

**MEETING SUMMARY
PRESIDENT'S CANCER PANEL
THE NATIONAL DIALOGUE ON CANCER
RESPONDS TO VOICES OF A BROKEN SYSTEM**

December 7, 2002
Washington, DC

OVERVIEW

The President's Cancer Panel (PCP) was chartered to monitor and evaluate the development and execution of the National Cancer Program and to report to the President on barriers to Program implementation. Throughout 2000 and 2001, the Panel held seven regional meetings exploring issues that prevent Americans from receiving the best cancer care available. Those meetings resulted in a report entitled *Voices of a Broken System: Real People, Real Problems*. On December 7, 2002, the Panel met with representatives of the National Dialogue on Cancer (NDC) to discuss ways in which other organizations can help evaluate and implement the Panel's recommendations.

MEETING PARTICIPANTS

President's Cancer Panel

LaSalle D. Leffall, Jr., M.D.

Harold P. Freeman, M.D.

Lance Armstrong

National Cancer Institute

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, PCP

Speakers

Elizabeth Duke, Ph.D., Administrator, Health Resources and Services Administration

Robert L. Comis, M.D., President and Chairman, Coalition of National Cancer Cooperative Groups, Inc./

Group Chair, Eastern Cooperative Oncology Groups, Alpha Oncology, Inc.

Patricia Nolan, M.D., M.P.H., Director of Health, Rhode Island Department of Health

Donald S. Coffey, Ph.D., Professor, Johns Hopkins School of Medicine

Charles Cutler, M.D., Chief Medical Officer, American Association of Health Plans

Gary M. Reedy, President, Ortho Biotech Products, L.P.

Armin Weinberg, Ph.D., Co-Founder, Intercultural Cancer Council

OPENING REMARKS—DR. LaSALLE D. LEFFALL, JR., CHAIRMAN

On behalf of the PCP, Dr. Leffall welcomed invited participants and guests and provided a brief history of the series of regional PCP meetings held in 2000 and 2001, during which the Panel heard testimony from nearly 400 people—representing all 50 states and the territories of America—about barriers that prevent them from receiving timely and effective cancer care services. Dr. Leffall acknowledged the presence of Dr. Paul Calabresi, who served as a PCP member at the beginning of that series of meetings.

- Dr. Leffall emphasized that the purpose of the meeting was to solicit feedback from related working groups of the NDC on what role other organizations can play in evaluating and implementing the Panel’s recommendations.
- Dr. Leffall encouraged all present to provide testimony, either during the meeting or in writing.
- Dr. Leffall acknowledged the presence of Dr. Paul Calabresi, a former Panel member and a current member of the National Dialogue on Cancer.
- In introducing Dr. Harold Freeman, Dr. Leffall commended Dr. Freeman for his years of service as Chair of the PCP.

VOICES REPORT AND VIDEO—DR. HAROLD FREEMAN

- Dr. Freeman observed that statistics are “numbers with the tears washed away.” He explained that the Panel had sought, through its series of regional meetings, to collect the stories of cancer patients, survivors, family members, and caregivers so that the statistics on cancer morbidity and mortality could be understood in the context of human experience. The report *Voices of a Broken System* is part of the Panel’s promise to those who testified to bring their story to the President, Congress, and other organizations able to impact the current system of cancer treatment.
- Dr. Freeman presented a brief video that contained excerpts from the remarks of individuals who provided testimony at the regional meetings.
- Dr. Freeman stated that the Panel learned from this testimony that many who seek cancer treatment are turned away; others do not seek treatment because they know they cannot pay for it. Some Americans face cultural and language barriers that make compliance with treatment difficult. Many are not seen until their disease is at an advanced stage.
- Dr. Freeman asked those in attendance to remember the faces seen and the stories that were told in the video. It is morally unacceptable, he stated, for Americans with cancer to go untreated, be bankrupted by treatment, or be required to fight the system harder than they have to fight the disease.
- Dr. Leffall thanked Dr. Freeman and explained that six representatives of the NDC would make presentations, followed by a period of open discussion.

ACCESS TO QUALITY CANCER CARE TEAM—DR. ELIZABETH DUKE

- Dr. Duke stated that she was speaking not as the Administrator of the Health Resources and Services Administration (HRSA), but as a spokesperson for the NDC Access to Care Team. She polled Team members concerning the questions sent by the Panel in advance of this meeting.
- The Team recommends that all insurance providers include coverage for cancer prevention as well as early detection and treatment. Catastrophic coverage should also be required for all Americans. Patient choice and access to disability coverage were identified as important issues.
- The Team considers lack of reimbursement for prescription drugs, including drugs to control side effects of treatment, a critical issue. A standard package of coverage should include screening, diagnosis, treatment, and palliative care. Incentives should be provided for practitioners to enroll patients in clinical trials by reimbursing them for the extra care involved.

- Other related issues the Team has focused on include educating health professionals in cultural competency, bringing minorities into health professions, eliminating bias in care, and ensuring wider disbursement of health professions across the country.
- Speaking as HRSA's Administrator, Dr. Duke noted that the agency is trying to increase participation of minorities in health care and extend the geographic distribution of health professionals. A program called Kids Into Health Careers seeks to engage children in the fourth through sixth grades to stimulate an interest in health-related careers.
- In her HRSA capacity, Dr. Duke also called attention to the Nurse Reimbursement Act, which attempts to address the nursing shortage, and an expansion of the Health Centers Network, which seeks to ensure broader access to care. The first Cancer Collaborative has been launched, involving 12 Centers in the Network..

CLINICAL TRIALS TEAM—DR. ROBERT L. COMIS

- Dr. Comis observed that in the last 10 or 15 years, issues related to clinical trials have come to the fore in discussions of access to quality cancer care. This is a large problem for all people, not just the underserved.
- Only 3 to 5 percent of adults with cancer participate in trials; thus, it takes an inordinate amount of time to bring beneficial treatments to the general public.
- The Clinical Trials Team has produced a document called *Barriers to Clinical Trials Participation*, which summarizes surveys on the subject of clinical trials. The Team has met with providers to address structural issues by developing models for best practices.
- The Team is addressing the fact, also mentioned by Dr. Duke, that doctors lose money when they put patients into clinical trials; it is collecting evidence to make the case for a more equitable level of reimbursement.
- Because most interesting new molecules are developed and owned by industry, the Team is addressing ways to improve collaboration among industry, the Government, and the clinical trials community in order to increase the speed of development.
- The Team is exploring ways to translate global issues into state and local issues, with an emphasis on incorporating clinical trials issues into state cancer plans.
- The Clinical Trials Team, in collaboration with the Teams on State Plans, Access, and Communications, plans to address issues related to underserved populations.
- Cooperative Groups are working with the National Medical Association and other organizations to find ways of increasing African-American and Hispanic participation in breast cancer prevention trials.
- Participation of underserved populations in therapeutic trials is low. The Coalition of National Cancer Cooperative Groups is sponsoring research into differences in attitudes toward clinical trials among African-American, Hispanic, and Appalachian populations. These findings will be incorporated into activities of the other NDC Teams.

STATE CANCER PLAN TEAM—DR. PATRICIA NOLAN

- Dr. Nolan stated that the goal of the State Cancer Plan Team is to ensure that by the end of 2003, each state has a data-driven plan for comprehensive cancer control developed by appropriate stakeholders, and that by 2005, the states will have implemented these plans.
- Within the past 10 years, the impetus for creating state cancer plans has grown out of the Centers for Disease Control and Prevention (CDC) Breast and Cervical Cancer Programs (BCCPs), which have concentrated on some of the issues identified by the PCP in its report. By increasing the number of women screened, these programs contributed to the adoption of policies in some states to provide Medicaid coverage of diagnostic work for women with abnormal screens.
- Galvanizing energy at the state level helps influence Federal policy. It also encourages the kind of coordinated efforts needed to address issues described by representatives of other NDC Teams.
- Dr. Nolan displayed a slide showing that most states either have implemented cancer control plans or are in the process of updating or creating plans. Eight states are not actively involved in the planning process.

- The State Cancer Plan Team seeks to translate some of the work of other NDC Teams into agendas for state planning officials to consider.
- The American Cancer Society (ACS), NCI, and CDC, all participants in the NDC, are sponsoring regional leadership institutes, bringing state leaders together to promote the planning process. The Team is looking into additional ways to involve NDC partners in cancer planning at the state level.
- The issues cited in the PCP report most relevant to the state cancer planning process are those focusing on the need for cancer information and improved access to service, which are activities that occur at the community level.
- Comprehensive state cancer control plans provide a means of measuring success and ensuring accountability in efforts to increase access to care.
- Recommendations in the PCP report relating to extending services to rural, frontier, and other underserved areas and promoting flexible use of categorical funds address important issues in the development of state plans.

WORK FORCE TEAM—DR. DONALD S. COFFEY

- Dr. Coffey noted that for the first time, he is beginning to see disparate organizations coming together to solve problems such as those identified in the PCP report.
- The nursing shortage is critical. Dr. Coffey reported that the number of deaths is inversely related to the number of nurses. For every dollar spent on nursing education, \$48 is spent training physicians. Allied health sciences, such as social work and public health, are in a similar situation.
- The cost of practicing medicine is making it difficult for many specialists to make a living. Obstetric and gynecology clinics are closing in many cities or restricting patient access to services.
- The NDC is working with the NCI, CDC, and HRSA to share information and develop strategies for addressing shortages among the 182 subcategories of health professions related to oncology.
- The Work Force Team is also working on these questions with representatives of other organizations, such as the National Association of Social Workers, Oncology Nursing Society, American Association for Cancer Research, the American Society of Clinical Oncology, and the American Society for Therapeutic Radiology and Oncology.
- Research has made it possible to reduce the burden of cancer, but this benefit cannot be delivered unless caregivers can be brought into communities. Going from bench to bedside means going to the street and to the country road.

AMERICAN ASSOCIATION OF HEALTH PLANS—DR. CHARLES CUTLER

- Dr. Cutler expressed his organization's support for the recommendations contained in the PCP report. Health plans, he stated, are doing many things in support of these recommendations. Such practices include education of health plan members; specific programs to increase screening in underserved populations; coordination of care; increased coverage of clinical trials; and decreased use of preauthorization and other administrative barriers.
- Increasing numbers of health plans are offering greater flexibility, although this is offset in some cases by less comprehensive benefits.

- Health plans use peer-reviewed medical evidence, as well as guidelines from professional organizations in making decisions on what to cover. To improve this decision-making process, better measures of outcomes and cost-effectiveness are needed.
- Rapidly increasing health care costs are putting pressure on the ability of health plans and other organizations to provide coverage. Some people are choosing benefit designs that cover only catastrophic illness, not screening or prevention. Health plans are looking for ways to provide comprehensive coverage that people can afford.
- The Panel's recommendations include consistent benefit design; however, the Association favors a design that considers clinical value and affordability in providing a choice of options, since not all people may be able to afford the same benefit package.
- Issues not addressed in the PCP *Voices* report include: (1) What constitutes quality cancer care?¹ (Some health plans have used National Comprehensive Cancer Network guidelines.) (2) What quality information and measures should be available to patients, physicians, and health plans? and (3) What information would be useful to consumers and employers to make informed decisions?

CEO ROUNDTABLE'S GOLD STANDARD TASK FORCE—MR. GARY M. REEDY

- Mr. Reedy explained that the CEO Roundtable is an arm of the NDC designed to engage American's corporate leadership in the fight against cancer. In its first two meetings, the group identified several issues it wanted to address, including early detection, prevention, and paying for the costs of clinical trials.
- At its third meeting, in June 2002, the Roundtable heard evidence from an ACS-sponsored study demonstrating the benefits of prevention, education, and early detection in reducing the impact of cancer on the workplace. Evidence was also heard that increasing access to clinical trials does not necessarily increase the cost of patient care. At that meeting, the Roundtable committed itself to developing and implementing a Gold Standard corporate cancer plan.
- In October, a group of senior Human Resources officers and corporate medical directors met to discuss various employee retirement and dependent populations and share information on best practices. This meeting produced a consensus on the elements of corporate Gold Standard:
 - Culturally sensitive assessment and planning that measure progress against corporate, health plan, and individual behavior targets
 - A worksite policy that includes leadership from the CEO and senior management to foster a workplace that supports smoking cessation, physical activity, diet, nutrition, screening, and standard-of-care treatment
 - Health promotion, encompassing onsite cancer control services, transportation, and help in arranging services to boost participation rates
 - Benefits design, ensuring no-cost coverage for prevention and screening services with reduced premiums or time-off incentives to capture the benefits of increased screening compliance
 - Patient support to minimize the stigma of a personal or family cancer experience and leverage health benefits through use of patient navigators and case managers

¹ The PCP addressed the definition of *quality care* in its 1997–1998 report, *Cancer Care Issues in the United States: Quality of Care, Quality of Life*.

- These elements will undergo several rounds of editorial review and will be presented to the full CEO Roundtable in spring 2003; they will then be brought to the NDC for endorsement.
- The group that met in October to develop the Gold Standard has recommended that it be widely publicized and that implementation guidelines be developed. The group also recommended establishing an ACS Gold Standard Award to recognize companies that meet these standards, as well as a Charter Gold Standard Award for CEO Roundtable corporations that commit to implementation of the standards by January 1, 2004.

ACCESS TO QUALITY CANCER CARE TEAM—DR. ARMIN WEINBERG

- Dr. Weinberg thanked the Panel for the opportunity to link the activities of the NDC with those of the PCP. He praised the Panel's report, *Voices of a Broken System*, for allowing NDC partners, whether public, private, or nonprofit, to walk in others' shoes and reenergize their commitment to addressing issues of access to care.

OPEN DISCUSSION

- Ms. Susan Braun, of the Susan G. Komen Breast Cancer Foundation, noted that the American Society of Clinical Oncology, the Komen Foundation, and several other organizations are supporting a study by the RAND Corporation and the Harvard School of Public Health on the quality of cancer care. This study is examining patient records to determine whether minimum standards are being practiced at several institutions around the country.
- Dr. Cutler added that the NCI and the National Quality Forum are working together to develop measures of cancer care quality, and the American College of Surgeons maintains an extensive database of quality-of-care information on its Web site.
- Dr. Martin Murphy, Executive Editor of the peer-review journal *The Oncologist*, commended the CEO Roundtable for its bold initiative.
- Dr. Anna Barker asked Dr. Freeman to estimate the number of Americans who are not receiving a reasonable standard of care and asked whether the Panel had any statistics on the underinsured population. Dr. Freeman said that an estimated 7 percent of people with cancer are not insured, whereas 15 percent of the general population is not insured. This difference exists because many people with cancer are old enough to be covered by Medicare. Thus, of 1.2 million new cancer cases per year, about 80,000 occur among the uninsured. One of the Panel's primary recommendations in the *Voices* report is to provide immediate medical coverage for the uninsured upon a diagnosis of cancer. Dr. Barker mentioned that a proposal to meet this recommendation through Medicare was not well received on Capitol Hill, in part because there is a misperception that the number of uninsured is higher.
- Dr. Nolan stressed the importance of the fact that states are now able to provide Medicare coverage for women who receive positive breast or cervical cancer screens through CDC-supported programs. Expansion of this model for colorectal and prostate cancers should be considered.
- Dr. Coffey asked that the report from this meeting reflect how quickly and effectively several Government agencies, including HRSA, have responded to help the NDC. He pointed out that the first President Bush was very supportive in the early days of the NDC. Dr. Coffey also thanked the ACS for its leadership.
- Dr. Judith Salmon Kaur, of the Mayo Clinic, who is Principal Investigator for the American Indian/Alaska Native Leadership on Cancer—part of NCI's Special Populations Network (SPN), thanked the PCP for its work over the years and Dr. Freeman in particular for his leadership in establishing the SPN. She volunteered to serve as a liaison between the SPN and the Clinical Trials Team.
- Dr. Karla Birkholz, of the American Academy of Family Physicians, praised the CEO Roundtable for its commitment to involving corporations in cancer prevention. The understanding that prevention is cost-effective is a major breakthrough. The Academy supports providing a package of coverage for basic needs, with no copay for screening procedures, accompanied by a flexible package for catastrophic coverage. She said that she supported coverage for cancer patients but expressed concern over the idea that one might have to have cancer before getting health care coverage. Dr. Freeman responded that the Panel's recommendation was not intended to suggest a lack of support for universal health coverage; rather, the Panel wanted to say that there is a moral and ethical imperative to provide care for people with a uniformly lethal disease.

- Mr. Reedy acknowledged the assistance of several people and organizations that helped the CEO Roundtable, including Marty Murphy, Roger Sullivan, Marguerite Donoghue Baxter, Bob Ingram, and the ACS.
- Dr. Weinberg noted that the Panel's report has demonstrated that the problem of access to cancer care is not limited to racial or ethnic minorities but is, rather, a problem faced by all Americans.
- Lance Armstrong thanked everyone for attending and urged the NDC to remain focused on its goals.
- Dr. Freeman observed that in the Chinese language, the word for *crisis* also means *opportunity*. He stated that the crisis of a broken health care system presents an opportunity to synergize the efforts of the PCP, NCI, NDC, ACS, the states, and others to transform and transcend the current health care system.

CONCLUDING REMARKS—DR. LaSALLE D. LEFFALL, JR.

- Dr. Leffall thanked his colleagues on the Panel, the invited speakers, and those in the audience for their attendance and attention to the issues raised by the PCP in its report; he also thanked Dr. Maureen Wilson, the Panel’s Executive Secretary, and her staff for their support.
- Dr. Leffall noted that the theme of prevention was heard repeatedly during this meeting. A surgeon who removes a cancer receives praise, while someone who advocates preventive lifestyle changes is often ignored. However, the goal of prevention is “to have people die young as late in life as possible.”
- Another theme to keep in mind, Dr. Leffall noted, is the focus on the patient. He stated that some patients have told him, “If I have to be like this, I would rather die.” People want to live, but they want to live with a meaningful quality of life. The hope expressed at meetings like this is not unrealistic but reflects real optimism that more can be done to help people with cancer.

I certify that this summary of the President’s Cancer Panel meeting, *The National Dialogue on Cancer responds to **Voices of a Broken System***, held December 7, 2002, is accurate and complete.

Certified by:

Date:

3/7/03

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Chair
President’s Cancer Panel