# MEETING SUMMARY PRESIDENT'S CANCER PANEL

# STRATEGIES FOR MAXIMIZING THE NATION'S INVESTMENT IN CANCER

January 28, 2008 New Orleans, LA

#### OVERVIEW

This meeting was the fourth in the Panel's 2007/2008 series focusing on strategies for maximizing the nation's investment in cancer. The meeting was designed as an interactive, facilitated working session to describe a vision for the future of the National Cancer Program and strategies for achieving that vision.

#### **PARTICIPANTS**

## President's Cancer Panel (PCP)

LaSalle D. Leffall, Jr., M.D., F.A.C.S., Chair

Lance Armstrong

Margaret Kripke, Ph.D.

## National Cancer Institute (NCI), National Institutes of Health (NIH)

John Niederhuber, M.D., Director, NCI

Abby Sandler, Ph.D., Executive Secretary, PCP, NCI

## Roundtable Participants

Kathryn Giusti, M.B.A., Founder and Chief Executive Officer, Multiple Myeloma Research Foundation and Multiple Myeloma Research Consortium

Kevin Guidry, M.H.A., Administrator, Our Lady of the Lake Cancer Center

Mark Israel, M.D., Director, Norris Cotton Cancer Center, Dartmouth-Hitchcock Medical Center

Barnett Kramer, M.D., M.P.H., Associate Director for Disease Prevention, Office of Disease Prevention, National Institutes of Health

Martin Murphy, Ph.D., Convener and Chief Operating Officer, CEO Roundtable on Cancer, and Founding Chairman and CEO, AlphaMed Consulting, Inc.

Scott Ramsey, M.D., Ph.D., Physician, Cancer Researcher, and Health Economist, Fred Hutchinson Cancer Research Center

Jonathan Samet, M.D., M.S., Professor and Chair, Department of Epidemiology, The Johns Hopkins University Bloomberg School of Public Health

John Seffrin, Ph.D., Chief Executive Officer, American Cancer Society

Doug Ulman, Chair, NCI Director's Consumer Liaison Group and President, Lance Armstrong Foundation

Sandra Millon-Underwood, R.N., Ph.D., Professor, School of Nursing, University of Wisconsin Milwaukee

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

On behalf of the Panel, Dr. Leffall welcomed invited participants and the public to the meeting. He introduced Panel members, provided a brief overview of the history and purpose of the Panel, and described the aims of the current series of meetings. Dr. Leffall explained that the meeting would employ a roundtable discussion format facilitated by Mr. Robert Mittman.

# **OPENING REMARKS—ROUNDTABLE PARTICIPANTS**

#### Mr. Robert Mittman, Facilitator

Mr. Mittman explained that the first objective of the roundtable discussion was to identify changes in the cancer enterprise most likely to have the largest positive impact on cancer mortality and morbidity. The cancer enterprise, for the purpose of this discussion, was defined as encompassing every facet of cancer research and care delivery, from research on the causes of cancer, to prevention, to treatment, to palliation in the final stages of the disease. Changes in the cancer enterprise can be suggested in areas such as policy, economics, infrastructure, research priorities, education, and regulation. The second objective was to develop recommendations on how to achieve needed changes and who should be involved in implementing those changes.

In the opening session, participants were asked to briefly introduce themselves and provide an example of one important change that could make the greatest impact on the cancer enterprise. The second session focused on balancing the cancer research portfolio; the third focused on maximizing return from the nation's cancer research investment; the fourth focused on cancer and public health; and the fifth focused on coordination of the cancer enterprise. Participants were asked to keep in mind the ways in which components of the cancer enterprise parallel those of a business enterprise: research and development is similar to basic biomedical research; manufacturing is similar to clinical and translational research; marketing is similar to professional and public education; and fulfillment is similar to care delivery and access to care.

## Mr. Kevin Guidry

- Mr. Guidry is Administrator of Our Lady of the Lake Cancer Center in Baton Rouge, Louisiana, a pilot site in the new NCI Community Cancer Centers Program (NCCCP).
- There is a disconnect between the end users of the cancer care delivery system and the financing of that system. A new model is needed to achieve universal payment for cancer care, bridging the gaps between Medicare, Medicaid, and private systems.

## Dr. Sandra Millon-Underwood

- Dr. Millon-Underwood is a Professor at the University of Wisconsin, Milwaukee, College of Nursing.
- Professional nursing organizations and other organizations of medical professionals could have a significant impact on cancer morbidity and mortality if they increased their collaborative efforts to understand which existing strategies are most effective and economically feasible within the community.

### Dr. Mark Israel

- Dr. Israel was trained as a pediatric oncologist, has spent most of his research career as a molecular biologist, and is Director of the Norris Cotton Cancer Center, an NCI-designated Comprehensive Cancer Center.
- Improving access to patient-centered, coordinated care through state-of-the-art facilities in all regions of the country would have a significant impact on cancer morbidity and mortality.

Many patients who have insurance coverage do not have access to the best available care because they live too far from the nearest cancer center.

#### Dr. Jonathan Samet

- Dr. Samet is Chair of the Department of Epidemiology at The Johns Hopkins University Bloomberg School of Public Health. His current research focus is on global tobacco control issues.
- The cancer enterprise must make better use of the epidemiological data already available through the Surveillance, Epidemiology, and End Results (SEER) program, as well as state and local cancer registries and other monitoring systems.

#### Dr. John Niederhuber

- Dr. Niederhuber is Director of the National Cancer Institute.
- In addition to basic and clinical research to address the biology and treatment of cancer, behavioral and communication research are essential to meet the cancer enterprise's responsibility for informing policy makers about the need to repair the nation's broken health care system.

## Mr. Doug Ulman

- Mr. Ulman, a survivor of chondrosarcoma and melanoma, is Chair of the NCI Director's Consumer Liaison Group and President of the Lance Armstrong Foundation.
- The cancer enterprise differs from a real-world business in that there is no Chief Executive Officer with the authority to make budgetary decisions for the entire enterprise. Greater coordination of strategies and resources for all aspects of Federal and private-sector cancer research would increase the impact of those efforts.

# Dr. Martin Murphy

- Dr. Murphy is the Convener and Chief Operating Officer, CEO Roundtable on Cancer, a workplace wellness initiative that focuses on prevention, early detection, and access to clinical trials.
- Dissemination is the responsibility of all organizations that have developed "gold standard" facilities, policies, and practices in cancer prevention, detection, and treatment—whether they are NCI-designated Comprehensive Cancer Centers or CEO Roundtable on Cancer member companies—so that other health care providers and employers can adopt those standards.

### Dr. John Seffrin

- Dr. Seffrin is Chief Executive Officer of the American Cancer Society (ACS). Most of his academic career has focused on issues related to tobacco use.
- The single most important way to reduce cancer morbidity and mortality is to ensure that every citizen has access to quality health care in general, not simply access to cancer care. Because the ACS is not restrained from lobbying (like Federal agencies) and does not face the economic restraints of a for-profit business, it has formed a 501(c) 4 organization to advocate for universal health care.

## Ms. Kathryn Giusti

- Ms. Giusti, a multiple myeloma patient, is Founder and Chief Executive Officer, Multiple Myeloma Research Foundation and Multiple Myeloma Research Consortium, and a member of the National Cancer Advisory Board.
- In spite of the diverse issues faced by cancer researchers, educators, manufacturers, and patients, the cancer enterprise needs to find a way to speak with one voice about the

magnitude of the challenges associated with cancer, particularly cancers for which effective treatments and preventive measures have not yet been discovered. Access to care is not the most crucial issue for people with such diseases.

## Dr. Scott Ramsey

- Dr. Ramsey is a physician and health economist at the Fred Hutchinson Cancer Research Center. He runs a cancer prevention clinic and conducts research on the political economy of cancer care.
- Low levels of participation in cancer clinical trials hinder the cancer enterprise's ability to collect the amount of information needed to make breakthroughs in cancer prevention and treatment. Steps should be taken to ensure that 100 percent of cancer patients are involved in clinical trials. All cancer care should produce data that contribute to the growth of knowledge.

#### Dr. Barnett Kramer

- Dr. Kramer is Associate Director for Disease Prevention at NIH and Director of the Office of Medical Applications of Research.
- Education about scientific methods is needed at every level of society. Because research methodology is inadequately taught in medical schools, physicians are poorly equipped to evaluate the research evidence presented to them. Continuing medical education is heavily influenced by the private sector, resulting in an emphasis on expensive drugs and technologies. Clinical investigators with limited training in research methodology often overstress the implications of their data. The cancer enterprise would also benefit if the public and policy makers were better informed about science.

# ROUNDTABLE DISCUSSION: BALANCING THE CANCER RESEARCH PORTFOLIO

- Investigator-initiated basic research supported by NIH and organizations like the ACS has produced significant knowledge, but the cancer enterprise has dedicated most of its resources to this type of research to the detriment of research in areas such as prevention, translation of knowledge, and policy. This lack of balance should not be addressed simply by redistributing funds from one area to another; support for basic research should continue and additional resources should be dedicated to expanding the portfolio into other areas.
- The promise of gains made in basic science is hindered by the lack of trials that create links with clinical data for correlative studies. As industry becomes more involved in supporting research, steps must be taken to ensure that clinical data and tissue samples are collected and evaluated for every patient.
- The cancer enterprise needs to set a research agenda designed to identify critical information gaps and decide what kinds of research activities are needed to fill those gaps. The investigator-initiated model for identifying research questions is not an adequate model for setting a broad agenda for all of the stakeholders in the cancer enterprise.
- Translational research conducted in controlled settings may produce outcomes that cannot be reproduced when interventions are introduced into real-life communities. Any examination of the cancer research portfolio should include evaluation of the practicality of the interventions that are being tested.
- Scientists involved in community-based research, as well as organizations involved in bringing new interventions into communities, need access to negative research findings in addition to success stories. It is important to know which promising experiments failed so that they are not repeated.

- Journals are reluctant to publish papers on trials that failed to prove the authors' hypothesis because they prefer to dedicate their limited resources to studies with positive outcomes. However, the data and results of studies with negative findings can be made available through the Internet, and some journals are now posting these types of papers online in forms that can be referenced in PubMed.
- The cancer enterprise serves as a model for the broader health care enterprise. Because of the complexity of cancer, the NCI research portfolio has contributed enormously to our understanding of the biology of all diseases. In terms of health care delivery, the push within the cancer enterprise for improved data collection and monitoring of care is leading to a broader understanding throughout the health care field of the need for electronic medical records.
- NIH is spending approximately \$900 million a year on health services research, but a recent Institute of Medicine study has shown that the findings of quality improvement research—a component of health services research—are difficult to interpret. Health services research has failed to live up to its potential for improving outcomes, in part because researchers have not asked the right questions or partnered with health care providers to design and conduct useful studies. In addition to increasing the amount of money spent on health services research, it will be necessary to improve its quality and to find more effective ways of translating health services research findings into practice.
- Companies that meet the CEO Roundtable on Cancer's Gold Standard series of cancerrelated recommendations can serve as a valuable source of data for scientists involved in health services research.
- The emerging concept of "large simple trials" should be applied in cancer research. These types of trials are less expensive and complex than traditional cancer clinical trials, with low barriers to entry. The risks and benefits of treatments can be tested in a wide variety of patients.
- Patients are often reluctant to enter controlled clinical trials because of the possibility that they will not receive the experimental drug being tested. Whenever possible, researchers should design their trials as crossover studies in which patients can move from one study arm to another.
- Advocacy groups and private research foundations are a rich source of information on patients. Many of these groups conduct market research to learn about patients' needs and the barriers they face; they also employ navigators to provide education and encouragement about participating in clinical trials and contributing tissue specimens for further research. Partnerships between these groups and researchers would improve accrual to clinical trials and enrich the data available for future research.
- Patients and their family members are using the Internet to identify cancer care resources, including doctors, facilities, therapies, and clinical trials. However, many find the information too complex, especially concerning criteria for inclusion in clinical trials, and have difficulty making informed choices. Intermediaries such as nurses, social workers, and navigators are essential for helping patients understand the option of participating in clinical trials.
- The allocation of limited research funds must be guided by scientific opportunities as well as perceived need. Although there is general agreement that the prevention of cancer is an important goal, few fruitful research opportunities in prevention have been identified. Some of the changes that would have a dramatic impact on cancer incidence, such as raising the price of tobacco products, are in the hands of policy makers rather than researchers.

# ROUNDTABLE DISCUSSION: MAXIMIZING RETURN FROM THE NATION'S INVESTMENT IN CANCER RESEARCH

- Scientists tend to prefer a steady stream of investigator-initiated grants to address short-term, low-risk questions rather than becoming engaged in long-term, high-risk research. Scientific training teaches researchers to focus on confirming what is already believed to be true, whereas high-risk science tests hypotheses that have the potential of proving that previously accepted knowledge is false. The cancer enterprise should place a priority not on increasing funding for high-risk research (which would probably not increase the number of discoveries) but on selecting the most appropriate "outlier" ideas to nurture and design high-quality studies to address them. The peer review system and NIH funding mechanisms may need modification to offer encouragement to investigators with creative ideas.
- An NIH committee has collected input from the extramural community on the peer review process and will soon complete its recommendations for modifying that process to reduce the impact of backlogs created by the large number of amended applications in the system.
- Research-related risk is defined differently by different stakeholders. For pharmaceutical companies, some studies are too high-risk because of the potential financial losses associated with failure. For the cancer enterprise as a whole, risk can be expressed in terms of future negative health outcomes that could be reduced if cancer research is successful.
- There is great potential for reaping a return on the investment in advances in genomics, resulting in more rapid generation of new knowledge and therapies.
- Return on investment can be improved by periodically reviewing the research portfolio to identify knowledge gaps and eliminate duplication of effort.
- Recent decisions to invest in certain high-risk research initiatives (e.g., a pilot project for genetic sequencing of lung, glioblastoma, and ovarian tumors) have been controversial. However, NIH places an emphasis on bringing experts together in workshops and task forces to provide advice on the potential of new research opportunities to produce a significant return on the investment required to pursue them. These initiatives are not launched in isolation from the scientific community.
- For the next several years, the NCI budget is not expected to increase. Due to inflation, the Institute is now losing approximately \$175 million each year in purchasing power. It has been estimated that every \$500 million reduction in the NIH budget could result in diminishing the academic research workforce by as many as 6,000 scientists, with similar reductions in the industry workforce. These reductions place the cancer research enterprise at risk. NCI is addressing this problem in part by funding new research centers that specialize in emerging technologies and by actively recruiting scientists in fields like physics, applied mathematics, and chemistry to consider focusing their research careers on applications of their disciplines in cancer research.
- One Voice Against Cancer is a recently organized coalition of approximately 50 not-for-profit organizations that is seeking innovative ways to deliver unified messages to policy makers and develop innovative approaches to reducing the burden of cancer, such as building a public trust fund.
- Advances in molecular biology are leading to the potential for developing therapies that target molecular pathways rather than organs or tumors. This presents a challenge because there may be as many as 20 to 50 pathway-associated breast cancer types that require individually targeted drugs; the market for each of these drugs will be relatively small, yet the cost of developing each drug will be very high. It may be possible to address this issue by positioning drugs in the market based on their effect on specific molecular targets that are associated with multiple cancers.

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- Development of targeted molecular therapies has several implications for the conduct of clinical research. Designing clinical trials to test these therapies will require a well-organized effort to collect and share clinical data and tissue samples. Changes in the FDA regulatory process may be needed to facilitate timely approval for drugs that target molecular pathways instead of diseases; NCI and other stakeholders will need to work with FDA to identify surrogate markers that will be acceptable for drug approval. As new targeted therapies are developed, new technologies, such as imaging applications, must also be developed to monitor the activities and effects of those agents.
- Because combinations of drugs are often aimed at molecular targets, intellectual property issues impact the design of trials when different drugs owned by different entities are used in combination.
- The design of clinical trials for testing new drugs is a partnership among the Federal Government (including the FDA), academic institutions, and pharmaceutical companies. No stakeholder is responsible for all of the problems that hinder progress in clinical research. Leadership is needed to develop a common vision and create compromise among stakeholders. Common language for contracts between pharmaceutical companies and cancer centers is needed.
- Several factors contribute to the low rate of participation in clinical trials. Patients who are not treated in academic settings, which includes most adult patients, are not informed about trials by their physicians. The cost of referring patients to trials is a disincentive for physicians, and many insurance plans limit or deny payment for some of the care provided as part of clinical research.

#### **PUBLIC COMMENT**

- The cancer care system is failing to deliver the progress promised 37 years ago at the beginning of the war on cancer; researchers and service providers compete in isolation without shared resources or coordinated agendas. Cancer researchers, advocates, and care providers need to take a serious look at the factors that have led to this failure, reexamine priorities, and develop an organizational mechanism for coordinating the cancer care enterprise.
- The public is an important partner in the cancer enterprise that has been missing from the discussion so far. Consumers are the ones who are impacted by cancer and should be included in discussions on how to reduce that impact.

#### ROUNDTABLE DISCUSSION: CANCER AND PUBLIC HEALTH

- Shifting attention to the public health aspects of cancer involves finding ways to optimally apply what is known to reduce the burden of cancer through prevention, screening, and early detection. In that context, a public health emphasis depends less on basic research and more on communication, dissemination, and other operational aspects of care delivery. For example, public health researchers want to know why only about 20 percent of eligible women participate in the Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which has been proven to be effective in reducing morbidity and mortality.
- A public health perspective brings attention to linkages between apparently different diseases. For example, some studies have suggested an association between obesity and certain cancers. Lifestyle changes can have a cross-cutting effect in reducing the risk of a variety of health problems.

- The linkage between obesity or body mass index (BMI) and cancer mortality is not as strong as the link between cancer and tobacco use. To date, no evidence has been found to prove that reducing weight will reduce cancer mortality risk. If the public perceives that messages about BMI are overstated, doubt may be cast on stronger messages (e.g., messages about tobacco and cancer). Thus, care must be taken in developing public education messages so that misleading or confusing information is not disseminated.
- Comprehensive Cancer Centers have become increasingly aware of the need to expand their activities into the community to translate new knowledge into practice. However, in comparison with research funding, few resources have been made available for community outreach.
- Lack of reimbursement is the most critical barrier to moving preventive interventions into the community. The larger societal savings that evidence-based prevention can deliver in terms of employee productivity and health care costs are not taken into consideration by current models of health care delivery and financing systems.
- Some cancers are best addressed through clinical interventions, while others can be effectively addressed through public health measures. The best example of the latter is cervical cancer, the impact of which is significantly reduced through routine Pap testing and now, potentially, through human papilloma virus (HPV) vaccination.
- Randomized clinical trials (RCTs) should not serve as the only threshold of evidence required to take action on associations between behavioral or environmental factors and cancer. RCTs cannot be conducted for all of these factors because they are too large, expensive, and time-consuming. In some cases, the threshold of evidence may consist of the best available knowledge, with appropriate acknowledgment of uncertainty. However, when an intervention poses a significant risk to the "healthy" population, the cost of an RCT may be warranted.
- Cancer can be described as a worldwide epidemic that is becoming a pandemic. History has shown that the only way epidemics and pandemics can be brought under control is through prevention.
- Although it is difficult to prove causality between lifestyle factors and disease, the public could be persuaded to make behavioral changes if a strong case were made that such change would reduce risk across the four areas that cause the majority of deaths in the United States—cancer, heart disease, stroke, and diabetes.
- Workforce issues, particularly nursing shortages, have an impact on capacity to implement prevention strategies. Oncologists and other physicians will not be able to incorporate prevention into health care without assistance. Overall workforce shortages and the growing need for manpower to provide preventive care may require new models for medical and allied health education.
- Prevention initiatives should make an effort to focus on underserved populations, those at increased risk, patients receiving palliative care, and cancer survivors. Cancer survivors have well-founded concerns about recurrence and multiple cancers, but little information is available to them about reducing their future risk.
- The trend toward personalized medicine based on molecular targeting may increase health disparities because some patients who are found to be candidates for targeted therapies will not have the resources to pay for those therapies. Over time, however, technological advances are likely to reduce the cost of mapping patients' genetic sequences so that multiple predispositions for disease can be identified for follow-up. Inexpensive screening may serve as a "loss leader" for hospitals because it will lead to delivery of additional billable services. Personalized medicine also has the potential to reduce waste in the health care system by

- reducing delivery of traditional, non-targeted therapies to those who are unlikely to respond to them.
- Some public health practices, such as encouraging dentists to check for oral cancers or asking dermatologists to check for melanoma, are not expensive. However, it is unclear who is responsible for the public and professional education efforts needed to increase these practices.

## ROUNDTABLE DISCUSSION: COORDINATING THE CANCER ENTERPRISE

- Coordinating entities targeting other health problems, such as the Diabetes Mellitus Interagency Coordinating Committee, cannot be used as models for coordinating the cancer enterprise due to the complexity of cancer, which comprises numerous individual diseases.
- A centralized coordinator for the cancer enterprise could be effective if given budgetary control. NCI does not play that role because its mandate is limited to research.
- The President's Cancer Panel's mandate is to "monitor the development and execution of the activities of the National Cancer Program," but the Panel does not have concomitant budgetary authority. In its advisory capacity, the Panel lacks the organizational power to implement its recommendations.
- Establishing a "cancer czar" to coordinate the conduct and funding of the cancer enterprise would be difficult; it may be more pragmatic to focus on strategies for achieving common goals through collaboration. Improved collaborative stewardship by all stakeholders in the cancer enterprise would improve the return on the nation's investment in cancer research and care delivery. The establishment of C-Change (formerly the National Dialogue on Cancer) and the CEO Roundtable on Cancer have been steps in the right direction.
- Next steps for a concerted effort to coordinate the cancer enterprise could include: identifying gaps in professional education; identifying success stories in addressing some cancers that could serve as "best practices" or models for addressing other cancers; and coordinating efforts to reduce cancer health disparities.
- Since no one entity is likely to be given authority over the entire Federal investment in cancer, stakeholders should collaborate to develop a business plan based on an analysis of the combined budgets of NCI, CDC, the Department of Defense, and other Federal agencies involved in cancer.
- Any centralized authority for the Federal cancer research budget would be a part of the U.S. Government and, thus, restricted in its ability to engage in advocacy. Changes in policy should be pursued by advocacy groups working in concert. Cancer-related advocacy groups should work not only with each other but also with those engaged in other health issues; cancer cannot be isolated from the overall picture of health care in the United States.
- When the United States was attacked in 2001, the nation responded by creating a new Department of Homeland Security. A similar action should occur in response to the devastation caused by cancer. The primary benefit for the cancer enterprise of identifying an individual as a "cancer czar" would be to make a clear statement about the seriousness of cancer that captures the public's attention and serve as a call for action.
- Many members of the public, and in fact many members of the cancer research and care communities, are not aware of the unique autonomy that was given to NCI through the National Cancer Act of 1971, such as Presidential appointment of the NCI Director, the ability to develop a budget request that goes directly to the President, and establishment of the valuable research resources at NCI Frederick. Care should be taken in contemplating a

new form of governance for the cancer enterprise so as not to jeopardize the historically significant reasons that NCI was set apart from other NIH components.

## ROUNDTABLE DISCUSSION: DATA SHARING AND LINKAGES

- The lack of published negative research results is probably not due to reluctance of journal editors to publish such findings. Editors look for definitive findings, and negative findings are often inconclusive because the factors that led to the negative result are unknown. Another factor may be a lack of interest among scientists and funding organizations to pursue negative findings to the point of understanding their significance; this further understanding could then lead to publication.
- Negative findings resulting from large, randomized, prospective trials are more likely to be published than those from early-phase trials, some of which are stopped due to factors such as toxicity.
- New regulations will require NIH-funded clinical trials to report their findings, whether positive or negative, in a public database. Details about this database, such as where it will be housed and who will be able to access it, have not yet been finalized. There are concerns about how the public might be able to interpret the information that will appear in this database. Some observations about clinical trials not mentioned in peer-reviewed publications, including less favorable outcomes, may need to be incorporated into the database.
- The CEO Roundtable on Cancer and representatives of the pharmaceutical industry have been discussing the idea of precompetitive sharing of information about drug targets, rather than drug candidates, without raising intellectual property issues. Such data are already being shared within certain consortia of researcher institutions.
- The collection of clinical data using electronic medical records is part of the NCCCP project. The project is addressing a number of issues such as ownership of clinical data and compatibility with caBIG.
- A database linking biospecimens and clinical data from treatment through outcome has the potential of supporting pharmacogenomic research focusing on exposures and outcomes. However, collection and tracking of tissue samples from multisite clinical trials is an expensive and labor-intensive effort, requiring dedicated personnel at each site. Unless all the data being examined came from the same trial or were collected using standardized methods, outcomes are difficult to compare.

## **CLOSING REMARKS—ROUNDTABLE PARTICIPANTS**

- The most important thing that can be done to improve support for cancer research is to make sure the public understands the human and economic value of research. An effective way to engage the public is to let them know when new drugs have been approved and explain that access to those drugs can be obtained through participation in clinical trials.
- Much can be accomplished in collaboration with established community-based groups that are committed to cancer prevention and control but are not actively engaged with the cancer research enterprise.
- Men's health is an area that has received too little attention. The CDC's NBCCEDP can be a model for programs to address cancers that affect men.
- Two important goals for the cancer enterprise are addressing the needs of underserved populations and educating the next generation of scientists and providers.

■ Problems in the cancer enterprise are exacerbated by problems throughout the health care system.

## PUBLIC COMMENT

- While the United States has produced unparalleled scientific advances and technologies, this capacity has not resulted in access to the benefits of those discoveries for all Americans. Most of those benefits are available only in academic cancer centers and affluent communities, not in the diverse and often remote communities in which most Americans live.
- The cancer enterprise should focus on conducting trials with potential for extending survival by at least 20 percent, rather than the survival rates of weeks or months delivered by many interventions.
- The younger generation is looking for a calling. The cancer enterprise, especially through advocacy groups, should create a national cancer agenda that the younger generation can understand and respond to.
- Prevention is difficult to sell to legislators because they do not see an immediate return on investment. By communicating the costs that occur throughout the cancer continuum in the absence of prevention, the cancer enterprise could do a better job of explaining the long-term benefits of prevention.

# CLOSING REMARKS—DR. LEFFALL, DR. KRIPKE, AND MR. ARMSTRONG

Dr. Leffall thanked the participants for making valuable contributions and assured them that the Panel would carefully consider the information collected at the meeting.

Dr. Kripke offered thanks to fellow member Lance Armstrong for suggesting that the Panel address the issue of maximizing return on investment in the cancer enterprise.

Mr. Armstrong thanked Dr. Leffall for his leadership of the Panel and Drs. Leffall and Kripke for the opportunity to work with them during his tenure on the Panel. He also expressed his gratitude for having had the opportunity to work with Dr. Harold Freeman, who chaired the Panel at the beginning of his tenure. He expressed his gratitude to all of the cancer survivors, policy experts, medical leaders, and others who contributed their valuable time to testify before the Panel during his two terms as a member, thanking them for the courage required to share their stories and recommendations. Although proud of what the Panel has accomplished, Mr. Armstrong stressed the fact that much remains to be done to ensure that Americans affected by cancer receive the care and support they deserve. He said that through his service on the Panel, he better understands the toll of this disease and learned that many of the barriers to reducing its burden are caused by bureaucratic roadblocks, lack of funding, and inadequate dedication at the highest levels. Since the cancer epidemic will worsen as the baby boom generation ages, leaders who will make cancer a national priority are needed. The United States, for example, should directly address the issue of tobacco control, including ratification of the Framework Convention on Tobacco Control adopted by the World Health Organization and 168 countries. Another priority should be reversal of recent erosion in the budgets of NIH and NCI. Renewed dedication and passion should be expected of the nation's leaders to fight a disease—cancer—that claims more than a half million lives each year.

# **CERTIFICATION OF MEETING SUMMARY**

I certify that this summary of the President's Cancer Panel meeting, *Strategies for Maximizing the Nation's Investment in Cancer*, held January 28, 2008, is accurate and complete.

Certified by:		Date:	May 10, 2008
	LaSalle D. Leffall, Jr., M.D., F.A.C.S. Chair President's Cancer Panel		