**National Cancer Survivorship Resource Center**
**Executive Summary: Year Two 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 (The 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. A summary of these recommendations can be found on www.cancer.org/survivorshipcenter in the "Summary of The Survivorship Center Year One Activities". A summary of The Survivorship Center's Year 02 accomplishments towards meeting the Year 01 Expert Panel strategic recommendations is outlined in this report.

## Quality of Life

In fall 2011, The Survivorship Center established a presence on the Society's web site at www.cancer.org/survivorshipcenter. Dissemination of The Survivorship Center's tools, resources and messaging continued through summer 2012 both internally within the Society's departments and Divisions and externally through The Survivorship Center's Steering Committee and workgroups, GWCI's network and survivorship clinic and at professional organization and society meetings. Tools and resources include:

- Strategic Recommendations and summaries of the Expert Panel findings
- *A Cancer Survivor's Prescription for Finding Information* tear sheet for providers (www.cancer.org/survivorshipprescription)
- *Life After Treatment – The Next Chapter in Your Survivorship Journey* booklet for survivors (www.cancer.org/survivorshipguide)
- *Cancer Survivorship: A Policy Landscape* Analysis provides an overview of the current policies impacting survivorship. (www.cancer.org/survivorshippolicypapers)
- Enrollment information for the *Cancer Thriving and Surviving* self-management program pilot, a randomized control trial to understand the impact of self-management on key health outcomes, quality of life, health care utilization and empowerment to manage post-treatment survivorship issues.

In addition to developing tools and resources, the Survivorship Center continues to gather information on post-treatment programs offered through cancer centers. The *Survivorship Program Resource Inventory* was piloted among the National Cancer Institute's Community Cancer Centers and Commission on Cancer approved facilities in Florida and New England. The inventory will be used to create a compilation of resources available to post-treatment survivors and made available as a searchable online directory.

In fall 2011, GWCI Survivorship center staff hosted a meeting of industry leaders, a Roundtable on Cancer Survivorship & Chronic Care, to discuss the Chronic Care Model's application to cancer, identify aspects of health reform that may benefit cancer survivorship care, and identify principles for advancing cancer survivorship. In addition, GWCI Survivorship Center staff assisted in preparing and hosting the

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first meeting of the National Patient Navigation Collaborative (NPNC), a first-of-its-kind effort to leverage the expertise and experience of diverse stakeholders to develop and implement a strategic plan to support patient navigation as an integral part of the healthcare system. GWCI Survivorship Center staff also assisted in the delivery of the GWCI's Executive Leadership Training on Navigation and Survivorship: Finding Your Patient Focus to initiate or expand survivorship and navigation programs nationally, which provides clinical care for post-treatment cancer survivors. Both the Society and GWCI provided ongoing support to cancer survivors through each organization's existing programs and services, specifically, The Society's National Cancer Information Center (NCIC) and the GWCI's Longitudinal Navigation Network.

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

In fall 2011, Survivorship Center staff began development of clinical follow-up care guidelines for post-treatment cancer survivors. Ten cancer sites were prioritized based on survivorship prevalence and severity of long-term and late effects. The sites include breast, colorectal, prostate, head and neck, lung, cervical, uterine, endometrial and uterine cancers. The Survivorship Center Steering Committee provided guidelines expert review panel nominees. To date, Survivorship Center staff completed draft follow-up recommendations for breast and colorectal cancer. A systematic literature review was conducted; expert review panels convened and follow-up recommendations were drafted. To facilitate the dissemination and utilization of the guidelines among primary care providers (PCP), in spring 2012, Survivorship Center staff initiated planning for a web-based educational training series to raise PCP awareness of cancer survivorship as a public health priority, the role of the PCP in caring for cancer survivors after active treatment, the long-term and late effects of cancer treatment and tools and resources - including the survivorship care plan and clinical care guidelines – that PCPs can use to care for post-treatment cancer survivors. In summer 2012, Survivorship Center staff drafted a dissemination plan to identify key partners for dissemination and engagement of the clinical follow-up care guidelines.

**Policy/Advocacy Workgroup**

In fall 2011, Survivorship Center staff assisted with the preparation and delivery of the GWCI's "Cancer Health Policy Scholars Program" to educate health care clinicians and researchers in the area of policy related to cancer survivorship and navigation. This three-day program, featuring speakers from national advocacy groups, renowned cancer centers, academia, and research institutions, also included a visit to Capitol Hill for participants to meet with legislative staffers of the Senate HELP Committee and the House Committee on Energy and Commerce. In spring 2012, Survivorship Center staff held a call with the ACS Cancer Action Network (ACS CAN) to identify ways to incorporate cancer survivorship into the ACS CAN legislative agenda. In addition, Survivorship Center staff drafted a policy white paper, Executive Summary of Cancer Survivorship: A Policy Landscape Analysis (www.cancer.org/survivorshippolicypapers).

**Operational Workgroups**

In fall 2011, Survivorship Center staff developed an Executive Summary of the Year 01 activities and published it to The Survivorship Center on cancer.org. In addition, Survivorship Center staff drafted a framework of the evaluation methodology for Years 02-05. As a continuation of Year 01 activities, Survivorship Center staff reviewed the draft Program Evaluation Guide. The review resulted in significant revisions. A second draft of the guide is in progress. As part of the work to identify and develop

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resources and tools to enhance survivorship activities in the Comprehensive Cancer Control Program (CCCP), in spring 2012, Survivorship Center staff held a call to provide the CCC Partnership Advisory Council with an overview of survivorship activities, resources and recommendations from a CCC Survivorship Survey conducted in fall 2011 and spring 2012 to examine the current status of CCCP survivorship activities and resources. In addition to working with the CCCP Partnership Advisory Council, the Survivorship Center provided guidance to the CCCPs on collaborative activities to include in the new CCC funding proposal to the CDC.

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