

# Statements from the President's Cancer Panel

## *President's Cancer Panel*

### *Living Beyond Cancer: Meeting the Challenges of Older Adult Survivors*

*November 04, 2003*

Adult cancer survivors-those diagnosed between the ages of 30 and 59-face challenges not unlike those of others living with a history of cancer. So concluded the President's Cancer Panel following testimony from survivors, caregivers, and cancer care professionals during a meeting held November 4, 2003, in Birmingham, Alabama. Panel members heard of the difficulties in accessing relevant post-treatment information; obtaining appropriate follow up screening and cancer care; acquiring necessary supportive services; overcoming financial and insurance-related barriers; and addressing cultural and language barriers to care. Workplace discrimination continued to be an issue for those whose cancer treatment or follow up was perceived by employers as requiring excessive or prolonged absences.

Whereas younger cancer survivors voiced their concerns about fertility issues following cancer treatment, adult survivors reiterated concerns regarding sexuality and intimacy. Ancillary services such as reconstructive surgery, physical rehabilitation, and counseling can help restore quality of life in these areas. Participants also spoke about lack of adequate pain management and disagreements between oncologists and primary care practitioners about appropriate pain control. An appeal was made to train more pain management specialists, better educate medical providers about pain, and conduct more research on pain pathways and effective pain treatments.

A diagnosis of cancer in adults can have a profound effect on immediate family. Adult cancer survivors are positioned as a "sandwich" generation-placed between raising children and caring for older adult family members. A cancer diagnosis, as well as the long-term chronic effects of cancer and its treatment, encumbers more than the survivor. Participants stated numerous times that "I" didn't get cancer, but that "we" got cancer, referring to the impact on their families as well as the need for support for the entire family.

The Panel heard from selected health care providers-a private practice community oncologist, a comprehensive cancer center pediatric neuro-oncologist, and an oncology nurse-about barriers to providing follow up cancer care services. One approach to managing long-term follow-up is providing standard post-treatment cancer care services in the community setting, coordinated by an oncologist or oncology nurse. However, it was acknowledged that comprehensive services for more complex late effects might be better managed at an academic or comprehensive cancer center. It was also noted that an unintended consequence of the Health Insurance Portability and Accountability Act (HIPAA) may be the limitations it places on the ability of cancer specialists to provide former patients with updated information on long-term effects of cancer treatment.

A representative of the American Society of Clinical Oncology described its guidelines for follow up of colon and breast cancer survivors. While useful in detecting recurrence of a primary cancer, the guidelines appear focused on surveillance rather than survivorship. The need to incorporate other post-treatment follow up, such as screening for secondary cancers, osteoporosis screening and management, and family counseling and risk assessment, may be addressed during the upcoming annual review of these guidelines.

The Panel heard again about the substantial difficulties of uninsured and underinsured citizens, for whom there are no easy solutions for obtaining cancer treatment, let alone post-treatment cancer care. Even for the insured, cancer exacts an enormous financial and emotional toll on patients and families-expressed as "the cost of survival." Addressing the long-term needs of the growing population of cancer survivors-both young and old-is a critical challenge for this nation.

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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).