National Coalition for Cancer Survivorship: Advocating for Quality Cancer Care for All

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As the oldest survivor-led organization advocating for quality cancer care for all Americans, the founders of the National Coalition for Cancer Survivorship (NCCS) were the first to define “survivor” and “survivorship” in relation to cancer nearly 20 years ago, and, along with our colleagues at Cancer Care, Inc., the first to participate in advocacy-related programs with ASCO. Today, NCCS is privileged to contribute to this first issue of the *Journal of Oncology Practice*.

The mission of NCCS is to advocate for quality cancer care for all Americans. We focus on how the public and private sectors research, regulate, finance, and deliver quality cancer care. As cancer survivors, we know that the first step in quality cancer care is being a knowledgeable and communicative partner with our healthcare team. As advocates, we recognize the power of working collaboratively with ASCO on cancer-related public policy issues. Whether it's co-hosting a policy briefing for reporters at the beginning of each Congress, or meeting with the Centers for Medicare & Medicaid Services, NCCS collaborates with ASCO and other organizations on program and policy issues that affect people with cancer and those who care for them.

In 2005, NCCS will focus principally in four areas that impact quality cancer care:

- **Survivorship issues** such as the long-term and late effects of cancer treatment, especially those that will be identified in the Fall 2005 Institute of Medicine report on adult cancer survivorship.
- **Medicare coverage and reimbursement issues**, particularly how the recent changes mandated by the Medicare Modernization Act may impact patient access to cancer care.
- **Food & Drug Administration reforms** that could impact the drug approval process.
- **Palliative care and symptom management issues.**

NCCS educational efforts for 2005 include an emphasis on wider dissemination of our award-winning program, the *Cancer Survival Toolbox*®. The *Toolbox* is a free program available in Spanish and English on CD-ROM and on our Web site, <http://www.cancersurvivaltoolbox.org/>. The *Toolbox* and other NCCS programs, publications, and survivorship information can be found at NCCS' main site, www.canceradvocacy.org. All NCCS publications and programs are designed to assist people with cancer to become better advocates for themselves and for others.

In 2004, NCCS launched a new grassroots initiative that builds on an individual's advocacy skills. Known as *Cancer Advocacy Now!*™ (*CAN!*), participants who join the Internet-based network at www.canceradvocacynow.org receive bi-monthly policy updates and legislative alerts. *CAN!* is designed to inform participants about current cancer-related policy issues, teach important advocacy skills, and provide *CAN!* participants with tips on talking with lawmakers. Like our work with ASCO, the *CAN!* Network creates a community of support for issues that impact everyone's access to quality cancer care.