

# Statements from the President's Cancer Panel

## *President's Cancer Panel*

### *Assessing Progress, Advancing Change: Challenges in Cancer Survivorship August, 2005*

The President's Cancer Panel held two 1-day meetings in Washington, DC, on August 25 and 26 to follow up on specific recommendations made in its 2003–2004 annual report, *Living Beyond Cancer: Finding a New Balance*. This report identified critical challenges faced by cancer survivors across the lifespan and made specific recommendations to address these challenges. The Panel considered the adoption of several of these recommendations vital to the progress of the National Cancer Program, prompting them to convene these meetings to assess progress since the recommendations were put forth and encourage commitments to advance their implementation. Key stakeholders and decision makers gathered in a roundtable format to identify actionable steps that can be taken toward furthering the Panel's recommendations.

The focus of the meeting on August 25 was: the need, following treatment, for cancer survivors to be given adequate documentation of care received (including clinical trials participation), recommendations for follow-up care, and information about relevant available resources. A single roundtable convened for the full day to address steps to develop adequate treatment records, better guidelines on long-term follow-up care, and ways to disseminate this knowledge into the field. Progress to date was reviewed, and the Panel heard of exciting initiatives already underway to develop patient-oriented clinical summaries and disease-specific guidelines for long-term cancer survivors. Participants pointed out continuing challenges: treatment information resides with multiple providers; creating treatment summaries takes time and resources; there is no standard template; communities lack electronic health records systems; clinical practice guidelines for follow-up are incomplete; cancer care follow-up is currently provided by a variety of practitioners; and data are needed that link follow-up care plans with improved patient outcomes. Despite these challenges, the group remained positive that progress can be made to implement these recommendations within the next 2 years. Specific action steps were generated and commitments made by roundtable participants.

On August 26, two separate roundtables were convened. The first addressed research issues related to adolescents and young adults diagnosed with cancer. As described in the Panel's annual report, this is an understudied population that is often grouped with other populations despite the fact that their tumor biology, developmental circumstances, and post-treatment experiences and needs can be markedly different. A significant hurdle has been reaching this itinerant population for follow-up and surveillance, which directly impacts research efforts. It was suggested that better models be developed that "go to the patient" in settings in which they feel more comfortable. Many issues relative to adolescent and young adult research and follow-up were discussed at length, and concrete

suggestions for improvement were put forth. Participants in the roundtable expressed their dedication to continuing to advance this area of research.

A second roundtable of experts looked at the Panel's recommendations relative to insurance coverage and access to care for cancer survivors of all ages. Evaluation of existing follow-up care clinics was also addressed. Insurers have a vested interest in cost-effective, evidence-based follow-up care for patients; thus, demonstrating cost-benefit advantages is one strategy for increasing coverage. Education about and awareness of available resources could enhance access to care, as could patient navigation programs that guide cancer survivors through the complex medical care system. Involving corporate partners in insurance/access issues was also proposed. Efforts to pursue studies and develop policy platforms are underway in a number of these areas. Specific steps were identified for moving the Panel's recommendations forward.

The Panel will be summarizing progress, reporting on commitments made, and proposing actions to be taken to advance change in its 2006 annual report to the President and Congress.

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The President's Cancer Panel, an advisory group established by Congress to monitor the Nation's efforts to reduce the burden of cancer, reports directly to the President on delays or blockages in that effort. For more information, visit the Panel's web site at <http://deainfo.nci.nih.gov/ADVISORY/pcp/pcp.htm>, call 301-451-9399, or e-mail to [pcp-r@mail.nih.gov](mailto:pcp-r@mail.nih.gov).