Statements from the President's Cancer Panel
Meeting

Improving Cancer Care for All: Real People, Real Problems
February 1-2, 2001

"I'm not going to do anything about it. I'll just die. I don't want to go to the grave with debt left to my family." This statement from a native Alaskan woman is a graphic example of the cultural and economic factors that prevent some Americans from getting the best available cancer care. On February 1-2, 2001, testimony presented to the President's Cancer Panel in Los Angeles by patients, survivors, family members, health officials, and health care providers from the western and Pacific regions of the United States gave human dimensions to the problem of cancer-related health disparities.

Some of the problems described by speakers from this region echoed the issues addressed in four previous regional meetings, including cultural, financial, geographic, and institutional barriers. Members of some communities avoid cancer screening because they believe the disease is shameful or contagious, because of distrust of health care providers, or because they know they cannot afford the necessary treatment. Cultural barriers persist: Native Americans and Asian Americans said that assertiveness is considered rude in their cultures; members of these populations are less likely to demand the information they may need to make the best decisions about their care. A Vietnamese woman testified to fear of talking about cancer, about the stigma attached to a diagnosis of cancer, about fear of becoming a financial burden on the family, and about the lack of knowledge about diagnostic tests, and preference for traditional Vietnamese physicians.

The Panel heard additional testimony from patients who are uninsured and underinsured. These patients are often diagnosed in later stages of cancer because they lack access to early detection; they also experience long delays between diagnosis and treatment caused by barriers to obtaining financial support. Grant-supported community outreach programs, by their very nature, lack sustainability beyond the period of the grant. Geographic isolation affects both providers and patients: services are not available in remote areas, and the distances traveled to receive care place both financial and social burdens on patients and their families. Language, lack of transportation, racialism (inherent biases toward providing care, such as for pain, according to race), failure of providers to understand cultural imperatives, and lack of coordinated services, resulting in failure to provide palliative care, were also cited as barriers to adequate care.

Several new issues were raised during this meeting. People with disabilities do not receive the same standard of screening; they face both physical barriers (including the lack of adaptive clinical equipment and procedures) and attitudinal barriers (including providers unwilling or unable to provide assistance to patients with physical disabilities). Gay and lesbian cancer patients face medical barriers (denial of care or substandard care), insurance barriers (discrimination and privacy issues), lack of social support (estrangement from family, partners denied participation in medical decision making, and lack of meaningful support groups), and exclusion from national research studies.

Two speakers at the Los Angeles meeting raised new questions about the financial barriers to care for cancer patients. Why does it take so long to turnaround applications for Social Security and disability insurance coverage for cancer patients? Why couldn't cancer patients, like victims of end-stage-renal disease, be made automatically eligible for Medicare upon diagnosis.

Upon taking control of the Pacific Territories, the United States made a commitment to the well-being of its new citizens, but the Panel heard moving testimony that per capita expenditures on health care in this area are a small fraction of those on the mainland, and few reliable statistics about the incidence and prevalence of cancer exist. Geographic issues are critical; travel to receive diagnostic tests and care is expensive-often costing as much as the treatment itself. In the Pacific Territories, patients often have to travel several thousand miles to Hawaii for treatment; in Alaska, the majority of towns and villages are located "in the bush" and patients can only reach cancer care by air. Western medicine's emphasis on the individual is often at odds in the islands with cultural values of family rooted in land ownership, harmony, tradition, and spirituality. Cancer care is no exception; for example, a woman may elect to forego cancer care if she and her family decide it is not in the best interests of the family or if accessing public assistance requires the loss of all material possessions, including land. Providing health care within this constellation of cultural concerns is a challenge for health workers in Hawaii, who are urging native Hawaiians to seek cancer screening and treatment for the sake of their children. It becomes even more complex in the Pacific territories.

The President's Cancer Panel is an advisory group established by Congress to monitor the Nation's efforts to reduce the burden of cancer. The Panel reports directly to the President annually on delays or blockages in that effort. The Panel is currently holding a series of regional meetings to explore problems that prevent us from getting the best known cancer care to all people. Participants in the Los Angeles meeting included representatives from Alaska, California, Hawaii, Nevada, Oregon, Washington State, and the U.S. Pacific Territories. 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.