

**Canadian Invitational**

**CANCER SURVIVORSHIP  
WORKSHOP:**

**Creating an Agenda  
for Cancer Survivorship**

March 25 – 26, 2008  
Toronto, Ontario

PREPARED FOR

The Cancer Journey Action Group  
of the  
Canadian Partnership Against Cancer

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# 1. EXECUTIVE SUMMARY

Cancer survivorship has been identified as a high priority for all provinces in Canada but there is both a lack of clarity and little consistence across provinces, organizations, and programs as to the type and nature of survivorship programs required. A National Invitational Cancer Survivorship Workshop was held in Toronto on March 25-26, 2008 for cancer survivors, health providers, policy-makers, decision-makers, and researchers to create an agenda for cancer survivorship in Canada. Eighty-four individuals, including 34 cancer survivors, participated.

Presentations from cancer survivors opened the first day of the Workshop and examined the unique aspects of dealing with cancer as a young adult and the difficult experience of adult cancer. Clinicians and researchers from Canada, Australia and the United States shared information on current programs and studies underway on both adult and pediatric cancers. Information from a recent environmental scan of Canadian survivorship programs was also shared.

Participants submitted responses to the presentations that were summarized and circulated for information on the second day. Significant messages emerged about the power of survivors' stories, the diversity of their experiences, and how they must continually re-define their lives and learn to adjust to a "new normal". Communicating with survivors "in their own language" and the special social and developmental challenges of young adults dealing with cancer was a new perspective to many participants. Comments addressed the importance of survivors, health providers and researchers to form partnerships that integrate research and patient care and increase access to supportive care.

Breakout discussions during the second day of the Workshop identified seven priorities for a Canadian survivorship agenda in the areas of survivorship care (standards and guidelines, care plans, and models of care), communication, advocacy, and survivorship research. Action plans for each priority were reviewed with implications for clinical care, education, and research.

Participants agreed that survivorship in Canada needs attention now. They fully acknowledged the importance of cancer survivorship and endorsed further action on a national agenda. There are also valuable lessons to be learned from the survivorship work being done in Australia, the United States, and the United Kingdom. The Survivorship Committee of the Cancer Journey Action Group of the Canadian Partnership Against Cancer will review the workshop results with survivors and develop an action plan to address cancer survivorship issues in Canada. This work will also inform and stimulate other cancer related organizations to address survivorship issues through policy changes, education and training, increased awareness and applied research to influence programming changes.

## 2. BACKGROUND

The **Canadian Partnership Against Cancer** is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. The Partnership is bringing together cancer survivors, patients and families, cancer experts and government representatives to implement the first pan-Canadian cancer control strategy. Its vision is to be a driving force to achieve a focused approach that will help prevent cancer, enhance the quality of life of those affected by cancer, lessen the likelihood of dying from cancer, and increase the efficiency of cancer control in Canada.

The **Cancer Journey Action Group** (formerly the ReBalance Focus Action Group) of the Canadian Partnership Against Cancer was created to provide leadership to “rebalance the focus” of cancer care. The challenge is to help move the system from a predominantly tumour-centred focus to a patient-centred approach. This rebalanced system would take into account the needs of the whole person (i.e., psychological, social, spiritual, informational, practical, emotional, and physical) during clinical care and treatment.

The mandate of this Action Group is to provide leadership to change the system so that patients and families are better served through a coordinated and less fragmented approach. Ultimately, the goal is to increase the quality of life for those living with, and after, a diagnosis of cancer and to decrease the burden of suffering throughout the cancer experience. The topic of cancer survivorship was identified as needing further attention and specific action.

### **3. WORKSHOP RATIONALE**

Cancer survivorship has been identified as a high priority for all provinces. However, there is both a lack of clarity and little consistency across provinces, organizations, and programs as to how to move forward. Hence, approaches to Canadian survivorship program development require careful review. In order to assist in the development of a national, comprehensive approach, the Cancer Journey Action Group created a Survivorship Committee to:

- undertake a systematic review to assess the current state of affairs of survivorship programs and services in Canada;
- consult with international experts regarding work in other countries that might be applied to the Canadian context;
- work with provinces and health regions to create an agenda for cancer survivorship care and identify ways that this plan can be disseminated and rolled out to their jurisdictions; and,
- convene a national consensus meeting to identify priorities for program development, education, and research.

## 4. WORKSHOP PURPOSE AND EXPECTED OUTCOMES

The Survivorship Committee wanted to address the wide disparity of needs and services for survivors across the country in the development of a national agenda for cancer survivorship follow-up care in Canada. The workshop was designed to be a highly collaborative process ensuring broad-based involvement, input with a wide sharing of opinions and perspectives. The focus was on the “whole person”, addressing the physical, emotional, mental, social, and spiritual needs of survivors and their families.

The working vision for the workshop was: “All Canadians experiencing cancer (and their families/significant others) will receive the necessary support, education, and navigation (or referral) to utilize accessible, acceptable, affordable, comprehensive and coordinated services to empower them to promote their health and well being with, through, and beyond cancer.”

The expected outcomes of the workshop were to:

- bring together survivors, clinicians, researchers, decision-makers and other experts in the field to identify key needs that to be addressed for program implementation throughout the country;
- analyze approaches currently underway in Canada through a literature review and environmental scan;
- create a national agenda for survivorship care and support for Canada; and
- galvanize support for a pan Canadian approach to survivorship through a consensus meeting.

## 5. PARTICIPANTS AND AGENDA

### *Participants*

The Survivorship Committee developed a list of invitees that included cancer survivors, clinicians, educators, policy makers, provincial and federal government representatives, researchers, and funders. Efforts were made to include regional, rural, and cultural diversity in the group. Eighty-four (84) people attended, of which 40% were cancer survivors. Representatives were invited from a wide array of stakeholder groups across Canadian jurisdictions and included those from British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia, Newfoundland, and Labrador as well as guests from the United States and Australia. The list of participants is shown in Appendix A.

### *Agenda*

The first day of the workshop (Tuesday, March 25<sup>th</sup>) set the workshop context and objectives. Presentations focusing on pediatric, young adult and adult survivorship issues and highlighted clinical, education, and research issues. Perspectives from Canada, the United States and Australia were presented.

The second day (Wednesday, March 26<sup>th</sup>) provided opportunity for discussion. Facilitator Diana Royce guided the participants through three break-out sessions. The discussion sessions addressed:

- key issues facing Canadian cancer survivors
- developing action plans for priority issues
- forging a plan of action: implications for clinical care, education and research

The full workshop agenda appears in Appendix B. Speaker biographies are in Appendix C.

## 6. DAY 1 KEY MESSAGES: PRESENTATIONS AND REFLECTIONS

### *Presentations*

Presentations aimed to set the stage for the break-out sessions from the following perspectives: patient, pediatric clinical and research, adult clinical and research, international and Canadian. Below is a summary of the presentations that includes the title, presenter's name and perspective and an overview of each presentation. Speakers' presentations slides are available on the Canadian Partnership Against Cancer website at [www.partnershipagainstcancer.ca](http://www.partnershipagainstcancer.ca)

- **PATIENT SURVIVORSHIP PERSPECTIVES**

*Supporting Survivors: One Survivor's Perspective*

**Ms. Lesley Washington**, Supportive Care for the Canadian Cancer Society, Alberta/NWT Division, Canada

Ms. Washington's presentation provided a survivor's perspective on the priorities for future work in the area of survivorship. Specifically, it offered her perspective on the physical and psychosocial aspects of cancer survivorship including recovery and healing issues; supports that work well and gaps/barriers to receipt of care; as well as the ways for improving delivery of psychosocial supportive care for survivors.

*Cancer, Young Adults, and the LiveSTRONG Young Adult Alliance*

**Ms. Heidi Adams**, Planet Cancer, USA

Ms. Adams shared her personal perspective on young adult survivorship, explaining how the system fails young adults. She described current initiatives for change, particularly the LiveSTRONG Young Adult Alliance. She noted that cancer is disruptive at any age and stage of life, but being a young adult cancer survivor presents unique challenges, issues and lessons. Until recently, young adults have not been recognized as a distinct group with unique needs, resulting all too often in patients falling through the cracks of resources, appropriate clinical care and support services. Ms. Adams shared her personal perspective on young adult survivorship, explaining how the system fails young adults. She described current initiatives for change, particularly the LiveSTRONG Young Adult Alliance.

- **CLINICAL AND RESEARCH PERSPECTIVES OF SURVIVORSHIP:  
Pediatric Perspective**

*The CAYACS Program: Cancer Survivor Research and Opportunities in Canada*

**Mary McBride**, Cancer Control Research, BC Cancer Agency, Canada

Dr. McBride described the CAYACS (Childhood, Adolescent, and Young Adult Cancer Survivor) Research Program, as an example of innovative research and knowledge translation for young cancer survivors that addresses gaps in knowledge of survivor issues, and takes advantage of unique strengths of the Canadian environment of health care and research. This program integrates research into population-based, clinical, and health services issues facing survivors of a cancer diagnosed before 25 years of age, and translates results to multiple stakeholders to change policy and practice for care of survivors.

*The Clinical and Research Pediatric Perspective of Survivorship*

**Dr. Les Robison**, Department of Epidemiology and Cancer Control, St. Jude Children's Research Hospital, USA

Dr. Robinson described the Childhood Cancer Survivor Study (CCSS) which was established to better understand the incidence/prevalence of, and risk factors for, the spectrum of adverse late effects experienced by long-term survivors of childhood cancer. Funded by the US National Cancer Institute, the CCSS consists of a cohort of over 14,000 five-year survivors of selected pediatric malignancies diagnosed between 1970 and 1986 at one of the 26 participating centres. Dr. Robinson also described plans for expansion of the cohort to include an additional 15,000 five-year survivors treated 1987-99.

- **CLINICAL AND RESEARCH PERSPECTIVES OF SURVIVORSHIP:  
Adult Perspective**

*Clinical, Research and Policy Perspectives on Adult Cancer Survivorship in the USA and Canada*

**Dr. Linda Carlson**, Division of Psychosocial Oncology, Department of Psychology, University of Calgary, Tom Baker Cancer Centre Canada

Dr. Carlson summarized the state of the research knowledge regarding issues facing adult cancer survivors, and discussed various recommendations for survivorship care put forth in a number of key reports. In addition to discussing care plans and models of survivorship care as well as highlighting programs already in place in the US, she discussed key areas for future research and implementation possibilities within the Canadian system.

- **INTERNATIONAL PERSPECTIVE OF SURVIVORSHIP**

*Cancer Survivorship Research, Programs and Support Services: An Australian Overview*

**Prof. Afaf Girgis**, Centre for Health Research and Psycho-oncology, Australia

Dr. Girgis described the state of cancer survivorship in Australia where survivorship is still a relatively new but fast-developing area of focus. The presentation included examples of research recently completed and underway, as well as results of a population-based study of the unmet needs and psychosocial well-being of cancer survivors 5-6 years post diagnosis. Examples of current initiatives to assist cancer survivors and the relative priority given to this field at the national level were discussed.

- **ENVIRONMENTAL SCAN**

*Environmental Scan of Cancer Survivorship in Canada: Conceptualization, Practice & Research*

**Dr. Svetlana Ristovski-Slijepcevic**, Canadian Partnership Against Cancer, Canada

Dr. Ristovski-Slijepcevic provided a Canada-wide overview of cancer survivorship conceptualization, research and practice. The environmental scan was based primarily on individual interviews with 47 key informants who represented the perspectives of Canadian researchers, practitioners, survivors, advocates and community groups. The overview included illustrations of several recent initiatives that have attempted to fill current gaps in cancer survivorship care. Key priorities for planning and implementing next steps in survivorship care and research as identified by informants were presented.

## **Reflections**

Following the presentations, participants reflected on what had been heard. It was clear that participants fully acknowledge the importance of cancer survivorship and endorsed further action on a national agenda. The following is a summary of the key messages and learnings collated from the verbal reflections in this reflection session as well as the responses and comments provided in written form by the participants:

- **There are varied definitions and perspectives of “survivors” and “survivorship”.** Questions were raised about when a person becomes a survivor, the conceptualization of short-term vs. long-term survivorship and whether families should be included in the scope of a ‘survivorship’ strategy. Family and friends are with the patient throughout the cancer journey, and especially when acting as caregivers, may have high levels of unattended stress. For the purposes of this workshop, it was decided to use the National Cancer Institute definition of “survivors” that includes all phases of the cancer journey as well as family members and caregivers.
- **The stories of survivors were powerful.** We need to understand more about the experiences of Canadian survivors, about their continual re-evaluation of their priorities, about *‘preparing to die while trying to live’*. New concepts for consideration emerge as survivors are continually re-defining their life and what is for them a *‘new normal’*, a new way of living life.
- It is important **to recognize the diversity of experiences** among cancer survivors and the context within which experiences occur. One’s experience with cancer is grounded in such influences as their age, life stage, gender, ethnic and cultural background, socio-economic status and geography. Survivor’s needs may also differ depending on the type of cancer they have, the type of treatments they have undertaken and the phase of survivorship they are in at a particular time. They may also have concerns about recognition of their needs by others, regaining a sense of control, finances (commuting, cost of parking, cost of medication, etc.), sexuality and intimacy, fatigue, pain and loss of appetite.
- **Survivors should be communicated to and supported ‘in their own language’.** Young adults, for example, have unique developmental and social needs that differ from those of older adults; they require appropriate communication strategies for information and resources. Similarly, Child cancer survivors are a vulnerable population. Most child survivors have undergone intense therapy and are at risk for significant persistent and delayed serious side effects. Survivors will have had widely different

tumours and range of side effects and will experience survivorship differently.

- The literature on survivorship is predominantly based on data from other countries. **We lack Canadian data** about the needs of survivors as well as about how to provide optimal care.
- People dealing with cancer must be prepared for each phase in their trajectory. Currently, however, survivors are abruptly left on their own after treatment. Providing support for transitioning between phases is a key issue for future action. **Living with cancer continues after treatment ends and this phase needs to be addressed.**
- **Research must be undertaken** to examine and integrate current evidence base regarding survivorship. There is no need to re-create the wheel for all questions. For example, there is much to be learned from palliative care, chronic care, health promotion literature. In addition, there are program and care models both in the literature as well as some across Canada that need to be evaluated. Beyond this, research must also build on current evidence base to develop new evidence to adequately assess and care for survivors in Canada.
- **Models of research in survivorship are needed.** This could be facilitated by a comprehensive database to evaluate a number of outcomes, impact of collaboration/ partnerships in research.
- Research conducted in Australia found surprisingly few unmet needs among survivors while unmet needs were high in caregivers. This data differs from clinical anecdotes and other psychosocial research regarding levels of distress. It would be extremely useful for **Canada to focus on unmet needs** of cancer survivors and their families and caregivers.
- **Knowledge exchange is key** for future action. Researchers must form partnerships with health professionals to integrate research and patient care and bridge the “know-do gap”. Much of knowledge that currently exists is not being used. This step will require adequate funding to develop not only policy and procedures but also appropriate programs of care.
- There is a need to **incorporate health economics**; once issues of cost are raised, messages are more persuasive for change.

- **The implementation of a survivorship strategy must be comprehensive and include** all levels of care. The work of community organizations must be part of the survivorship agenda as they offer tremendous expertise in providing education and support.
- Funding for cancer is largely directed to diagnosis and treatment, while **the survivorship phase of cancer care is under-funded**. Realistic funding strategies must be identified to support financing of survivorship strategies. These funding strategies should also address ways to **minimize or eliminate the cost burden for survivors**.
- **There must be an increased focus on a holistic approach**. Concerns around late effects, fatigue, infertility, fear of recurrence, coping and healing play a big role for survivors. Screening for emotional distress should be part of standard care. The role on ongoing rehabilitation and lifestyle interventions must be addressed.
- Future action on survivorship **must ensure better access to information and resources**. General physicians can play a larger role in the care of survivors. Health professionals need continuous education and training about ongoing survivorship support and ways to access oncology expertise when needed. Community and not-for-profit organizations can play a critical role by providing the resources not offered in the cancer care system. **Suggested future actions were to develop consistent follow-up practices, guidelines, standards, care plan(s) and to employ transition coordinators** to support needs around information, resources and transitions.
- Future action on survivorship **must recommend mandates for survivorship care**, and address the following questions: at what level (national/provincial) will infrastructure be provided? What will be the responsibilities of the formal cancer system? Does the philosophy of cancer treatment centres need to evolve to that of wellness centres?

## 7. DAY 2 KEY MESSAGES: DISCUSSIONS & REFLECTIONS

### *Key Messages and Priorities*

The majority of the second day of the workshop consisted of three breakout sessions:

- Break-out session #1: Key issues facing Canadian cancer survivors
- Break-out session #2: Developing action plans for priority issues
- Break-out session #3: Forging a plan of action - Implications for clinical care, education and research

Workshop participants were divided into eight workgroups facilitated by designated discussion leaders, scribes and rappers. The role of the discussion leaders was to moderate and stimulate discussion among all group members. The role of the scribes was to record key points raised. Rappers reported back consensus points to the entire group at the end of the session. The notes were turned in as a record of the discussion at the end of the day. For each break-out session participants were allocated to different tables in such a way as to ensure each table included a mix of participants representing survivors, healthcare professionals and researchers from a variety of geographic locations.

In Break-Out Session #1, each working group was asked to recommend two key issues that should be addressed by a Canadian cancer survivorship agenda. Participants generated the following priorities for a Canadian Cancer survivorship agenda that addressed clinical care, research, education and administrative structures. The priorities were not ranked in order of importance but include:

- Establishing **National Standards and Guidelines** for survivorship care
- Identifying appropriate **Models of Care Delivery** to meet the long-term needs of survivors
- Developing and Implementing **Survivorship Care Plans**
- Promoting Survivorship **Research**
- Ensuring effective **Knowledge Translation**
- Facilitating a comprehensive **Communications Plan**
- Promoting a consortium of **National Survivor Advocacy Groups**

**Establishing an Office of Cancer Survivorship** in Canada to take action on these priorities generated a lot of discussion. Participants also agreed that it was important to address these issues by considering the cross-cutting nature and commonalities of some themes but also the uniqueness of issues relating to adult, pediatric and young adult survivors.

During Break-Out Session #2, key issues were discussed under the topic of *“Developing Action Plans for Priority Issues”*. Workshop participants were assigned to one of seven different tables, each table working on one of the seven key issues agreed upon in Break-Out Session #1: survivorship care plans, national standards and guidelines, knowledge translation, national survivors advocacy, research, communications and models of care.

For each key issue, the following questions were assigned for discussion:

- a. Why is this issue a priority component of a Canadian cancer survivorship agenda? What is its impact on survivors?
- b. What are the challenges inherent in addressing this issue?
- c. What actions need to be taken in the short and long terms to address this priority?
- d. Who needs to be involved?
- e. Are there opportunities for strategic collaboration with partner organizations
- f. What would success look like?

Considering the priority actions identified and related action plans that were recommended, in Break-Out Session #3 participants were asked to discuss the following questions:

- a. What roles should this sector (either clinical care, education or research) play in the development and implementation of a multi-faceted national cancer survivorship agenda?
- b. What particular survivorship challenges could this sector address?
- c. What difference could this make for cancer survivors?
- d. Who needs to be involved?

A summary of the key messages from the three sessions follows.

## **Establishing National Standards and Guidelines**

Practice standards and guidelines on a national level are needed to support survivorship care through all phases to end-of-life, provide consistency in quality and establish minimum levels of care. Such standards and guidelines would represent a statement of consensus from a panel of experts, based on both evidence where data exists and the collective experience of experts. They would be aligned with available resources and prioritized based on relevance and cost-benefit analysis. Further action on this priority will include: funding agency endorsement; identification and linkages among key Canadian stakeholders (e.g., the Canadian Association of Psychosocial Oncology; the Canadian Association of Nurses in Oncology; cancer information and support organizations like the Canadian Cancer Society; survivor advocacy and support organizations, etc.) and international stakeholders; and, survivorship research.

## **Identifying Models of Care**

Models of care should be profiled that identify common core elements and common frameworks for cancer patients and health professionals to work together to provide care. These models can be applied as a national. The current status of survivorship programs in Canada provides an opportunity to develop a national standard on core elements and reduce or eliminate current challenges of fragmentation, redundancy and wasted costs. Models may vary according to individual circumstances, i.e., rural or urban dwellers, availability of programs, specifics of illness, gender, culture, etc. A variety of models have been described in the literature, from cost-effective to others more comprehensive that could potentially serve as templates. This will be a complex task that will extend beyond healthcare perspective to politics and economics. Survivors, health care, academia, agencies and government will need to be involved in the design, development and implementation of models with provinces as key players. A national framework document should be disseminated at local, regional, provincial and national levels. The goal is to have models of care included in provincial cancer implementation plans and evaluated locally.

Clinical care needs to take a part in the planning, development and coordination of services. Rather than inventing something new, successful programs for learning, supportive care, and referrals could be refined from models already in place, e.g. Heart and Stroke and HIV AIDS. The new models of care may include community care, nurse practitioners, triage, etc. Greater coordination of clinical care would reduce cost and improve outcomes which can be attributed to the availability of different levels of care, greater access to mental health care, appropriate referrals, access to community care, etc.

## **Developing and Implementing Survivorship Care Plans**

While the term and nature of care plans was a debated issue, participants agreed that survivors need a plan—an initial tool that will summarize their important personal information, treatments undergone and resources available to enable them to feel empowered to continue managing their own care. Care plans would be holistic (inclusive of the medical/clinical, psychosocial and lifestyle aspects), life-long and would bridge across the transitions of cancer survivorship. Care plans have been well-identified as a priority both in a recent environmental scan of cancer survivorship across Canada and in the literature (e.g., *Lost in Translation*, Institute of Medicine, National Research Council, USA). Templates of survivorship care plans are being developed and tested both in Canada and in the United States (American Society of Clinical Oncology and National Coalition of Cancer Survivors), with some examples already implemented for child survivors in Canada (i.e., the Pediatric Oncology Group of Ontario's *Passport to Health*). Existing templates can be used as a base for further action. Other details remain to be worked out including the formatting (electronic or paper format), responsibilities for completing care plans for survivors as well as gathering research data to evaluate the effectiveness of care plans.

## **Promoting Survivorship Research**

Research into survivor issues is still in its infancy and there are significant gaps that need to be addressed. However, the environmental scan presented at the Workshop revealed that there are strong researchers in Canada who have dedicated many years to survivorship issues and are recognized internationally. Canada is well-placed because of its access to population-based research. Survivorship research will provide an evidence base upon which action to improve health, quality of care, and economic decisions. Research can distinguish myth from fact and address new issues and legitimize survivorship issues. Current challenges include: lack of funding; lack of researcher interest; less than optimal research environments; and, lack of tools and instruments to measure the survivorship population. Further action is needed to: increase support for a broad base of survivorship (biomedical, population-based, health services) at all levels (micro, meso, macro) and through a variety of methods (qualitative and quantitative).

Such research should be conducted for all stages of survivorship and should, through knowledge translation activities, link findings from research to practice. Support should cover programs of survivorship research in addition to single research studies. All types of research organizations (Canadian Health Services Research Foundation, funding bodies, cancer agencies, community funding organizations, research centres, the Centre for Behavioural Research and Program Evaluation, academic institutions across faculties, government) should be involved. Opportunities for strategic collaborations include the above-mentioned organizations as well as the Canadian Cancer Society, national organizations (e.g. the Palliative Care Network) and cancer charities. Further

action is also needed to identify what research is most relevant to survivors and to learn from other jurisdictions and diseases. Success will be accomplished through an active well-funded, coordinated research agenda across disciplines that would lead to organized follow-up care, improved quality of care and quality of life.

## **Ensuring Effective Knowledge Translation and Synthesis**

Recognition of cancer survivorship is increasing but there is lack of knowledge about how to address cancer survivorship issues in the Canadian context. Creation of new knowledge does not always lead to implementation in practice. Closer ties between research and practice were recommended to disseminate knowledge into widespread practice in Canada. However, evidence exists for some issues, whether based on evidence in the literature or from experiences of others within and outside Canada that should be evaluated and modified for the purposes of the particular context and translated into practice. Collaboration within and beyond the health care cancer community is imperative. Involvement with community organizations that have hands-on experience in the delivery of cancer support services was identified as a strategy. These groups also have a role in advocating for knowledge translation and exchange. Knowledge translation, therefore, will need to be addressed through multi-faceted mechanisms to exchange and share knowledge that will be integrated into program and clinical research. Further action might involve implementing a knowledge translation training program and using innovative schemes with technology to develop web-based systems where survivors, clinicians, and researchers can share information. Collaboration and learning with industry and other chronic disease groups like the Heart and Stroke Foundation, the Canadian Diabetes Association, etc. was also recommended.

One strategy for knowledge translation and synthesis suggested by participants was education. Education can address a number of significant roles in the development and implementation of a multi-faceted national cancer survivorship agenda. Educators influence undergraduate and graduate curricula and there is the potential to develop interprofessional courses on survivorship. Participants considered the need for new educational strategies for healthcare providers and survivors and how to these might be incorporated into existing organizations. A wide group of players needs to be involved if advances are to be made in implementing the agenda. Representation and involvement is needed from all sectors. This would include, but not be limited to: survivors, patient advocacy groups, support groups, community organizations (who have expertise and deliver support services), provincial governments, the federal government, non government organizations, professional associations, universities, colleges, and, the business sector.

## **Facilitating a Communications Plan**

As there exists a general lack of knowledge and understanding about survivorship issues among health professionals, employers, researchers, policy-makers and

survivors themselves, a survivorship communications plan was seen as a method to raise awareness of and disseminate information about all aspects of cancer survivorship. There is currently lack of community-shared language and there is diverse expertise in dealing with the issues and defining survivorship. The media tends to focus on survivor “superheroes” whose stories are not representative of most survivors’ experiences. There are diverse levels of understanding based on language, age, and socio-economic factors. Survivorship is a complex concept that blurs boundaries between treatment and post-treatment.

A survivorship communications or awareness plan would incorporate public relations, marketing and advocacy perspectives. Challenges will involve attempting to communicate and “market” survivorship as it is not an easy concept to convey. It will be important to have a clear, highly visible message with local, provincial, national highly visible champions. “Duelling cancer sites” must be avoided. Marketing experts to assist with crafting messages will be needed as a short-term investment while the creation of an attitude to promote change, brand alignment, target branding survivorship will be needed as a long-term investment. Champions to drive agenda out into public consciousness are needed. Communication will need to be targeted to multiple audiences including professionals, employers and survivors. Funding is needed for future efforts. Training of healthcare professionals and adding survivorship to post-secondary professional education curricula will be necessary.

### **Promoting a Consortium of National Survivors Advocacy Groups**

Participants recognized that a national cancer survivorship agenda needs the survivor voice at the table to initiate, lead, and catalyze change and to interact with both policy-level funders and providers. Advocates have led important initiatives that have contributed to important steps forward in the cancer survivorship agenda both in Canada and wider. Previous advocacy experiences can, thus, provide important lessons for future action in cancer survivorship in Canada. The two cancer advocacy organizations in Canada, the Canadian Cancer Action Network (CCAN) and the Campaign to Control Cancer (C2CC) were not well known to some participants. There was a perception these groups have focussed on issues pertaining to access (drugs, supportive care, etc.) for cancer patients, less on survivorship issues. To maximize survivorship support efforts and to build on the work of CCAN and C2CC and chronic disease advocacy groups, participants suggested the development of a unified action-coordinating organization that would link survivors to advocacy resources (not a brand new organization but a supra version of the existing organizations). This activity would increase awareness, visibility and accessibility the survivor networks; develop linkages with existing organizations and support groups; and, galvanize survivors “voices” to move the policy, research and political agendas forward.

## **Office of Cancer Survivorship**

While not identified as a priority, the creation of an **Office of Cancer Survivorship**, based on the American model created by the National Cancer Institute was seen as a strategy to implement the priorities for action. The purpose of an office of cancer survivorship would be to unite all interested in cancer survivorship including researchers, educators, practitioners, and survivors. The office would advise on research priorities, provide a unifying voice for survivors and would report to the Canadian Partnership Against Cancer. It will have at least five divisions including advocacy, research, education, clinical services, and local initiatives model to ensure equitable access to care across Canada. The Office would include a survivorship champion who will work with health authorities and both provincial and federal governments.

## ***Reflections***

At the end of Day 2 participants evaluated the Day 2 sessions as well as the workshop as a whole. What participants particularly enjoyed was the:

- strong presence of survivors: their personal stories and comments were recognized and respected;
- range of individuals from a variety of backgrounds, roles and perspectives;
- broad approach taken, inclusive of:
  - pediatric, young adult and adult cancer survivors
  - short and long-term survivorship
  - national and international perspectives
  - balance of key stakeholders;
- interaction, networking and the exchange of ideas that facilitated increasing awareness of the wealth of information, activities and resources already available;
- great discussion of ideas; and,
- commitment of the agenda and participants to arrive at recommendations and next steps.

Suggestions for future workshops on survivorship included incorporating work accomplished on disease sites and other issues (i.e., chronic diseases, aging); allowing time for discussion of the specific needs of different cancers; and focussing more attention to multicultural issues. Presentation of developed and implemented care models both within and outside Canada was suggested along with examples of how to implement survivorship programs. Organization of focussed workshops on research, advocacy, models of care, etc, for the future was also recommended.

## 8. CONCLUSION

The Survivorship Workshop confirmed the growing interest by many cancer survivors, health professionals, researchers, and cancer organizations on the topic of survivorship. The Workshop was the initial step in understanding the viewpoints and areas of focus for those involved and in developing a Canadian agenda for survivorship. The identified priorities reflect a consensus based on a range of perspectives and the need that these priorities have a “champion” to create high visibility for a survivorship agenda. Lessons can be learned from the survivorship work being done in Australia, the United States, and the United Kingdom. Survivorship models of care, care plans, standards, research, knowledge exchange, advocacy and awareness emerged as key areas of importance for those in attendance. Survivors’ and patients’ involvement was recognized as essential to the success of advancing a Canadian survivorship agenda.

Survivorship is an important yet under-developed, under-sourced, and under-researched aspect of the cancer trajectory. More dialogue is needed to prioritize the activities to move the agenda forward. Survivors, survivor advocacy groups, the Survivorship Committee, and the Cancer Journey Action Group of the Canadian Partnership Against Cancer will review the identified priorities identified at this workshop to begin development of a coherent action plan for cancer survivorship in Canada.

## **9. WORKSHOP ORGANIZERS AND SUPPORT**

A planning subgroup of the Survivorship Committee included Kathy Scalzo, Richard Doll, Dr. Margaret Fitch assisted by Melissa Friesen and Irene Nicoll. This group was responsible for the administration, marketing, and coordination of the event.

Diana Royce of The Deerfield Group was the consultant responsible for facilitation of the meeting. Vicki Alton, Fay Bennie and Melissa Friesen assisted with onsite coordination.

The Workshop report was prepared by Dr. Svetlana Ristovski-Slijepcevic, Irene Nicoll and Fay Bennie and was reviewed by the Survivorship Committee.

## 10. APPENDIX A: List of Participants

Name	Employer	Location
Adams, Heidi	Planet Cancer	Austin, TX
Allison, Val	Hôpital Régional de Sudbury Regional Hospital	Sudbury, ON
Annable, Gary	CancerCare Manitoba	Winnipeg, MB
Antonick, Pat	CancerCare Manitoba	Winnipeg, MB
Arsenault, Deborah	Saskatchewan Cancer Agency	Saskatoon, SK
Balamatowski, Sue		Winnipeg, MB
Barr, Ronald	McMaster University	Hamilton, ON
Beck, Ayala	Wellspring	Toronto, ON
Bennie, Fay	Canadian Partnership Against Cancer	Toronto, ON
Bernstein, Mark	IWK Hospital	Halifax, NS
Brazil, Kevin	St. Joseph's Health System Research Network	Hamilton, ON
Bultz, Barry	Tom Baker Cancer Centre	Calgary, AB
Campbell, Sharon	University of Waterloo	Waterloo, ON
Canavan, Janet	Canadian Cancer Society – Ontario Division	Hamilton, ON
Carlson, Anne		Victoria, BC
Carlson, Linda	University of Calgary	Calgary, AB
Carney, Sibohan	McGill University	Montréal, PQ
Catton, Pamela	Princess Margaret Hospital	Toronto, ON
Cervinka, Tony		Toronto, ON
Chapman, Kim		Fredericton, NB
Chobanuk, Janice	Alberta Cancer Board	Edmonton, AB
Collacutt, Vivian	Alberta Cancer Board	Edmonton, AB
Collyer, Gerry		Uxbridge, ON
Corsini, Linda	Ottawa Regional Cancer Centre	Ottawa, ON
Dimarco, Anna		Winnipeg, MB
Doll, Richard	BC Cancer Agency	Vancouver, BC
Dorion, Hélène		Québec, PQ
Drysdale, Elaine		Vancouver, BC
Dunleavy, Vicki		Creemore, ON
Eades, Margaret	McGill University Health Centre	Montréal, PQ
Easley, Julie		Fredericton, NB
Fillion, Lise	Université Laval	Québec, PQ
Fitch, Margaret	Odette Cancer Centre	Toronto, ON
Freisen, Melissa	BC Cancer Agency	Vancouver, BC
Girgis, Afaf	University of Newcastle	Newcastle, Australia
Goulet, Sonia	Université Laval	Québec, PQ
Greenberg, Mark	Pediatric Oncology Group of Ontario	Toronto, ON
Grunfeld, Eva	Cancer Care Nova Scotia	Halifax, NS
Hart, Kimberly Banks	Canadian Institutes of Health Research	Ottawa, ON
Hasker, Pamela		Winnipeg, MB
Haylock, Pamela		Medina, TX
Jalbert, Linda	Cancer Advocacy Coalition of Canada	Toronto, ON

Katz, Anne	Cancer Care Manitoba	Winnipeg, MB
Kean, Lesley	RealTime Cancer	St. John's, NL
Kelly, Shirley		Riverview, NB
Koch-Schulte, Diane		Winnipeg, MB
Leclerc, Pierre		Québec, PQ
Ledwell, Elaine	Newfoundland Breast Screening Program	St. John's, NL
Lee, Rose		Vancouver, BC
Leibovitz, Christine		Montréal, PQ
Loch, Christina		Vancouver, BC
Loiselle, Carmen	SMBD Jewish General Hospital	Montréal, PQ
Loney, Kerri	Hôpital Régional de Sudbury Regional Hospital	Sudbury, ON
McBride, Mary	BC Cancer Agency	Vancouver, BC
McDermid, Wendy	Canadian Cancer Society	Regina, SK
Messer, Lori	Canadian Cancer Society	Toronto, ON
Michelin, Elizabeth	Labrador Health	Goose Bay, NL
Nathan, Paul	University of Toronto	Toronto, ON
O'Brien, Suzanne	Hope & Cope	Montréal, PQ
Parkinson, Maureen	BC Cancer Agency	Vancouver, BC
Pauderis, Maris		Toronto, ON
Payeur, Nancy	BC Cancer Agency	Victoria, BC
Pearsall, Marc		Toronto, ON
Richmond, Diane		Marathon, ON
Ristovski-Slijepcevic, Svetlana	BC Cancer Agency	Vancouver, BC
Robison, Les	St. Jude Children's Research Hospital	Memphis, TN
Rosberger, Zeev	SMBD Jewish General Hospital	Montréal, PQ
Ross, Elisabeth	Ovarian Cancer Canada	Toronto, ON
Royce, Diana	The Deerfield Group	Burlington, ON
Rutledge, Robert	Nova Scotia Cancer Centre	Halifax, NS
Scalzo, Kathy		Vancouver, BC
Schmidt, Peg	Saskatchewan Breast Cancer Network	Saskatoon, SK
Scott, Brian		Thunder Bay, ON
Secord, Scott	Princess Margaret Hospital	Toronto, ON
Smith, Anne M.	Queen's University	Kingston, ON
Taylor, Ardythe	Breast Cancer Supportive Care	Calgary, AB
Taylor-Brown, Jill	Cancer Care Manitoba	Winnipeg, MB
Tompson, Margaret		Saskatoon, SK
Truant, Tracy	BC Cancer Agency	Vancouver, BC
Underhill, Lisa	Public Health Agency of Canada	Ottawa, ON
Underhill, Theresa Marie	Cancer Care Nova Scotia	Halifax, NS
Washington, Lesley	Canadian Cancer Society - Alberta/NWT Division	Calgary, AB
Wiernik, Neil		Toronto, ON
Wiernikowski, Jennifer	Hamilton Health Sciences Centre	Hamilton, ON
Wiljer, David	Princess Margaret Hospital	Toronto, ON

# 11. APPENDIX B: Workshop Agenda

CANADIAN PARTNERSHIP AGAINST CANCER  
NATIONAL INVITATIONAL WORKSHOP:

TOWARDS AN AGENDA FOR CANCER SURVIVORSHIP

Tuesday – Wednesday, March 25 – 26, 2008

Novotel - Champagne Ballroom

Time	Tuesday, March 24, 2008
11:30–12:15.	<b>Registration and Lunch</b>
12:15–12:20	<b>Welcome</b> <i>Ms. Kathy Scalzo</i> , Survivorship Work Group Chair
12:20 – 12:35	<b>Context setting and workshop objectives</b> <i>Dr. Margaret Fitch</i> , Canadian Partnership Against Cancer, Rebalance Focus Action Group Chair
12:35 – 12:45	<b>Roundtable introductions</b> <i>Diana Royce</i> , EdD, <i>Workshop Facilitator</i> , The Deerfield Group Inc.
12:45 – 13:25	<b>Patient Survivorship Perspective</b> <i>Ms. Lesley Washington</i> ( <i>adult perspective</i> ) Manager of Supportive Care for the Canadian Cancer Society, Alberta/NWT Division, Canada <i>Ms. Heidi Adams</i> ( <i>pediatric perspective</i> ) Founder and Executive Director, Planet Cancer, USA
13:25 – 14:10	<b>Clinical and Research Perspective of Survivorship</b> <i>Dr. Mary McBride</i> ( <i>pediatric perspective</i> ), Senior Scientist, Cancer Control Research, BC Cancer Agency, Canada

	<i>Dr. Les Robison (pediatric perspective)</i> , Department of Epidemiology and Cancer Control, St. Jude Children's Research Hospital, USA.
14:10 – 14:30	<b>Refreshment Break</b>
14:30 - 15:30	<b>Clinical and Research Perspective of Survivorship, to include USA and Canada perspectives</b>  <i>Dr. Linda Carlson (adult perspective)</i> , Enbridge Endowed Research Chair in Psychosocial Oncology, Associate Professor, Division of Psychosocial Oncology, and Adjunct Associate Professor, Department of Psychology, University of Calgary, Tom Baker Cancer Centre – Alberta Cancer Board
15:30 - 16:15	<b>International Perspective of Survivorship</b>  <i>Dr. Afaf Girgis (Australian perspective)</i> , Centre for Health Research and Psycho-oncology, Australia
16:15 – 17:00	<b>Environmental Scan</b>  <i>Dr. Svetlana Ristovski-Slijepcevic (Canada perspective)</i> , Research Consultant, Canadian Partnership Against Cancer, Canada
17:00 – 17:30	<b>Wrap-up - Key Learnings</b>  <i>Diana Royce, EdD, Workshop Facilitator</i> , The Deerfield Group Inc.
17:30	<b>Adjournment</b>  <i>Ms. Kathy Scalzo</i>
18:00 – 19:00	<b>Informal Meet and Greet</b>

<b>Time</b>	<b>Wednesday, March 25, 2008</b>
8:00–8:30	<b>Breakfast</b>
8:30–8:35	<b>Welcome</b>  <i>Ms. Kathy Scalzo</i> , Survivorship Work Group Chair

8:35–8:40	<p><b>Day 2 Workshop Objectives</b></p> <p><i>Diana Royce, EdD, Workshop Facilitator, The Deerfield Group Inc.</i></p>
8:40–9:40	<p><b>Break-out Session #1: Key issues facing Canadian cancer survivors</b></p> <p><b>TO DISCUSS:</b></p> <ol style="list-style-type: none"> <li>1. Identify the: Strengths/Weaknesses/Opportunities/Gaps in the current systems, structures and supports related to cancer survivorship in Canada</li> <li>2. What are the top issues for cancer survivors?</li> </ol> <p><b>TO REPORT BACK ON:</b></p> <ol style="list-style-type: none"> <li>3. What are the top two priority issues that your group recommends be addressed by a Canadian survivorship agenda?</li> <li>4. Note if these priority issues are relevant to adult and/or pediatric survivors</li> </ol> <p>All Participants</p>
9:40 -10:15	<p><b>Break-out Session #1: Reporting Back</b></p> <p>Rapporteurs</p>
10:15–10:35	<p><b>Refreshment Break</b></p>
10:35–11:30	<p><b>Break-out Session #2: Developing Action Plans for Priority Issues</b></p> <p>Specific tables have key issues relevant to adult or pediatric survivors identified on tent cards. Select an issue and age group of interest to you and join the discussion leader at that table to discuss:</p> <ol style="list-style-type: none"> <li>a. Why is this issue a priority component of a Canadian cancer survivorship agenda? What is its impact on survivors?</li> <li>b. What are the challenges inherent in addressing this issue?</li> <li>c. What actions need to be taken in the short and long terms to address this priority?</li> <li>d. Who needs to be involved?</li> <li>e. Are there opportunities for strategic collaboration with partner organizations?</li> <li>f. What would success look like?</li> </ol>

	All Participants
11:30 – 12:20	<b>Break-out Session #2: Reporting Back</b>  Rapporteurs
12:20 – 13:00	<b>Break</b>
13:00 – 14:00	<b>Break-out Session #3: Forging a Plan of Action: Implications for Clinical Care, Education and Research</b>  Considering the priority actions identified by workshop participants and related action plans that have been recommended: <ul style="list-style-type: none"> <li>a. What roles should this sector (either <b>clinical care, education or research</b>) play in the development and implementation of a multi-faceted national cancer survivorship agenda?</li> <li>b. What particular survivorship challenges could this sector address?</li> <li>c. What difference could this make for cancer survivors?</li> <li>d. Who needs to be involved?</li> </ul> All participants
14:00 - 15:00	<b>Break-out Session #3: Reporting Back</b>  Rapporteurs
15:00 – 15:30	<b>Next steps, concluding remarks</b> <ul style="list-style-type: none"> <li>▪ Confirming priority recommendations, action items, and processes to be incorporated into a plan to develop a Canadian cancer survivorship agenda</li> <li>▪ Concluding remarks Ms. Kathy Scalzo and Dr. Ronnie Barr</li> </ul>
15:30	<b>Adjournment</b>  Ms. Kathy Scalzo

## 12. APPENDIX C: Speakers' Biographies

**LESLEY WASHINGTON** is a leukemia and stem cell transplant survivor, having been diagnosed and treated for this disease in 2004/2005. Lesley, who is a social worker, now works as the Manager of Supportive Care for the Canadian Cancer Society (Alberta/NWT Division) where she is involved in the strategic development of supportive care programs for people living with cancer. In addition to her work with the Canadian Cancer Society, Lesley volunteers her time facilitating a Leukemia and Lymphoma Society support group for leukemia patients and their families, and is undertaking a Masters degree in Clinical Social Work, with a focus on psychosocial oncology.

**HEIDI ADAMS** is a Ewing's sarcoma survivor and the founder and executive director of Planet Cancer, an innovative model of peer support developed by and for young adult cancer survivors to aggregate, educate and empower their community members. She is also a founding member and the advocacy co-chair of the LiveSTRONG Young Adult Alliance, a coalition of nearly 80 organizations dedicated to improving survival rates and quality of life for young adults with cancer.

### **MARY MCBRIDE**

Mary McBride has degrees in Mathematics and Medical Genetics, and is a senior epidemiologist at the British Columbia Cancer Agency (BCCA), as well as Clinical Associate Professor in the Department of Health Care / Epidemiology, University of British Columbia. She also holds faculty appointments in the Department of Paediatrics and at the Centre for Health Services and Policy Research at University of British Columbia. She has a longstanding research focus on childhood cancers, and is currently the Program Leader for a National Cancer Institute of Canada-funded research program into survivorship issues for those diagnosed with cancer under age 25 years.

**LESLIE ROBISON** is the chair of the Department of Epidemiology & Cancer Control and the Associate Director, Cancer Prevention and Control at St. Jude Children's Research Hospital in Memphis, Tennessee. Dr. Robison, a pediatric cancer epidemiologist has conducted large national epidemiologic studies of childhood cancer and is currently the principal investigator of the Childhood Cancer Survivor Study, a multi-institutional consortium – now anchored at St. Jude – evaluating a cohort of more than 20,000 five-year survivors of childhood cancer. He is also Associate Chair of the Children's Oncology Group (COG), a national network of institutions and investigators who care for children with cancer. He holds current positions on numerous national committees, task forces, councils and advisory boards in the fields of epidemiology, etiology, pediatric oncology and cancer survivorship. Dr. Robison obtained his under-graduate degree in Public Health from UCLA and subsequently completed MPH and Ph.D. degrees in Public Health, and Epidemiology, from the University of Minnesota. He is the author of more than 300 original papers published in peer-reviewed journals.

**LINDA CARLSON** is the holder of the Enbridge Endowed Research Chair in Psychosocial Oncology and Associate Professor in Psychosocial Oncology in the Department of Oncology, Faculty of Medicine at the University of Calgary. She also holds an Adjunct Associate Professor appointment in the Department of Psychology. She is Director of

Research and works as a Clinical Psychologist at the Department of Psychosocial Resources at the Tom Baker Cancer Centre. Dr. Carlson trained as a Clinical Health Psychologist at McGill University in Montreal, researching the area of psychoneuroendocrinology. She worked as a post-doctoral fellow at the Tom Baker Cancer Centre in Calgary, sponsored by a Terry Fox Postdoctoral Research Fellowship from the National Cancer Institute of Canada/Canadian Cancer Society and subsequently received a Canadian Institutes of Health Research New Investigator award from 2002-2007. She has recently been awarded an Alberta Heritage Foundation for Medical Research Health Scholar Award from 2008-2012. Dr. Carlson received the Kawano New Investigator Award from the International Psycho-Oncology Society in 2006, and the William E. Rawls Prize in cancer control from the National Cancer Institute of Canada/Canadian Cancer Society in 2007.

**AFAF GIRGIS** is the Director of the Centre for Health Research & Psycho-oncology (CHERP). The Cancer Council NSW and The University of Newcastle, and Conjoint Professor in the School of Medicine and Public Health, Faculty of Health, University of Newcastle. Professor Girgis has extensively researched and published much highly regarded work in the areas of the unmet needs of cancer patients and their providers; supportive care for cancer patients; the training needs of health care providers; patient-provider interaction; and the communication skills of health professionals. She has considerable experience in developing needs assessment and screening tools and clinical practice guidelines and in training health professionals in communication skills to encourage adherence to such guidelines. She has a strong commitment to translating research in to policy and practice, and in training postgraduate students and junior researchers in behavioural and psychosocial research. She is the Chair of the Survivorship Advisory Group of the national Breast & Ovarian Cancer Centre in Australia.

**SVETLANA RISTOVSKI-SLIJEPCEVIC** is the Research Coordinator for the CIHR Team in Supportive Cancer Care at the Cancer Rehabilitation/Sociobehavioural Research Centre, BC Cancer Agency. Svetlana holds a PhD in Human Nutrition from the University of British Columbia with research interests in the sociocultural determinants of health and illness. In her previous training, she has used perspectives from social theory to explore how people of different ethnocultural backgrounds engage with broader societal discourses about food and health. As part of her new role at the Sociobehavioural Research Centre, Svetlana recently conducted an environmental scan regarding conceptualization, research and practice in cancer survivorship across Canada.

Speakers' presentations slides are available on the Canadian Partnership Against Cancer website at [www.partnershipagainstcancer.ca](http://www.partnershipagainstcancer.ca)

# SURVIVORSHIP WORKSHOP

*Photos courtesy of Dr. Afaf Girgis*



Workshop Participants

