

# Statements from the President's Cancer Panel Meeting

*Improving Cancer Care for All: Real People, Real Problems*  
**October 12-13, 2000**

A diagnosis of cancer is a terrifying experience for approximately 34,000 people in the United States every day. The experience is made even more difficult by barriers erected through lack of information, lack of support, lack of cultural sensitivity, lack of insurance, and confusing reimbursement criteria even when health care coverage is available. Passionate testimony before President's Cancer Panel in Billings, Montana on October 12th and 13th, 2000, put human faces on these issues as patients, survivors, family members, state health officials, and health care providers graphically highlighted the barriers they face in accessing and providing health care in Idaho, Minnesota, Montana, North Dakota, South Dakota, Wisconsin and Wyoming.

Although this region of the country is characterized by a pioneer stoicism and Native American pride that allows people to endure tremendous hardship, the financial barriers created by lack of insurance among the poor or self-employed, as well as underinsurance and high deductibles, are devastating. Cancer survivors may lose jobs, homes, and businesses as the impact of the disease and cost of care forces them into severe debt or bankruptcy. Disparities in access created by unequal Medicare and other insurance reimbursement for services at distant medical centers versus local, rural clinics compounds these hardships. The lack of reimbursement parity between medical centers and even capable rural clinics is large enough that chemotherapy or pain medication sometimes can not be dispensed locally, because health care reimbursement, if available outside of a medical center, does not even cover the full cost of the drug. Similarly, even large medical centers cannot always afford the costs to bring complex technologies to rural areas, where the patient volume is too low and the reimbursement insufficient to offset the cost. For the poor, screening for breast and cervical cancer may be available through programs funded by the Centers for Disease Control, but there have been no programs that can provide treatment for the newly diagnosed.

There are also physical barriers created by the rural frontier nature and vast, sparsely populated expanses in many of these states. Likewise, the harsh weather experienced in this region of the country may prevent or delay travel to nearest medical facility, interrupting treatment regimens. On the other hand, simple lack of available skilled physicians or medical facilities capable of delivering necessary treatment, even for those with insurance, makes travel outside the home state a necessity for individuals with rare diseases needing complex treatments or requiring treatment in a Veterans Administration facility.

Lack of information related to cancer, including guides to healthy behavior as well as information about screening, treatment, pain management, and palliative care

options, was repeatedly cited as a problem by cancer survivors, providers, and their families. This is a special problem for Native Americans, whose social history in the United States has made them distrustful of non-Native Americans and whose cultural history has made the discussion of cancer unacceptable, even among family members, for fear that discussion will bring cancer to the reservation. When cancer screening is available and accepted on a reservation, there are limited options for treatment. The Indian Health Service (IHS), the principle provider of service, interacts with other health care payors in a very complex way; it appears to make the IHS the payor of last resort, but also the portal through which all Native Americans living on reservations must enter the health care system. Lack of continuity of health care providers who rotate through the reservations for very short durations has further eroded Native American trust in the system. This lack of trust and the general inadequacy of culturally tailored educational materials has created barriers to access to cancer care not only for Native Americans, but for African Americans living in this region of the country.

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. 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).