

# National Cancer Survivorship Resource Center

## Executive Summary: Year One Overview

### Introduction

The National Cancer Survivorship Resource Center (The Survivorship Center) is a collaborative effort to shape the future of survivorship care and improve the quality of life of cancer survivors post-treatment. The Survivorship Center is managed by the American Cancer Society and the George Washington Cancer Institute (GWCI), with funding through a cooperative agreement from the Centers for Disease Control and Prevention. In April 2011, The Survivorship Center convened Operational Workgroups and an Expert Panel composed of 130 survivorship experts representing 52 diverse organizations to help shape The Survivorship Center's strategic plan and direction for the future. These experts divided into topic-focused workgroups with specific objectives and deliverables. This summary provides an overview of the accomplishments thus far and strategic recommendations of the Expert Panel.

### Quality of Life: Information Delivery Workgroup

This workgroup identified the informational needs of survivors, gaps in resources and the various channels available for survivors to access information and resources. The workgroup recommends the adaptation of existing health promotion materials and programs to meet the post-treatment needs of cancer survivors. The workgroup also recommends that health care professionals (HCP) should be aware of the various types of information and resources and communicate these resource options to survivors. To assist in survivor-HCP communication, the workgroup created three resources: a resource "prescription" pad for HCPs to give to survivors with referrals to provider, community, phone and Web based information resources; an information tip sheet for survivors to increase their awareness of cancer survivorship, possible late effects, links to resources and a checklist for finding trusted online resources; and an information resource inventory. The information resource inventory can assist both HCPs and survivors in finding a specific type of resource on a specific topic (ex: a video on physical activity or a book on late effects).

### Quality of Life: Programs and Navigation Workgroup

This workgroup discussed the post-treatment needs of cancer survivors, available resources and the process of developing, evaluating and sustaining survivorship programs. The workgroup identified a gap in research and survivorship programs directed towards medically underserved populations of survivors. The workgroup recommends that programs be evaluated to demonstrate effectiveness within specific populations and those effective programs are further disseminated. The workgroup also suggests that existing Chronic Disease Self-Management models be adapted to help cancer survivors' transition out of treatment and empower survivors to facilitate post-treatment follow-up care. The workgroup also recognizes the diverse group of HCPs assisting survivors in their recovery and recommends the inclusion of patient navigators in survivorship programs. To assist in the development of culturally tailored resources, the workgroup developed a survey to capture information on existing survivorship programs. The survey will be distributed fall 2011 to a variety of community cancer centers and incorporated into the Society's community resource connection (CRN). The CRN is a Web based tool that allows survivors, caregivers and providers to identify local resources. The workgroup also developed a survivorship program evaluation guide. This resource provides guidance for program evaluation and recommends evidence-based measurement tools to assist survivorship programs in evaluating the program's impact on survivorship. GWCI developed and launched the first in a Patient Navigator Survivorship Training series. This web-based training addresses the workgroup's recommendation to include Patient Navigators as a resource for Survivorship care.



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### **Systems Policy and Practice: Clinical Survivorship Care Workgroup**

This workgroup explored the role of HCPs in providing timely, quality care to cancer survivors and identified the clinical and educational opportunities to enhance HCP capacity. The workgroup recommends the creation of clinical survivorship care guidelines addressing the physical and psychosocial needs of cancer survivors post-treatment. They recommend the utilization of survivorship care plans to facilitate communication between HCPs and between HCPs and cancer survivors. Finally, the workgroup recognizes the need to incorporate survivorship into clinical training and continuing education programs for HCPs. Actionable steps by the group to advance these recommendations include the creation of site and symptom specific guidance grids on the follow-up care of survivors, an overview of the history and current status of clinical survivorship care guidelines and development of an inventory of available HCP trainings on survivor needs and survivorship care.

### **Policy/Advocacy Workgroup**

This workgroup focused on identifying the steps and tools necessary to educate policy makers, employers and payors on cancer survivors' medical, physical and psychosocial needs as well as corollary public health implications. The workgroup recommends educating key stakeholders on the importance of funding for research, consistent reimbursement for clinical care and the need for survivorship education and training for HCPs. To facilitate the education of key stakeholders, the workgroup will develop a series of white papers focusing on the aforementioned topics.

### **Operational Workgroups**

There are four Survivorship Center operational workgroups aimed at monitoring the project's progress and disseminating the findings and work of the Expert Panel. The four workgroups are: Evaluation, Outcomes and Surveillance, the Division Advisory Council and the Comprehensive Cancer Control (CCC) Partnership Advisory Council. The Evaluation workgroup provides guidance on the development and implementation of The Survivorship Center evaluation plan. The Outcomes Surveillance workgroup provides input on measurement resources to monitor key performance indicators outlined by each of the Expert Panel workgroups. To inform this work, the workgroup developed a landscape analysis of the current surveillance environment in cancer survivorship. The CCC and Division Advisory Councils are composed of CCC and Society staff nationwide. These councils offer a system of checks and balances as they provide input on how to leverage the work of the Expert Panel to meet the need to provide high quality survivorship care. Ultimately, these workgroups will play a significant role in disseminating the work of the Expert Panel.

### **Expert Panel Summit**

The work of the Expert Panel culminated with a meeting of the Expert Panel Steering Committee and workgroup staff leads in Atlanta, GA on August 31, 2011. The Expert Panel Summit offered an opportunity for the participants to view the products of the Expert Panel workgroups and discuss the steps necessary to develop clinical care guidance to facilitate HCPs in providing quality follow-up care to survivors. The Expert Panel recognizes that the development of clinical care guidance is a necessary first step to advance many of the strategic recommendations set forth by the Expert Panel workgroups. The Expert Panel also recommends the concurrent development of educational and program resources to empower survivors to manage follow-up care and to train HCPs on survivorship needs. These priorities, combined with the dissemination of the survivorship resources developed in year one, will be the focus of The Survivorship Center in year two. Materials developed by the Expert Panel will be available on [www.cancer.org](http://www.cancer.org) in fall 2011.

