Statements from the President's Cancer Panel

President's Cancer Panel
Survivorship Issues and Challenges Among Pediatric Cancer Survivors
September 5, 2003

The President's Cancer Panel continued its series of meetings on challenges in living beyond diagnosis and treatment of cancer in Denver, Colorado, on September 5, with a focus on pediatric cancer survivors (those diagnosed from birth to age 14). An overview of findings from the recently published Institute of Medicine report, *Childhood Cancer Survivorship: Improving Care and Quality of Life*, was followed by presentations from pediatric cancer survivors and/or their family members from various regions of the United States.

Unlike their counterparts in Europe, participants at this meeting identified with the term *survivor*, perceiving it in many respects as a "badge of honor." Many still choose, however, whether and with whom to share this personal information.

The most recent estimates show that close to 200,000 pediatric cancer survivors are alive today in the United States. The high survival rate of children with cancer is a great success story-it is estimated that 77 percent of children diagnosed with cancer up to the age of 14 will be alive 5 years later. However, it is also known that aggressive therapy at younger ages, during periods of rapid growth and development, creates significant chronic and late health effects for cancer survivors.

Defining the needs of pediatric cancer survivors and developing recommendations to address them was the focus of this meeting, with implications for future research, clinical care, and service delivery. There was universal desire for better information and communication regarding long-term effects of cancer treatment. Survivors described considerable variation in *what* information about long-term effects is shared, *when* it is shared, and *how* it is shared. Participants also asked to know more about promoting healthy behaviors and integrating complementary therapies into their long-term care.

Developing a better system for coordination of post-treatment care was raised as a significant need, both in terms of documenting medical history (including clinical trials participation) and coordinating follow-up among primary care physicians, specialists, and other health providers. It was emphasized that childhood cancer survivors have a unique medical history that is critical to communicate accurately. Participants described the difficulty of going to see multiple specialists post-treatment-e.g., oncologist, endocrinologist, dermatologist, neurologist, psychiatrist, dentist-with little or no assistance in coordinating the complex array of services among these individuals.

Creating a comprehensive "survivorship" health center where survivors can go for information, resources, and support without reliving their treatment experience-be it a virtual or physical center-was suggested. Continued funding and improved accessibility of support groups for children and families were mentioned repeatedly; such programs appear vital to families coping with childhood cancer. This desire was consistent with concerns that the burden of cancer on families and caregivers receive more recognition and support.

Speakers drew attention to the unique educational support needs of children diagnosed with cancer. The Panel heard of unpredictability in the availability and quality of tutoring during treatment and disparity in the process for integrating children back into the educational system following treatment. School systems may be ill equipped to deal with chronic conditions experienced by pediatric cancer survivors. Parents testified to struggling to get special accommodations for cognitive dysfunctions. There are also challenges posed by interrupted attendance as a result of post-treatment effects and care requirements.

The Panel will continue to deliberate on these and other survivorship issues and challenges in subsequent meetings among adolescent, young adult, and older adult age groups.

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.