, BC. The conference was attended by 28 Subspecialty Residents and Fellows, from 6 Training Programs across Canada, 5 Program Directors and 7 guest speakers. Fourteen research projects were presented as part of a resident research competition. The top 3 research presentations were awarded \$200.00 each.

1st Prize: *The Development of a HQOL Inventory for Children on Long Term Warfarin KIDCLOT PAC QL*, Dr. Aisha Bruce (University of Alberta)

2nd Prize: *Prescription Psychotherapeutic medication Use among Survivors of Childhood, Adolescent and Young Adult Cancer compared to the General Population of BC*, Dr. Rebecca Deyell (BC Children's Hospital)

3rd Prize: *Receptor Cross Talk as Novel Targets for Therapeutics in Pediatric Brain Tumor Cells*, Dr. Halah Obaid (University of Calgary)

Norma Auger Education Scholarships

2009 Recipients

Karen Flemming, Sick Kids *
APHON Annual Conference

John Wiernikowski, McMaster *
SIOP 2009

Emily Hopkins, Sick Kids *
APHON Annual Conference

Cindy Stutzer, BCCH *
APHON Annual Conference

Angela Pretula, BCCH
European Symposium on Late Complications After Childhood Cancer

Andrea Johnson, BCCH
Family Therapy Externship

Jane Hilliard, CHEO *
Hematology/Oncology Pharmacy Assoc

2010 Recipients

Annette Penney, IWK Health Centre *
SIOP Annual Conference

Elizabeth Cooper, IWK Health Centre *
SIOP Annual Conference

Denise Mills, Hospital for Sick Children
APHON Annual Conference

Marilyn Wright, McMaster Children's *
2011 World Confederation of Physical Therapy Congress

Pat Lesser, CHEO *
International Nursing Conference on Children and Adolescent Cancer

Eleanor Hendershot Sick Kids *
APHON Annual Conference

Michelle Lee-Scott, Sick Kids *
SoCRA Conference & COG Meeting
* Poster or presentation





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C¹⁷ CPAC Adolescents and Young Adults Workshop

The "Workshop on Adolescents and Young Adults with Cancer, Towards Better Outcomes in Canada" was held March 11-13, 2010 in Toronto, Ontario. It brought together 100 Canadian and international stakeholders to discuss critical issues relating to the development of a national AYA plan; 25% of attendees were survivors or family of survivors. The Task Force's goal is to improve outcomes and health-related quality of life for AYA with cancer and AYA survivors of cancer in childhood by developing a list of recommendations for their care and strategies for implementation and identifying research priorities for these groups. Conference proceedings will be published in the journal *Cancer* in 2011. The AYA Task Force is sponsored by CPAC and C¹⁷.

C¹⁷ Developmental Therapeutics Committee

Under the leadership of Co-chairs Sylvain Baruchel and Sandra Dunn, the C¹⁷ Developmental Therapeutics (DVL) Committee was created last year to provide greater access across Canada to Phase I trials; allowing children and their families to stay closer to home. There are eight C¹⁷ centres participating, providing access across Canada for 80% of the children eligible for these studies. The sites are: BC Children's (Vancouver), AB Children's (Calgary), Stollery Hospital (Edmonton), CancerCare (Winnipeg), Hospital for Sick Children (Toronto), Children's Hospital of Eastern Ontario (Ottawa), Ste. Justine (Montreal) and IWK (Halifax). The C¹⁷ DVL Committee has a partnership with NCIC CTG, and the first study opened in September 2010, and has enrolled 4 patients. Two additional studies with pharmaceutical companies are in development. The C¹⁷ DVL Committee is also in the process of bridging the gap from bench to bedside with the development of a preclinical program, linking researchers across the country to work together to bring evidence from the lab into clinical studies.

C¹⁷ Standards & Guidelines Committee

The C¹⁷ Guideline for *Platelet Transfusion Thresholds for Pediatric Hematology/Oncology Patients* has been adopted and disseminated by the Standards and Guidelines Committee. It is available on the C¹⁷ website www.c17.ca. The APHON Guideline for *Prevention of Infection in Asplenic Patients* is under consideration for endorsement. Three other guidelines are currently under review for 2010-11.

Cancer in Young People in Canada (CYP-C) - Cancer Chez Les Jeunes aux Canada (CCJC)

CYP-C was originally the Canadian Childhood Cancer Surveillance and Control Program (CCCSCP). The program objectives of the CCCSCP, launched in 1992, were to fill gaps in knowledge from cancer registries and clinical trials and to evaluate cancer control across its entire continuum.

The program, renamed and redeveloped as Cancer in Young People in Canada (CYP-C), or Cancer Chez les Jeunes aux Canada (CCJ-C), is administered by a management committee made up of representatives from the Public Health Agency of Canada and C¹⁷, the two main partners of the project. In 2008, PHAC funded the CYP-C project and have signed 5 year contracts with all centres (except Ontario), with over \$1 M per year supporting this project. Agreements are being discussed with POGO to obtain data from their registry on POGONIS.

CYP-C continues work on a national, population based, cancer surveillance system for children and youth, by establishing a database that can be used by researchers to examine patterns of incidence, health care utilization, treatment and outcomes. Data collection forms are developed and translated into an electronic system, constructed by Dapasoft, Inc. Each pediatric oncology centre collects their own data, and transfers anonymized information to the national database administered by PHAC. The electronic system has been installed at five out of 11 centres, and data is being collected on paper forms at the others. The first phase of the project, retrospective data collection for children under the age of 15, who were diagnosed between 2001 and 2008, is well underway.