

Meeting Report

Paediatric/Adolescent/Young Adult Cancer: A Pan-Canadian Initiative

Quantity of Survival

New diagnostics

Improved Surveillance

Cardiotoxicity

Tumour Biology

Improved Prognosis (Delayed Diagnosis)

Fertility Issues

Behavioral changes, sleep disorders, stress

Predictors for late effects

New therapeutics

Self-Identification

Isolation

Predictors of treatment response

Palliative and End-of-Life Care

Quality of Life Issues

Second Cancers

Neurological/cognitive impairment

Transitioning from paediatric to adulthood

CIHR IRSC
Canadian Institutes of Health Research

Institute of Cancer Research
Institut du cancer

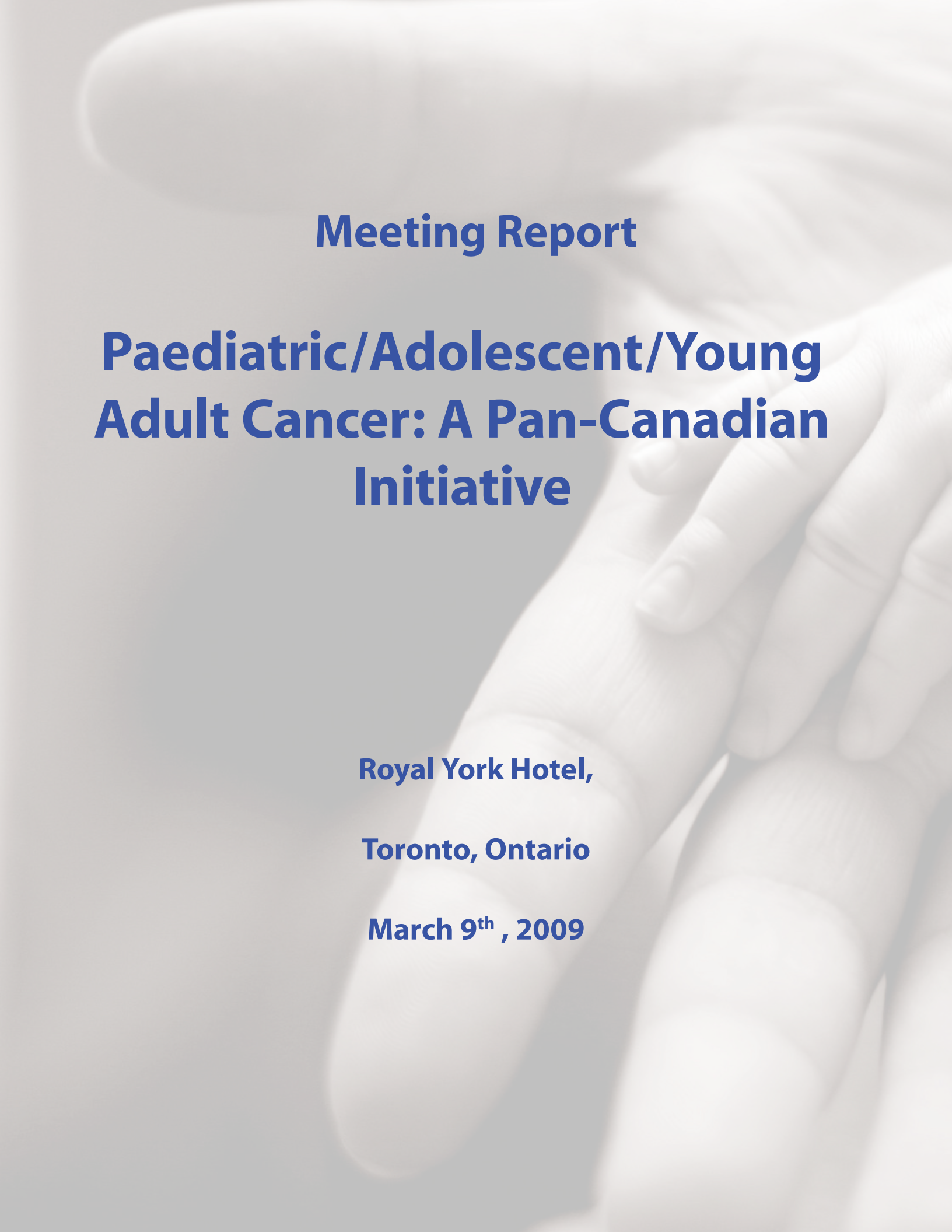
ROYAL YORK * MARCH 9, 2009 * TORONTO, ONTARIO

Written by: Dr. Judith Bray, PhD, Assistant Director, ICR
Desktop Publishing: Diane Christin, Project Officer, ICR

Canadian Institutes of Health Research
160 Elgin Street, Room 97
Address Locator 4809A
Ottawa, ON K1A 0W9

CIHR Institute of Cancer Research
3655 Sir-William-Osler Drive, Room 701
Montreal, Quebec H3G 1Y6
Phone: 514-398-5611
Fax: 514-398-8845

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Meeting Report

**Paediatric/Adolescent/Young
Adult Cancer: A Pan-Canadian
Initiative**

Royal York Hotel,

Toronto, Ontario

March 9th , 2009

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Background



Background

As a result of improvements in diagnosis and treatment, more cancer patients are now surviving their disease and living for many years following therapy. This is particularly true for the paediatric, adolescent and young adult population, in which over eighty percent of those diagnosed with cancer survive five or more years after diagnosis and in many cases are cured of their disease. However, these improved survival rates often come at a cost to the patient in terms of the short and long term effects of the initial disease and its treatment. There is enormous variation in the late effects experienced by cancer survivors including neurocognitive impairment, cardiotoxicity, hearing loss, obesity, osteoporosis, loss of fertility and a number of debilitating quality of life issues such as fatigue, anxiety, stress and a profound sense of isolation. In the paediatric, adolescent and young adult population some of these late effects persist for many years and can be life threatening.

Many national and international cancer organizations have recently identified survivorship as an emerging priority area, including the Canadian Institutes of Health Research (CIHR) Institute of Cancer Research (ICR). One important element in the cancer survivorship domain is research. Initiatives such as the Canadian Breast Cancer Research Alliance (CBCRA) "Special Research Competition on Psychosocial Aspects of Breast Cancer," and the ICR "Biomedical and Clinical Approaches to Improving Quality of Life for Cancer Survivors – Catalyst Grants," have already been launched and others are in the planning stages.

ICR has identified cancer survivorship, including the special issues experienced by paediatric, adolescent and young adult cancer patients, as an Institute research priority and is interested in working with survivors, researchers and other funding organizations to develop a research agenda that will align with a broader approach to survivorship coordinated through the Canadian Cancer Research Alliance (CCRA). As a first step in this process, ICR brought together interested parties to explore the possibility of building on our unique Canadian strengths to establish a pan-Canadian research strategy focused on paediatric, adolescent and young adult patients with cancer and the links between the survivorship issues in this population and in survivors of adult-onset disease. It is likely that many of the adverse effects experienced by young cancer patients will share common elements with those experienced by adult cancer patients.



Goals and Objectives

Goals and Objectives

This initial meeting provided an opportunity for survivors, researchers and funding organizations to meet, interact, and explore ways of working together to improve the survival and the quality of life for paediatric, adolescent and young adult cancer patients. The objective was to promote an increased awareness of the specific challenges experienced by this population and to generate linkages that will initiate or strengthen alliances among the various groups represented at the meeting. It is estimated that almost three quarters of adult survivors of paediatric cancer will experience chronic health problems related to their cancer or its treatment underscoring the need for these patients to be followed, once they leave paediatric care, by health specialists with an understanding of their unique health risks. Protocols for enrolling young adult patients in therapeutic clinical trials are urgently needed to improve the survivorship and quality of life for this unique population. Specifically, ICR was seeking advice and guidance in the development of a multi-partnered strategic research initiative that could potentially be ready for launch in 2009.

As the field of cancer survivorship is broad, it is unlikely that any single group or organization will be able to address all the issues involved. A combined, collaborative and coordinated approach will be required, where individual organizations identify and take ownership of special interest topic areas. An analogy would be the many individual squares that go into making a patchwork quilt. To remind participants that this was the model we were aiming for, not only for survivorship in general, but also for the paediatric, adolescent, young adult area itself, the quilt analogy was used throughout the meeting, supported by two actual patchwork quilts donated for the day by POGO. It is hoped that the "quilt maker" or coordinating body, in this case, will be the CCRA, represented at the meeting by Elizabeth Eisenhauer.



Meeting Participants and Agenda

Meeting Participants

The organizations represented at the meeting are listed in Appendix 1, including a brief description of their respective mandates or areas of interest and the website links, as a source of further information. Additional organizations identified by meeting participants as possibly having an interest from the research perspective include: the Terry Fox Foundation (<http://www.terryfoxrun.org>); Leucan (http://www.leucan.qc.ca/index_en.asp); CAPO (<http://www.capo.ca/eng/index.asp>); Fertile Future (<http://fertilefuture.ca/en/>); and the Canadian Pharmacogenomics Network for Drug Safety (<http://www.genomeweb.com/dxpgx/genome-bc-project-aims-launch-pgx-test-predict-adverse-drug-reactions-children>). Internationally, the Lance Armstrong Foundation would be an appropriate organization to approach. Ronnie Barr has existing connections with the Foundation, and will discuss this with them in the following weeks. Also the Childhood Cancer Survivor Study coordinated by St. Jude's Children's Research Hospital in the US provides an excellent example of survivorship research in paediatric cancer populations. Two of the meeting participants (Paul Nathan and Mark Greenberg) are members of a group of five paediatric cancer centres known as the "Consortium for Paediatric Interventional Research (CPIR)." CPIR, which is also coordinated through St. Jude, carries out interventional studies aimed at preventing or mitigating the late effects of childhood cancer therapy." (<http://www.stjude.org/stjude/v/index.jsp?vgnextoid=0d5dd3ce38e70110VgnVCM1000001e0215acRCRD&vgnnextchannel=cc66c08e1f5d3110VgnVCM1000001e0215acRCRD>).

Agenda

The meeting Agenda, Appendix 2, was intended as a guide for discussion rather than a prescriptive document and, as such, focused on the current research landscape; the issues surrounding paediatric, adolescent and young adult cancer that would benefit from additional research; and potential mechanisms for pooling expertise and resources to both increase the number of survivors and their quality of life.



Definitions and Research Landscape

Definitions

Although it is generally accepted that the paediatric age range is 0 to 14, and that adolescents range from 15 to 19 years of age, the definition of a “young adult” has less clarity, particularly at the upper limit - ranging from 29 to 39. It is recognized that not only do individuals have very different clinical, developmental and psychosocial needs that are often age-related but that the incidence and biology of the tumours and the expected clinical outcomes also differ significantly with age at diagnosis. Meeting participants felt that it would therefore be appropriate, rather than set a fixed upper limit in the young adult age range, to base the definition on the incidence and specific biology of the tumour under study and the needs of the patient both at the time of diagnosis and going forward after treatment. For example in the case of breast cancer, it might be more appropriate to consider the disease pre- and post-menopause rather than by age. The same could be said for those cancers arising during the pre- and post-pubescence years. It is likely that individual research initiatives will require their own parameters and definitions based on the area of study and focus of the research.

Research Landscape

A review of the available statistics for Canadian research funding in childhood cancer (from the CCRA survey data) drew attention to the difficulty in capturing investments made through clinical trials, or by health charities, and hospital foundations and that, although a good indication, the survey data may not reflect the true magnitude of the research investment. The data suggests that CIHR is the biggest single research funder in this area, providing roughly fifty percent of the total investment captured by the survey. A further analysis of the CIHR funding in paediatric, adolescent and young adult cancer revealed a total investment in 2007/2008 of only \$4 million (less than 0.5% of the total CIHR budget), with no strategic funding, suggesting that this is an area of research need. The research that is currently funded through the CIHR open grants competition falls into either the biomedical or psychosocial streams with little research focused on linking the two areas together.



Issues in Paediatric, Adolescent and Young Adult Cancers

Issues in Paediatric, Adolescent and Young Adult Cancers



The following list of issues and potential research topics was drawn from a combination of suggestions provided by participants prior to the meeting and topics that arose during the discussions.

Lack of understanding of the unique biology of many P/A/YA cancers	Need for new diagnostics and therapeutics	Lack of validated predictors of response to treatment - would enable patient stratification leading to personalized medicine	Lack of predictors to determine the individual risk for treatment side effects (short, medium and long-term).
Infertility issues following treatment	Potential cardiotoxic effects of treatment	Potential neurological and cognitive impairment following treatment	Hearing loss following treatment
Development of secondary cancer	Behavioural changes, post-traumatic stress and sleep disorders following treatment	Hormonal effects of treatment e.g. early menopause, impotence, weight control	Quality of life issues – e.g. social isolation, depression, sexuality/body image issues, juggling family and work, economic factors
Need for complementary therapies and their value in the management of stress during and after treatment for patients and family members	Health services research e.g. models of care - transitioning from paediatric to adult clinics and difficulties in surveillance and follow-up	Issues related to the management of the medical late effects of cancer treatment for long-term survivors: surveillance for them, diagnosis (even perhaps of subclinical or unrecognized toxicity), and treatment	Impact of diagnosis and treatment delays on prognosis
Isolation and self-identification	Palliative and end-of-life care		



Building on the original quilt analogy as a model for collectively addressing all the aspects of survivorship, the above topics were grouped, divided according to whether they addressed mechanisms to improve survival (**quantity** of life) or survivorship (**quality** of life), and posted on a poster board (see photo on front cover of report). Participants were asked to place a sticker on those issues that were of interest to their organization. Appendices 3 and 4 show the results of this exercise and the diverse and often overlapping range of interests among the group. As expected the list of issues and the discussion they generated covered the entire spectrum including:

genomic studies to identify risk factors for disease (patient mutations) - potentially leading to preventive measures;
tumour sequencing (tumour mutations) linked to clinical outcomes as a means of developing new diagnostics and therapies and predicting the responses to existing therapies and the risk of late effects;
multidisciplinary approaches to investigate ways to prevent late effects or mitigate those that have already occurred, e.g. cardiotoxicity, neurotoxicity, infertility;
mechanisms to address patient-identified needs related to psychosocial and quality of life issues;
capacity building in research targeting young adult cancer patients, including a process for self identification (probably a marketing issue) improved surveillance, and a mechanism for establishing links between paediatric and young adult clinics in order to establish a network for young adults that is similar to the highly successful C17 network that exists for paediatric patients; and
palliative and end-of-life care issues specific for children and young adults – a topic that would likely be broader than cancer.

Despite the diversity of topics, it was generally agreed that a research continuum that linked everything together was the preferred approach. Although genomic and psychosocial research may appear to be far apart at first glance, in fact there is a long history of biomedical research spawning psychosocial research. When considering both biologic and psychosocial survivorship issues, the first goal is to increase the number of survivors and the second is to improve the quality of life of survivors by preventing or reducing adverse late effects. At present, although there is work being done to map out the survivorship issues, there is very little research being done on changing the trajectory. For studies on late

effects, a multidisciplinary approach is required that links the field of oncology to cardiology, neurology, sociology and psychology and unites biomedical, clinical, health services and population health researchers.

It was recognised by the group that there are significant differences between the paediatric and young adult populations, with adolescents falling somewhere in the middle. These differences do not only reflect differences in tumour type and incidence, or age-related factors but also the capacity and organizational structures in the two fields. Whereas there are 17 paediatric clinics across Canada, linked by C17 and enrolled in the US based Children's Oncology Group (COG), there are currently only two dedicated young adult clinics in Canada. One is located in Montreal, and the other, a support group specifically for young women with breast cancer (PYNK), is located in Toronto at the Sunnybrook Hospital (<http://www.sunnybrook.ca/media/item.asp?i=261>). Therefore the needs in the two groups are very different and will require different approaches. By focusing on the five most common tumour types in the young adult age range, roughly 60 to 70 percent of cases would be captured, perhaps representing the best initial approach for network building and for identifying and tracking patients that are currently seen in adult clinics.

In the paediatric field, because of the existing networks and infrastructures (such as tumour banks), it is feasible to consider the possibility of establishing a cohort study that links genome sequencing of both the patient and their tumours, with existing databases to establish predictors of risk. As a member of the Cancer Genome Sequencing Consortium, OICR (in partnership with C17 and POGO) is ideally placed to undertake paediatric tumour genome sequencing, which could be linked to population databases (e.g. the Ontario educational and paediatric cancer databases), and form the basis of a cohort of paediatric patients that could be followed over time. Through a partnership between POGO and the Public Health Agency of Canada (PHAC), a clinical network has already been developed that will follow all the paediatric cancer patients across Canada and be linked to a clinical database. It is possible that a paediatric biobank could be added to this network, which might serve as a magnet to attract clinicians and researchers working with the young adult population. If clinical trials were also included, it is possible that PHAC could be interested in being involved. A cohort study done on a large scale and in a connected way would address many of the research questions that have been identified. In addition, this example could serve as a model for the young adult population which are a notoriously difficult group to follow over time.



Next Steps

Next Steps

In keeping with the quilt analogy, the recommendations from the March 9th meeting will be tabled at the April 6th, 2009 CCRA Cancer Survivorship meeting, where groups with an interest in cancer survivorship will explore mechanisms to coordinate ongoing projects and research initiatives. Opportunities for partnership will be identified and a process for developing a national strategy will be developed.

This meeting report will be circulated to ICR Institute Advisory Board (IAB) members in preparation for a discussion and planning session at the May, 2009 IAB meeting. Based on the recommendations in this report and the input from the IAB, ICR hopes to be in a position to work with interested partners to develop a research initiative to be launched in December 2009.

In the young adult cancer field, the first step will be to organize a workshop to bring together individuals from diverse backgrounds (e.g. oncologists, researchers, survivors, funders), but with a common interest in young adult cancer. It will be important to link the paediatric and young adult communities around common themes such as biobanks, clinical trials and surveillance. The workshop will be organised by a small working group, currently consisting of Dr. Petr Kavan, Geoff Eaton and representatives from ICR, C17 and POGO. Input will also be sought from other meeting participants who expressed an interest in this area. The goal will be to chart a path forward that will build capacity, increase the number of young adult cancer clinics across the country, and support a level of organization and networking in the young adult cancer field that is comparable to that currently existing for children's cancer. Those working in the young adult cancer field will seek advice and guidance from others working in the more established paediatric cancer field to learn from their experience. Both C17 and POGO have already offered their help in this regard and discussions are underway with the NCIC Clinical Trials Group and Health Canada to address protocols and regulatory issues.

With respect to late effects, there are essentially two approaches: i) to prevent or mitigate adverse effects at the outset; and ii) to find ways to reduce late effects that have already occurred. It was recommended that late effects studies should be linked to genomic and biomarker studies as they may hold the key to understanding why some individuals experience adverse effects and others do not and may also cast light on the differences in the incidence and severity of late effects at a population level. In dealing with late effects a multi-disciplinary approach would be ideal - in which oncologists and experts from other fields such as cardiology, endocrinology or neurology are brought together in research teams. As a first step ICR will approach other CIHR Institutes to gauge the interest in partnership on a research initiative in this area. In addition, ICR will work with other meeting participants (from this meeting and the CCRA meeting in April) who have an interest in this area towards the planning of a workshop that will promote communication among the different disciplines and research areas.



For the genomic studies, the favoured approach would be to focus on selected paediatric cancers and, using new or existing tumour banks, begin genome sequencing studies in a cohort of paediatric cancer patients who could be followed over time. By taking advantage of existing networks and databases (e.g. C17, OICR), it should be possible to link sequencing data to clinical outcome and identify predictors of response. Although some of this work is already in progress, through the BC-based Genotype-specific Approaches to Therapy in Childhood (GATC) project and the US-based Children's Oncology Group (COG), so far no one is looking at cohorts in which serial samples are taken for follow-up. This could be a unique feature of a Canadian study. Similarly, genomic studies on the patients may lead to the identification of predictors of risk for late effects. CCRA will hold a genome sequencing meeting on April 9th 2009 to bring together parties interested in this area of research as a first step towards building a genomic consortium focussed on paediatric cancer that will be part of the Cancer Genome Sequencing Consortium. If a clear vision can be developed, and a paediatric champion identified, then OICR is confident that this initiative could move forward. If the funds can be raised to begin the process then the scope can be extended to include young adult cancer.

It was recognised by participants that the quality of life and psychosocial issues surrounding cancer survivorship are of great importance and that the driver in studies in this area should be patient needs. This is particularly true in the young adult population, which is not currently part of an organized, age-appropriate support group. The development of a research agenda in this area will be discussed at the CCRA survivorship meeting on April 6th 2009, at which there will be representatives from organizations that have already expressed an interest in these issues. At this time, ICR is planning to focus primarily on the biomedical and clinical aspects (treatment and intervention studies) of survivorship, but will do so as part of a national framework, coordinated by CCRA.

The March 9th, 2009 meeting generated a great deal of enthusiasm among participants towards working together to build a Canadian strategy on paediatric, adolescent and young adult cancer. Connections and linkages established during the day are already leading to interactions and collaborations between groups and the momentum generated will be sustained through subsequent discussions and focused meetings. It is likely that the group will meet again in the near future to evaluate progress and continue the joint planning process.

**Paediatric/Adolescent/Young Adult Cancer: A Pan-Canadian Initiative
Royal York Hotel - Toronto, ON
March 9, 2009**

Institution	Name & Details	Information
C17 Council And C17 Research Network	<p>Kathy Brodeur-Robb Executive Director C17 Council Kathy.BrodeurRobb@capitalhealth.ca www.c17.ca</p> <p>Paul Grundy Research Chair, C17 Research Network, and Vice Chair of C17 Council Paul.Grundy@capitalhealth.ca</p> <p>Tammy Mah-Fraser Director of Research, C17 Research Network tammy.mahfraser@capitalhealth.ca</p>	<p>The C17 Council is an organization composed of the institutionally appointed heads of the sixteen pediatric hematology, oncology, and stem cell transplantation programs in Canada. This organization acts as an authoritative Canadian voice representing the interests of children and adolescents with cancer and blood disorders. The C17 Council has a strong record of accomplishment and has developed a clear strategy for continuing its mission to improve health outcomes and quality of life for children and adolescents in Canada with cancer and blood disorders.</p>
Canadian Breast Cancer Research Alliance (CBCRA)	<p>Pascale Macgregor Director of Research Program pmacgregor@cbcra.ca www.breast.cancer.ca</p>	<p>As Canada's primary granting agency for breast cancer research, CBCRA plays a national leadership role in setting priorities and directions for breast cancer research.</p> <p>Established in 1993, the Canadian Breast Cancer Research Alliance is unique collaboration of organizations from the public, private and non-profit sectors that joined forces to coordinate breast cancer research efforts in Canada to maximize synergies and reduce potential duplication. CBCRA member organizations are: Avon Canada, the Canadian Breast Cancer Foundation, the Canadian Breast Cancer Network, the Canadian Cancer Society, the Canadian Institutes of Health Research, Health Canada and the Public Health Agency of Canada. CBCRA is committed to reducing the incidence of breast cancer, improving survival, and enhancing the lives of those affected by the disease. CBCRA offers research grant support to fund high quality research across the full spectrum of breast cancer research and to promote its translation into benefits for society.</p>

Institution	Name & Details	Information
<p>Canadian Cancer Research Alliance (CCRA)</p> <p>AND</p> <p>Canadian Partnership Against Cancer Corporation (CPACC) Research Action Group</p>	<p>Elizabeth Eisenhauer Chair of the Canadian Cancer Research Alliance (CCRA) Board of Directors, and Chair of the Canadian Partnership Against Cancer Corporation (CPACC) Research Action Group EEisenhauer@ctg.queensu.ca www.ccra-acrc.ca www.partnershipagainstcancer.ca</p>	<p>The Canadian Partnership Against Cancer is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians.</p> <p>CPACC is a partnership of cancer experts, charitable organizations, governments, patients and survivors, determined to bring change to the cancer control domain.</p> <p>CPACC works to stimulate generation of new knowledge and accelerate the implementation of existing knowledge about cancer control across Canada.</p> <p>The Partnership evolved from the Canadian Strategy for Cancer Control – a volunteer-driven coalition working to counteract the growing burden of cancer on Canadian society.</p>
<p>CCRA</p>	<p>Stuart Edmonds Program Director stuart.edmonds@partnershipagainstcancer.ca www.ccra-acrc.ca</p>	<p>CCRA is an alliance of cancer research funding organizations and affiliated partners working together to enhance the overall state of cancer research funding in Canada through improved communication, cooperation and coordination.</p> <p>CCRA started within the context of the Canadian Strategy for Cancer Control (CSCC), which represents a very broad partnership of Canada's leading cancer organizations.</p> <p>CCRA is now composed of many of the major cancer research funding organizations from the federal and provincial governments, and the voluntary sector as well as other key stakeholders within the Canadian research scene.</p>
<p>Childhood Cancer Foundation</p>	<p>Mary Lye Director, Marketing and Communications mlye@childhoodcancer.ca www.childhoodcancer.ca</p>	<p>The Childhood Cancer Foundation Candlelighters Canada is a national, volunteer governed, charitable organization dedicated to improving the quality of life for children with cancer and their families.</p> <p>CCF is the only national organization dedicated entirely to the fight against childhood cancer through a variety of programs and services: 1) The funding and promotion of childhood cancer research. Through a unique partnership with all of Canada's 17 childhood cancer hospitals and treatment centres. 2) Support and resource programs for children with cancer and their families. By administering many support programs, including the Family Support Kit, Scholarship Program and Benevolent Fund and several programs that provide information and resources to families at critical stages in their cancer journey. 3) Issues of Advocacy. The Foundation plays a leadership role in advocating for progressive social and healthcare policies in support of childhood cancer.</p>

Institution	Name & Details	Information
CIHR Institute of Cancer Research	Morag Park Scientific Director morag.park@mcgill.ca www.cihr-irsc.gc.ca/e/12506.html	ICR is one of 13 virtual institutes that make up the Canadian Institutes of Health Research (CIHR). ICR is dedicated to supporting research that reduces the burden of cancer on individuals and families through prevention strategies, screening, diagnosis, effective treatment, psycho-social support systems, and palliation. The Institute of Cancer Research (ICR) community is made up of researchers, scientists, community groups, and individuals from around the world who share an interest in cancer research. A highly respected Scientific Director and a small, professional staff manage ICR day-to-day activities. A dedicated Institute Advisory Board (IAB) provides essential input and guidance for ICR.
	Judith Bray Assistant Director judith.bray@cihr-irsc.gc.ca	
	David Hartell Associate, Institute Strategic Initiatives david.hartell@cihr-irsc.gc.ca	
CIHR Institute of Human Development, Child and Youth Health (IHDCYH)	Anne-Cécile Desfaits Assistant Director The Montreal's Children Hospital anne-cecile.desfaits@cihr-irsc.gc.ca www.cihr-irsc.gc.ca/e/8688.html	IHDCYH supports research that ensures the best start in life for all Canadians and the achievement of their potential for optimal growth and development. Through our support, researchers address a wide range of health concerns, including those associated with reproduction, early development, childhood, and adolescence.
Coast To Coast Against Cancer Foundation	Jeff Rushton Founder and Chair jeff.rushton@coasttocoastagaincancer.org www.coasttocoastagaincancer.org	The Coast to Coast Against Cancer Foundation role is to provide financial support through organized events to registered Canadian charities whose programs most positively impact the achievement of this mission. The Coast to Coast events are designed to inspire a life-long pursuit of wellness, to encourage a high level of volunteerism, and to create a sense of purpose within everyone who is involved with these events.
	Louisa Cantelon Co-founder & National Director, Events louisa.cantelon@coasttocoastagaincancer.org	
	Steven Sokolowski Co-founder and Board Member soko@courtyardgroup.com Steven.Sokolowski@coasttocoastagaincancer.org	

Institution	Name & Details	Information
<p>Institute for Clinical Evaluative Sciences (ICES) representing OICR and CCO health services research interests</p>	<p>Craig Earle Director of the Health Services Research Program craig.earle@ices.on.ca www.ices.on.ca/webpage.cfm</p>	<p>ICES' work encompasses the assessment of care delivery, patterns of service utilization, health technologies, drug therapies and treatment modalities. Key to the knowledge produced at ICES is the ability to anonymously link population-based health information on an individual patient basis, using unique ICES identifiers that ensure the privacy and confidentiality of health information. Linked data allows researchers to obtain a more comprehensive view of specific health care issues, than could be achieved with unlinked data.</p>
<p>McGill AYA Oncology Program</p>	<p>Petr Kavan Director McGill University petr.kavan@muhc.mcgill.ca www.medicine.mcgill.ca/oncology/programs_adolescent.asp</p>	<p>The Adolescent and Young Adult Oncology Program was established in 2003 as a joint venture between the Department of Oncology and the Department of Medicine.</p> <p>The program—the first of its kind in Québec—addresses the exceptional needs of cancer patients between the ages of 18-29 years.</p> <p>The goals of Adolescent and Young Adult Oncology include the following: 1) To provide optimal multidisciplinary care to this unique patient population, that requires a distinctive treatment approach; 2) To register more adolescents and young adults in multi-centre research protocols and projects, at the national and international levels; 3) To develop and participate in in-house protocols for this patient group; 4) To improve the quality of teaching and research in this field of cancer therapy; 5) To improve patient access to social services, and psychological and psychiatric support.</p>
<p>McMaster University (Michael G. DeGroote School of Medicine)</p>	<p>Ronnie Barr Professor of Pediatrics, and, ICR IAB member rbarr@mcmaster.ca www.mcmaster.ca/research/sciencecity/barr.htm</p>	<p>Ronald D. Barr is a pediatric cancer specialist known locally, nationally and internationally for his work in the field of pediatric oncology, as co-author and author of seven books and more than 400 scientific articles. He received his medical degree from the University of Glasgow and is a fellow of the Royal College of Physicians (UK), the Royal College of Physicians and Surgeons of Canada, the Royal College of Paediatrics and Child Health, and the Royal College of Pathologists (Hematology).</p> <p>Dr. Barr's main professional interests are international health, particularly cancer in childhood; late effects of cancer treatment, especially on nutritional status; and measurement of health-status and health-related quality of life (as a co-developer of the Health Utilities Index).</p>

Institution	Name & Details	Information
Ontario Institute of Cancer Research (OICR)	<p>Tom Hudson President and Scientific Director tom.hudson@oicr.on.ca jackie.peca@oicr.on.ca www.oicr.on.ca</p>	<p>The Ontario Institute for Cancer Research (OICR) is a centre of excellence in cancer research with a focus on prevention, early detection, diagnosis and treatment of cancer.</p> <p>The Institute is an independent, not-for-profit corporation funded by the Government of Ontario through the Ministry of Research and Innovation.</p> <p>The Institute is bringing together multi-disciplinary, multi-institutional collaborations, which will allow complex questions to be pursued. It is translating research findings into programs, technologies and therapies.</p> <p>Established in December, 2005, the Institute supports more than 50 internationally recognized principal investigators; with a strong core of scientists at the MaRS Centre and the remainder in nodes of excellence around the province.</p>
Pediatric Oncology Group of Ontario (POGO)	<p>Mark Greenberg Medical Director mgreenberg@pogo.ca hcraig@pogo.ca www.pogo.ca</p>	<p>The Pediatric Oncology Group of Ontario (POGO) was founded in 1983 by a group of pediatric oncologists to champion childhood cancer care and control. As the representative voice of the childhood cancer community, POGO works to ensure that all of Ontario's children have equal access to state-of-the-art diagnosis, treatment and required ancillary services.</p> <p>The organization is a collaboration of the five specialty pediatric oncology programs; The Hospital for Sick Children (Toronto), McMaster Children's Hospital (Hamilton), Children's Hospital of Western Ontario (London), Kingston General Hospital and Children's Hospital of Eastern Ontario (Ottawa), as well as a growing number of partners drawn from community hospitals, community services, other members of the health care sector, families of children who have, or have had cancer, corporate and private benefactors and volunteers.</p>
The Hospital for Sick Children	<p>Paul Nathan Staff Oncologist paul.nathan@sickkids.ca www.sickkids.ca</p>	<p>SickKids Foundation is the largest non-governmental granting agency in child health in Canada. Established in 1972, SickKids Foundation has granted over \$500 million to The Hospital for Sick Children and over \$60 million to researchers across the country.</p> <p>Through its National Grants Program, SickKids Foundation invests \$4 million annually across Canada in paediatric research, focusing on issues important to children's health which have not been addressed elsewhere.</p> <p>Their mission is to inspire our communities to invest in health and scientific advances to improve the lives of children and their families in Canada and around the world.</p>

Institution	Name & Details	Information
Young Adult Cancer Canada	<p>Geoff Eaton Executive Director geoff@youngadultcancer.ca www.youngadultcancer.ca</p>	<p>Young Adult Cancer Canada was established in 2000 [originally as RealTime Cancer] by Geoff Eaton, after his first cancer challenge. Geoff's vision focused on educating and supporting young adults. At the core of that vision was the belief that cancer, like all of life's challenges, brings with it valuable lessons and experiences.</p> <p>Today, Young Adult Cancer Canada is focused on the promotion and evolution of its four primary programs: the public education program, the RealTime Cancer Community, the retreat and an annual survivor conference, as well as the continued growth of the organization. Currently, Young Adult Cancer Canada is based in St. John's, Newfoundland and Labrador, with an office team of four; plans for physical expansion and new partnerships with local groups are in development.</p>

APPENDIX 2

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AGENDA

Meeting: Paediatric, Adolescent, Young Adult Cancer: A Pan-Canadian Initiative

Date: Monday March 9, 2009

Royal York Hotel, Toronto

Room : Salon 3, 19th Floor

Facilitator: Judy Bray

Item	Time	Description	Lead
	09:00	<i>Cheese, fruit, coffee and water will be available when you arrive</i>	
1	09:30	Call to Order and Welcome	Judy Bray/ Morag Park
2	09:45	Round table introductions <ul style="list-style-type: none">Brief introductions and overview of participants backgrounds, perspectives and interests – only one speaker per organizationWhy are you here?Who's missing?	All
3	10:45	Discussion of current research funding landscape <ul style="list-style-type: none">Pie chart and CIHR fundingCancer statisticsOther potential funding sources – national and international	Judy Bray
	11:00	<i>Break - coffee</i>	
4	11:15	Discussion on identified research priorities <ul style="list-style-type: none">Discussion of priorities suggested by participantsIdentification of any additional prioritiesWhich priorities are already being addressed and by whom?Are there Canadian "niche" areas where we have significant expertise or resources?	Ronnie Barr
5	12:00	Priority areas that are not directly related to research <ul style="list-style-type: none">What other important issues are there that it may not be appropriate to tackle through research?How could these issues be addressed and by whom?	Ronnie Barr

	12:30	<i>Lunch – Networking opportunity</i>	
6	13:30	What do we want to do? <ul style="list-style-type: none"> • If money was no object what would we want to achieve and why? 	all
7	13:30	What can we do? <ul style="list-style-type: none"> • What is achievable in the Canadian context? • Are there international opportunities for partnership? • Is a Canadian research network feasible and what would it include? • Do we have the necessary expertise and infrastructure? 	all
8	15:00	How can we do it – what kind of programs would we need? <ul style="list-style-type: none"> • What kind of programs or networks would be required? • How would we begin – small vs.large programs? • Do we currently have the necessary program “tools”? • How can we coordinate research across the full spectrum from diagnosis to palliation? • Who will do what – should we divide research areas among organizations? 	all
9	15:30	How much money would we need to get started and to sustain momentum and how can we raise it? <ul style="list-style-type: none"> • Can we work together to raise the necessary funds? • Is a staged approach appropriate? • Can targeted fundraising be done? 	all
10	16:00	Next steps <ul style="list-style-type: none"> • Do we need another meeting? • Do we need to hold a research workshop? • Should we allocate the lead for different priorities to different organizations? How will we coordinate? • Do we need to form an “executive” group? • What are the timelines for launching initiatives e.g. CIHR? 	Judy Bray/ Morag Park
	16:30	<i>Adjournment</i>	

Thank you all for coming – hopefully we will leave with a plan!

APPENDIX 3

Research Priority “Quilt”

Paediatric, Adolescent, Young Adult Cancer: A Pan-Canadian Initiative

	CBCRA	OICR	C17	ICR	CCF	POGO	ICES	Kavan	YAC	IHD CYH	CTCACF	total
Improving Quantity of Life	Tumour biology											7
	Predictors for late effects											9
	New Diagnostics											6
	Improved Prognosis											8
	New Therapeutics											7
	Predictors of treatment response											7
	Second Cancers											8
	Improved Surveillance											7
Improving Quality of Life	Fertility Issues											6
	Self Identification											4
	Palliative and End of Life Care											7
	Neurological & cognitive impairment											7
	Cardiotoxicity											7
	Behavioural changes											6
	Isolation											5
	Quality of Life											7
Transitioning from paediatric to adult care											7	

<p>CBCRA: Canadian Breast Cancer Research Alliance – www.breast.cancer.ca</p> <p>OICR: Ontario Institute of Cancer Research – www.oicr.on.ca</p> <p>C17: C17 Research Network – www.c17.ca</p> <p>ICR: CIHR Institute of Cancer Research – www.cihr-irsc.gc.ca/e/12506.html</p> <p>CCF: Childhood Cancer Foundation – www.childhoodcancer.ca</p> <p>POGO: Pediatric Oncology Group of Ontario – www.pogo.ca</p> <p>ICES: Institute for Clinical Evaluative Sciences – www.ices.on.ca</p>	<p>Kavan: Dr. Petr Kavan, Director of the McGill Adolescent and Young Adult Oncology Group of Ontario – www.medicine.mcgill.ca/oncology/programs_adolescent.asp</p> <p>YAC: Young Adult Canada – www.youngadultcancer.ca</p> <p>IHD CYH: CIHR Institute of Human Development, Child and Young Health – www.cihr-irsc.gc.ca/e/8688.html</p> <p>CTCACF: Coast to Coast Against Cancer Foundation – www.coasttocoastagaincancer.com</p>
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Research Priority Interest for Paediatric, Adolescent, and Young Adult Cancer in Canada

