

Statements from the President's Cancer Panel Meeting

Improving Cancer Care for All: Applying Research Results, Ensuring Access, Ending Disparities

March 8, 2000

"Current knowledge is not being applied sufficiently or consistently to alleviate the burden of cancer in the neighborhoods of America," stated Panel Chairman, Harold Freeman, in the first of a series of meetings to be held in 2000 and 2001. These meetings, he stated, will focus on the disconnect between advances in research findings and the delivery of the benefits from those findings to the public. This disconnect hinders the rapid application in the community of cancer-related discoveries for the benefit all people with cancer and those at risk.

In his report to the Panel, Dr. Richard Klausner, Director of the National Cancer Institute, expressed his support for the Panel effort and restated his conviction that improving access to cancer for all Americans will require a greater integration of basic research and public health concerns, rather than a static process in which research findings are "translated" into clinical applications. "Public health issues," he argued, "should determine which research questions are asked, how research programs are designed, where research is conducted, and how findings are disseminated." Dr. Klausner noted that disparities must be monitored and defined before they can be eliminated, suggesting that factors affecting access to care are similar to other risk-related factors that must be studied to reduce the impact of cancer.

Other representatives from federal and private and advocacy organizations presented diverse concerns for the Panel to consider in convening its future meetings. Dr. Edward Sondik, of the National Center for Health Statistics, said that there is little understanding of why disparities exist and whether they will change with changes in the health care system. He recommended short- and long-term research efforts to first identify the causes of disparities and longitudinal studies of the effects of various factors, such as poverty, housing, income, and class, on cancer outcomes. Dr. Charles Bennett, of the Veterans Administration, called attention to the effects of literacy levels and issues of trust, that can impact the utilization of care even among a population with access to care. He also cited frustration at the lack of Medicare funds to pay for treatment of disease diagnosed through clinical trials. Dr. Allan Rosenfield, of the Mallman School of Public Health at Columbia University, cited the disparity in funding for medical and public health research. He recommended working closely with community-based groups to focus national attention on the problems of the underserved.

Dr. Otis Brawley, of the NCI's Office of Special Populations Research, explained that for many underserved Americans, their health problems begin with environmental and social causes long before those individuals present themselves for

diagnosis. He cited studies supporting the hypothesis that equal care produces equal outcomes. Dr. Brawley also argued that while education is often described as a civil right, access to quality health care can be described as a human right.

Dr. Robert Hiatt, of the NCI's Division of Cancer Control and Population Sciences, related disparity issues to broader social and cultural issues, suggesting that many of the problems confronted by those trying to eradicate cancer are the same problems faced by society as a whole.

Ms. Susan Butler, of the Ovarian Cancer National Alliance, observed that scientists often talk exclusively to each other. She recommended taking advantage of outside experts to learn how to effectively deliver information to the public and to policy makers. Ms. Butler said that change only comes when the misery level becomes high enough. She suggested that the key to effective community activism is partnership, citing AIDS community activism during the 1980s as an example.

Dr. Ralph Coates, of the CDC's Division of Cancer Prevention and Control, proposed addressing disparities by identifying specific points of concern and developing public health solutions. Community concerns, social issues, biases, and economic forces must be considered in designing community interventions, and all interested parties, including the underserved, insurers, and practitioners, must be involved in planning and evaluating interventions.

Dr. Peter Greenwald, of the NCI's Division of Cancer Prevention, recommended that the Panel look at the President's proposed Patients' Bill of Rights as a model for its discussion of disparities in access to cancer care. He suggested that the concept should be broadened to become a Public Health Bill of Rights.

Dr. Don Sharp, of the CDC's Office on Smoking and Health, described CDC efforts to reduce smoking among American youth. He stressed the need to increase smoking cessation as a means of quickly meeting Healthy People 2010 goals, since cessation shows more immediate effects than prevention. He also argued in favor of dedicating larger portions of tobacco settlement payments to State anti-smoking campaigns.

Dr. Jon Kerner, of the Lombardi Cancer Center, pointed out that no single agency has the responsibility to ensure diffusion of new knowledge, but NCI acknowledges its role and will work with others to find solutions. He said that not enough is known about infrastructure problems or how to influence public demand for quality cancer care. Dr. Kerner observed that many cancer centers are located near communities that are disproportionately affected by cancer, but spend little or no effort reaching out to those communities. Cooperative efforts are needed to train practitioners in communities with the greatest need.

In his closing remarks, Dr. Freeman said that he agreed with Dr. Klausner on the need for integration of research and care delivery, but he stressed the point that there is a need for action in the communities of America that lies outside the context of

research. While research must be ongoing, he argued, we must deliver the best care that is available to all who need it. "American science," Dr. Freeman concluded, "is at a crossroads--recent advances in basic science and technology are mindboggling, but the scientific community has not paid adequate attention to the quality of care for all Americans." There is not an adequate balance between discovery and delivery. The challenge for all of those involved in the effort to fight cancer is to maintain a dialog with the goal of reconnecting and integrating these two essential components of that effort.