

Statements from the President's Cancer Panel

President's Cancer Panel

Living Beyond Cancer: Challenges for Adolescent and Young Adult Survivors September 22, 2003

On September 22, 2003, in Austin Texas, the President's Cancer Panel held the third in a series of meetings on cancer survivorship issues. The focus of this meeting was *Challenges for Adolescent and Young Adult Cancer Survivors*. Participants diagnosed with cancer from ages 15 to 29 testified about distinct problems they face in living beyond their cancers.

The meeting opened with a portrayal of challenges to adolescent and young adult survivors. According to 1999 data, cancer was the leading cause of death due to disease for those aged 20 to 39. Disturbing trends among this group include lower participation in clinical trials, lower rates of post-treatment follow-up, high rates of lack of medical insurance, and lower overall improvement in cancer mortality rates as compared to other age groups. Adolescent and young adult survivors were referred to during testimony as the "lost cohort" due to scarcity of age-targeted research, data, and applicable health education information.

With this in mind, the Panel heard directly from adolescent and young adult cancer survivors about their post-treatment challenges and possible ways to address them. Loss of budding independence as a result of diagnosis is a major social and emotional setback; familial over-protectiveness and dependence on caregivers can become disabling. One speaker described time during and immediately following treatment as a "psychosocial stalling" that made reintegration into college and work settings especially difficult. To temper this, it was suggested that adolescents and young adults be included fully in their treatment processes and discussions of treatment effects. Additionally, more effort should be made to socialize, rather than "psychologize," members of this age group. One example is promoting discussions of "life after cancer"-including emotional challenges to expect; resources for peer and other support; and ways to address employment, insurance, and other, similar issues.

Testimony pointed to a critical need for peer-based support among this group; peers are particularly qualified to understand fears of recurrence, uncertainty, and social issues specific to adolescents and young adults. Because many in this age group are still single, worries about long-term relationships, fertility, and early menopause are prevalent. The Panel heard that speaking with others with similar experiences provides enormous benefit. It was suggested that strong peer-support relationships may also encourage compliance with recommended follow-up care, but it remains difficult for adolescent and young adult survivors to locate each other.

Employment and insurance are significant issues for this population. Participants shared examples of being "job locked" to maintain insurability, passed over for promotion, and perceived as taking unneeded leave time following the "cure" of their cancers. Uncertainty about the future-possible cancer recurrence or negative health effects from treatment-may impact career-related decisions. Gaps exist in health coverage for follow-up services and screenings other than those considered standard or symptom-related.

Concerns raised in prior meetings were again brought to the attention of the Panel, such as: the need to develop a better system for coordinating post-treatment care; need for a manageable process for documenting and transferring cancer-related medical information; desire for a centralized place to access age-appropriate survivorship information and resources; and guidelines discussing possible long-term effects. Long-term follow-up may be more difficult among this cohort because of other dynamics, including competing social priorities, a higher level of transience, and a strong drive to return to "normalcy." These need to be accounted for in developing follow-up strategies.

Adolescents and young adults make up a constituency that is often grouped together with other populations, even though the biology of their tumors, developmental circumstances, and post-treatment experiences and needs can be markedly different. The Panel will work to formulate recommendations to address knowledge and resource gaps in this area.

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.