

Statements from the President's Cancer Panel

*President's Cancer Panel
Living Beyond Cancer: A European Dialogue
May 27-28, 2003*

The President's Cancer Panel held its first international meeting in Lisbon, Portugal, May 27-28, commencing a series of new meetings to consider challenges in living beyond diagnosis and treatment of cancer. Present on behalf of the Panel were Dr. LaSalle D. Leffall, Jr., Chair; members Dr. Margaret Kripke and Mr. Lance Armstrong; former Panel Chair Dr. Harold P. Freeman; and National Cancer Institute Director Dr. Andrew von Eschenbach. A distinguished group of experts presented an overview of cancer survivorship statistics and trends in both Europe and the United States, followed by presentations from cancer survivors and care providers from various regions of Europe.

The term *survivor* met with ambivalence from European representatives who testified; many stated that there is no such word in their native languages. The concept of "survival" appeared to be perceived as medically related-i.e., prevailing through one's treatment-rather than focusing on an extended life beyond cancer. Stigmatization of cancer and its association with death was a common theme during the one and a half days of testimony: "We don't talk about cancer much because we don't want to be viewed as different, weak, or disabled." (Swiss participant); "There is no discussion about cancer because it is usually a synonym for death." (Portuguese participant); "No one knows I have cancer, and people would not believe it anyways." (participant from Spain). In the United Kingdom, one provider/advocate noted she has rarely heard people describe themselves as survivors. The message to the Panel was that in Europe, unlike in the United States, talking about cancer remains taboo; symbols of survivorship, like Lance Armstrong, are far from customary.

While the language of survivorship may differ, Panel Chair Dr. Leffall reflected that many stories were, nevertheless, the same. The Panel heard about a common desire to return to some form of "normal life"; receive support in transitioning from the intense personal care provided during treatment to self-reliant daily living; receive assistance for long-term emotional as well as physical/clinical needs; and transform the experience of cancer into something positive-i.e., through advocacy, volunteerism, and other means. Information presented to the Panel indicates a changing demography and the beginning of a culture of survivorship among Europeans affected by cancer. A steady increase in the number of people living with a history of cancer for longer periods of time is raising awareness of survivorship issues across the European community. Globally, there are an estimated 22.4 million people with a history of cancer. Dr. von Eschenbach reflected on this "strategic moment" of changing metaphors and views of cancer. "We are beginning to view cancer not only as an acute disease to be eradicated, but as a chronic disease to be

managed long-term, whereby one ultimately dies of something else." This creates, the Panel noted, medical, social, and political challenges to determine how to best reduce suffering and promote long-term quality of life-the "science" of living beyond cancer.

This meeting illustrated opportunities for collaboration and sharing of best practices in many areas. Cancer is a global problem, and its burden is enormous. Surviving treatment is not the end of the story, remarked Panel member Dr. Kripke; many gaps in service and care remain for European citizens, and personal stories vividly illustrated these points. While we are "blessed" in the United States with excellent treatment for cancer, this care is not available to all citizens; access to care is not an absolute right in the United States (as it is in Europe). This is a deficiency the Panel continues to address. As with its deliberation of other matters of significance to the National Cancer Program, the Panel hopes to put a human face on the issues related to cancer survivorship and develop concrete recommendations for change.

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.